

Mothers of children and adolescents with intellectual disability: social and economic situation, mental health status, and the self-assessed social and psychological impact of the child's difficulties

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Abstract

Background Few large-scale studies with well-constructed samples have compared the socio-economic circumstances and social impact of raising a child with intellectual disability (ID). The aims of the present paper were to: (1) compare the socio-economic situation of mothers raising a child with ID to that of mothers of non-ID children; (2) assess the contribution of raising a child with ID to negative psychological outcomes for mothers; and (3) identify variables associated with negative psychological outcomes among mothers of children with ID.

Methods The 1999 Office for National Statistics survey, *Mental Health of Children and Adolescents in Great Britain, 1999*, collected information on a multistage stratified random sample of 10 438 children between 5 and 15 years of age across 475 postal code sectors in England, Scotland and Wales. Secondary analysis was undertaken of the social and economic circumstances, and stress reported by 245 mothers of sam-

pled children with ID and a comparison group of 9 481 mothers of sampled children who did not have ID.

Results *The results indicate that:* (1) families supporting a child with ID were significantly economically disadvantaged when compared with families supporting a child who did not have ID; (2) when compared with mothers of sampled children who did not have ID, mothers of sampled children with ID reported that their child's difficulties resulted in greater social and psychological impact; (3) having a child with ID marginally reduced the odds of mothers screening positive for having mental health problems (once all other variables were taken into account); and (4) among mothers of children with ID, mental health problems were associated with the child's difficulties having a greater social impact, having a boy, the child experiencing more than one potentially stressful life event, poverty, receipt of means-tested welfare benefits and 'unhealthy' family functioning.

Conclusions These results highlight the importance of combating poverty among children with ID and their families, and the need to develop more complex models of understanding and intervention.

Keywords adolescents, children, economic situation, mothers, stress

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Introduction

In most if not all countries, the vast majority of children with intellectual disability (ID) live in a family context with either their biological or substitute parent(s) (Fujiura 1998; Braddock *et al.* 2001). Research investigating the context within which families raise a child with ID has addressed a number of connected themes. These have included the socio-economic context faced by families and the impact that raising a child with ID may have on parental and family functioning (Crnic *et al.* 1983; Ramey *et al.* 1989; Baker *et al.* 1997; Blacher & Hatton 2001; Seltzer *et al.* in press).

Evidence from the UK and USA suggests that families bringing up a child with ID often do so in a context of pervasive economic and social disadvantage. In an analysis of data collected in 34 000 households in the USA, Fujiura (1998) reported that households containing a person with ID, when compared with households generally: (1) included more people; (2) received lower aggregate household incomes; (3) were more dependent on means-tested income support; and (4) were more likely to subsist below the poverty line (20% versus 13%).

Evidence from both the USA and UK suggests that families from minority ethnic groups and lone parents are particularly at risk of facing significant economic disadvantage (e.g. Fujiura & Yamaki 1997; Fujiura 1998; Hatton *et al.* 2001).

Historically, research investigating the impact of raising a child with ID has focused on a range of negative outcomes experienced by parents, primarily mothers (Crnic *et al.* 1983; Ramey *et al.* 1989; Baker *et al.* 1997; Blacher & Hatton 2001; Seltzer *et al.* in press). These have included: low rates of employment or delayed entry to the workforce (e.g. Shearn & Todd 2000; Seltzer *et al.* 2001), social isolation (e.g. Seltzer *et al.* 2001), stress (e.g. Quine & Pahl 1985, 1991; Sloper *et al.* 1991; Stores *et al.* 1998; Hatton *et al.* 2001) and depression (e.g. Blacher *et al.* 1997; Olsson & Hwang 2001).

More recently, research on the family context has broadened its scope and sophistication to examine such issues as: the benefits associated with bringing up a child with ID (e.g. Beresford 1