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Families of 40-Year Olds With Down Syndrome

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Abstract

A population sample of people with Down syndrome (DS) and their families has been followed since the age of six weeks, most recently at the age of 40 when there were 28 people with DS and 16 non-disabled controls still in the study. The paper looks at the well-being of the parents and siblings of both groups, and focuses on their health, social life and friendships, and, in the case of those in the DS group, on their experience of services. Although primarily concerned with the data from age 40, where relevant, reference is made to findings from previous stages of the study.

Sixty years ago, the literature relating to people with intellectual disabilities scarcely recognized the existence of parents. For example, Wolfensberger (1967) noted that "Very little mention was made of parents, of their feelings and sensibilities, or of the impact of the diagnosis on them" (p. 329). Change was on the way, however, with what Wolfensberger referred to as a "first a trickle of armchair papers" discussing parent dynamics, and then "almost a flood of such papers." Since then, studies have become more research oriented, comparing families of children with different types of disability, or those of children with or without disabilities.

Recent studies of families with a child with Down syndrome (DS) have identified lower levels of stress in the families than might have been expected, although Cuskelly, Jobling, Chant, Bower, & Hayes (2002) anticipated that stress might increase as the families, and their children, aged. Low stress levels have been found in families of adults with DS (Baine McDonald, Wilgosh, & Mellon, 1993; Chen, Ryan-Henry, Heller, & Chen, 2001). The same remained true as families aged still more: even with mothers with a mean age of 67, Krauss and Seltzer (1993) concluded that "providing decades of care for a child with a disability does not have marked deleterious effects on the physical, psychological and social well-being of these older mothers" (p. 54).

Families of adults with DS have been reported to fare rather better than did those of adults with a developmental disability due to other causes (Seltzer, Krauss, & Tsunematsu, 1993), while families of adults with developmental disabilities fared better than did those with a child with a mental illness (Seltzer, Greenberg, Floyd, Pettee, & Hong, 2001), a finding echoed by other research (e.g., Brown, MacAdam-Crisp, Wang, & Iarocci, 2006; Holmes, 1988). Seltzer, Greenberg, and Krauss (1995) found that mothers of adults with autism were distressed by high levels of caregiving demands but not by behaviour problems, while the reverse was true for mothers of adults with developmental disabilities. The authors suggested that this "unexpected" outcome might be due to the confounding of lifelong expectations: mothers of adults with autism become accustomed to dealing with behaviour problems, as do mothers of adults with developmental disabilities to coping with caregiving demands; when, in each case, the alternative problem arose it was unanticipated and caused greater distress.

Research on fathers of children with developmental disabilities has found them to be more stressed than were those of children without disabilities, though this is less the case for mothers (Beckmann, 1991), and fathers may be less likely than mothers to show psychiatric symptoms (Wing, 1975). Pruchno & Patrick (1999) compared fathers and mothers of adults with developmental disabilities or with schizophrenia. Fathers perceived their offspring as more violent and non-compliant, and of lower functional ability, and reported less caregiving burden but also less caregiving satisfaction than did the mothers. Neither parent group scored highly on depression, but for both fathers and mothers caregiving burden was less in families with a child with a developmental disability than in those with schizophrenia.

Studies of siblings have also focussed mainly on young children, with negative outcomes seen in early reports (Farber, 1959; Fowle, 1968; Holt, 1958) being followed by others showing fewer and less adverse effects (Gath & Gumley, 1984).

Reports gathered directly from the siblings themselves have shown them to be well adjusted people (Graliker, Fishler, & Koch, 1962; McConachie & Domb, 1983), not different in their behaviours and self-perceptions from siblings of children without disabilities (Cuskelly & Gunn 2006). This also was the case for siblings of adults with severe developmental disabilities (Cleveland & Miller, 1977), although the greater burden for female, and especially the eldest, siblings, already identified by Fowle (1968), was supported.

Method

This paper provides data, derived from semi-structured interviews and from Rutter's Malaise Inventory (see Carr, 2005) on the survivors of a group of families of 40-year-olds with Down syndrome, and another of non-disabled people. Both groups were followed since the 40-year-olds were infants. Health, social life and friendships of both groups were considered, and, in the case of the families of people with Down syndrome, their experience of services. All interviews were conducted by the author. All the data presented and discussed below are ordinal, apart from IQs and data derived from the Malaise Inventory, and non-parametric statistical methods (Mann Whitney U tests) were used throughout.

Participants

Participants were the families of the 34 surviving 40 year olds with Down syndrome, of whom 21 had at least 1 parent—7 fathers and 18 mothers—still alive. In three cases, both parents

(including one step-father) were alive. Sixteen families of controls, 14 fathers and 14 mothers, were still in the study, 12 with both parents alive. Average age of mothers in the Down syndrome group was 75.9 (range 59-87), and of fathers, 75 (range 65-88). Average age for control mothers was 69.6 (range 60-80), and for fathers 70.6 (range 64-77). Two mothers in each group were still working: one in the Down syndrome group worked full time and the other part time; the two in the control group worked part time. Of the people with Down syndrome who had at least one parent alive, 11 (52%) still lived at home, while four lived with a sibling—three with sisters and one with her brother. The people with Down syndrome had an average of 2.4 siblings (range 0-7), and the controls had an average of 2.1 (range 0-4).

Results

Mothers' Health

As in earlier studies with this sample, mothers were asked to rate their own health (Table 1). Two-thirds of those in the Down syndrome group and half the controls said it was good, with a minority (sizeable in the case of the controls) saying it was poor. Just under half in each group (DS, 44%; controls, 43%) had had what was judged to have been a serious medical condition —operations on joints, hysterectomy, stroke, myasthenia gravis, and others. As before, mothers' health was not related to age, marital status, family contacts, loneliness, nor to a wide range of factors connected with the people with Down syndrome (co-operation, living situation, ability, behaviour problems, level of self help skills, etc.), nor to how satisfied the mothers were with services. Poorer health was reported by mothers whose family members with Down syndrome were not allowed to go out alone beyond the garden (z=-1.99, p=<.05). In contrast to the findings at all previous stages of the study, fewer mothers of people with Down syndrome than of controls now said they currently felt run-down and depressed.

Table 1. Mothers' Self-Perceived Health

	% DS Group	% Control Group
Overall health		
Good	67	50
Fair	22	28
Poor	5	21
Felt run-down &/or depressed		
Run-down	5	7
Depressed	29	7
Both	17	29
Neither	67	57
Malaise Scale		
Mean	2.56	2.25
Range	0 - 7	0 - 5
Score 6+	11	11

On the Malaise Scale, mean scores for both groups were slightly lower than at age 35, a decline of 0.72 points for mothers of people with Down syndrome and of 0.25 points for the controls. A number of factors were examined, as before, connected with the mother herself and with the person with Down syndrome. Where factors connected with the mothers were concerned, none that had previously been significantly associated with Malaise scores (rating their health as poorer, saying that they felt they had been made lonely by having had a child with Down syndrome, that they felt run-down or depressed) was now significantly associated, although the trends in the figures were the same. For the first time in the study, mother's age was significantly associated with malaise, older mothers having a higher mean score (p=<.05). In addition, mother's friendships were now significantly associated, those with fewer friends having a higher mean score (p=<.05), reflecting a finding similar to that found at age 30 (Carr, 2005).

Where factors connected with the people with Down syndrome themselves were concerned, as before, only dependence was significant, mothers' Malaise scores being higher in those whose offspring could be left in the house alone for no more than half an hour (z=-1.99, p=<.05). Although this might be attributed to chance, in view of the number of analyses carried out resulting in the single significant finding, the fact that dependence has been related to Malaise scores at previous stages of the study (Carr, 1995, 2005) lends credibility to the finding (Cunningham, 1987).

Looking at mean Malaise scores over the years for those mothers still in the study at 40 years (Table 2) it can be seen that, in this group of mothers of people with Down syndrome, the means fluctuated around 3, while in the mothers of the controls they were somewhat lower. At 11 years, the mean for the mothers of the people with Down syndrome was at its highest level, and for the mothers of the controls it was at its lowest. By 40 years, the difference between the means of the two groups was less than at any other time.

Higher malaise scores, then, were found in older mothers of people with Down syndrome, and in those with fewer friends and a more restricted social life. Of the factors relating to the people with Down syndrome themselves, only dependence could be shown to have an effect, although poorer maternal health was also a factor that approached significance. Other factors, which in other research have been related to the mother's stress, could not be shown to do so in this study.

Social life

The mothers were asked how much they were able to go out, on their own or with their partners; about membership of, and attendance at, social and leisure groups; and about holidays.

Replies to these questions were divided into those who engaged in any activity often (once a month or more) and those who did so less often. Table 3 shows that mothers of people with Down syndrome went out somewhat less often, and more wished they could go out more often than they did, than did the controls. Four of the seven who wished they could go out more cited the person with Down syndrome as the reason for their restriction, the rest giving financial and other reasons. As at ages 21, 30 and 35, fewer mothers of people with Down syndrome were able to have a holiday independently of the adult child, but the difference is not now significant. The mothers were asked whether having a child with Down syndrome now made them lonely. Only one (out of 13 for

Table 2 Mean Malaise Scale scores, 11 years – 40 years, (mothers still in the study at 40 years)

	DS Group (n=18)	*Control Group (n=16)*
Age		
11 years	3.33	1.5
21 years	2.83	2.5
30 years	3.0	2.56
35 years	3.28	2.5
40 years	2.56	2.25

Table 3. Mothers' social life and friendships

	% DS Group	*% Control Group*
Went out 1/month or more		
accompanied	23	58
alone	50	50
to clubs etc.	60	55
Would like to go out more	35	20
Had a holiday last year		
no, or only with N	60	33
Has no or few friends	42	53
Has many friends	26	40
Sees family 1/month or more	74	93
Family gave much help	71	-

whom the question was appropriate) said it had, many saying that the opposite was true—"I was always very shy, when I had him I had far more friends"—while others felt that the person with Down syndrome was good company: "He's always there for me, he's a great comfort. I wouldn't be without him."

A composite social life factor was arrived at by combining the mothers' scores for going out, with or without her partner, for club attendance, and for holidays. Again, the mean score for the mothers of people with Down syndrome was lower (poorer) than was that for the controls (DS: 5.35, controls: 6.86), indicating a more restricted social life, but the difference is not significant.

All the above analyses were re-run to take into account, first, the mother's age, and second, where the person with Down syndrome lived (at home or away from home). Younger mothers tended to have a more active social life than did older mothers, but the difference is non-significant. Mothers whose person with Down syndrome lived away from home were also more active socially, with significantly more having holidays independently of the person with Down syndrome (Mann Whitney U test, p=.011).

Asked about friends, and about family relationships, overall there was little difference between the groups in their contact with friends (Table 3). Mothers of people with Down syndrome had had somewhat fewer contacts with other family members than had controls, but said that they had had a good deal of help from them.

Fathers and Siblings

Data on fathers and siblings were derived from information supplied by the mothers, and in the case of the fathers of people with Down syndrome, from a very small number. Eighty per cent of fathers of people with Down syndrome and 72 per cent of controls were said to be in good health; 40 percent of fathers of people with Down syndrome were said to be rundown, and 43 per cent of controls to be depressed. The remainder in each group was neither rundown nor depressed.

As mentioned, four people with Down syndrome were living with and being cared for by a sibling. Other siblings continued to keep in contact, two-thirds (68%) of the people with Down syndrome having much contact with at least some of their siblings compared with under half (40%) of the controls. Over a third (37%) of the people with Down syndrome were looked after at least occasionally by a sibling, including one woman, living with her brother, who was taken out every weekend by another brother. Only 21% ever stayed in a sibling's home.

Asked whether they had any worries (predominantly health concerns) about their other children, proportionately fewer of the mothers of people with Down syndrome than of controls—17% compared to 54%—said that they had, a difference that at p=.051 (Fisher's Exact Test, two-tailed test) just failed to reach significance. It seemed possible that mothers of people with a significant disability such as Down syndrome might play down problems in the rest of the family that other parents would identify as worrying, and thus that the concerns of the controls would be relatively minor. However, in all but one control family (where the concern was of attacks of flu) the problems identified were judged to be relatively serious—multiple sclerosis, kidney and gall stones, diabetes, neurological disability and significant obesity. At the least, it may be concluded that the mothers of the people with Down syndrome were not having to contend with a greater number of pressing problems in their other children than were experienced by other mothers.

Services

Mothers of people with Down syndrome were asked how satisfied they were with a range of services, on a scale from 1 (very dissatisfied) to 5 (very satisfied). Table 4, [page 40], shows the number who had been in contact with each service, and the percentage dissatisfied (ratings 1 and 2) and the percentage satisfied (ratings 4 and 5).

Ratings were generally high, with over 80% being at least satisfied with each service apart from two, social workers and speech therapists (though only two had had contact with the latter), and, in the case of hospital consultants and dentists, over two-thirds saying they were very satisfied. No mother was dissatisfied with all the services, and more than half (56%) were satisfied with all. As before (Carr, 2005), there was a trend towards more mothers in manual workers' families being satisfied with all—64% compared with 31% of mothers in non-manual workers' families—but the difference again is not significant.

Social workers were the main focus of dissatisfaction. Examples cited were that the mother's concerns were dealt with by a duty social worker or a "care manager," not by an individual assigned to her; of rapid turn-over of staff, and staff who were ill-informed about people with intellectual disabilities. A number of mothers were affronted by what they saw as politically over-correct attitudes, typified by one mother's experience with a dental service: "She can see the dentist at the Day Centre, if she agrees. They won't see her unless she 'opts in,' and she doesn't. Her gums are bleeding and I don't think she should be given the option of refusing, but there is nothing I can do."

Respite care, singled out by several mothers as something they wished was more readily available, was used by only eight families. This was fewer than half of those for whom it might have been appropriate. Only four of these had been given respite as much as once a year.

Table 4. Percentage of Parents Satisfied and Dissatisfied With Services

Service	*n*	*% Dissatisfied*	*% Satisfied*
GP	30	3	93
Hospital doctor	12	-	100
Dentist	23	4	91
Optician	18	11	89
Social worker	18	39	50
Speech therapist	2	-	50
Chiro-podist	17	6	88
Day Centre	23	3	83

Figures exclude those neither satisfied nor dissatisfied with a service.

Discussion

The latest phase of this study has largely borne out the principal findings of previous phases: that these, now very elderly, parents of people with severe intellectual disabilities were functioning in ways quite similar to those of parents whose adult children did not have disabilities. In the main, the mothers felt themselves to be in good health, not depressed, and not unduly stressed, and this accords with findings from other research already cited. Older mothers, and those with fewer friends and a less active social life had higher stress scores, but severity of disability, residential status and behaviour problems of the person with Down syndrome, which have been implicated in previous studies (Baine et al., 1993, Militiades & Pruchno, 2001), could not be shown to have done so here. Only dependency was related to the mothers' stress, being also related to her health ratings. Since dependency was itself rated by the mothers – how far they were prepared to allow the people with Down syndrome to go from home, or how

long to be left in the home alone – the question arises as to whether, rather than dependency contributing to her stress, the mother's own mental state led her to place restrictions on the person's independence. Both dependency factors were, however, significantly related to ability (IQ and going out, z=-2.35, p=.018: staying home, z=-2.42, p=.015) so the mothers' decisions seem to have been quite realistic.

It should perhaps be noted that, throughout this study, mean Malaise scores have been quite low. Mean scores for mothers in the general population have been given as 3.22 (Rutter, Tizard, & Whitmore, 1970) and 4.15 (Rutter et al., 1975), and for mothers of physically disabled children, 5.13 (Dorner, 1980) and 6.08 (Tew & Laurence, 1973). In the present study, mean scores of the mothers of the people with Down syndrome are below those of mothers of physically disabled children, and indeed are close to those of the general samples. The absence of more recent studies in the general population of the Malaise scale raises the possibility that scores generally have reduced over time. Nevertheless, the mothers' mean scores when the people with Down syndrome were aged 11 and 21 years (Carr, 1995), that is, contemporaneously with the Rutter et al. studies cited, were 3.5 and 4.2 respectively, also close to those of Rutter et al. The apparent similarity, in this respect, between the present group of mothers of people with Down syndrome and general samples of mothers seems to be a valid one. Means for the controls have been lower still, so it is possible that some environmental factor, such as location in the relatively affluent South East of England, has had some effect.

On the whole, mothers were well satisfied with the mainly generalist services about which they were asked. The more specialist services were provided by hospital doctors, Day Centres, and social workers. Of these, only social workers were less well thought of, as were the disability services reported on by Brown et al. (2006). Mothers looked for continuity of and individualization in these services, that workers should know those they deal with as people rather than only as numbers on a case load, and their failure in this respect is clearly a problem that services need to address.

Despite reservations regarding the data presented here on other family members, that these were derived not from the people in question but from reports from the mothers, these are in broad agreement with the findings of other research, showing fathers and siblings of older people with Down syndrome to be well adjusted and not unduly subject to strain. As before, brothers and sisters have continued to have good relationships with their siblings with Down syndrome, and rather more contact with them than was the case for the controls and their siblings, while worries about these brothers and sisters were no more numerous than for the controls. This supports Cuskelly's (1996) view that "(The) perception of a child with Down Syndrome as a disruption to normal family functioning and the cause of poor sibling adjustment is not tenable" (p. 415).

Attrition of study populations is commonly found in longitudinal research (Botwinick, 1984), and this has certainly been the case here, with the number of parents considerably diminished over the years by deaths. Among the survivors, however, there is no indication in the group as a whole that their lives have become more stressful over the years, nor their families traumatised. If this had been put to the parents when their babies were first diagnosed, at a time when apprehensions about the future loom large for these mothers (Kingston, 2007), as the most likely prospect for them in 40 years time, they would I believe have been greatly comforted and encouraged.

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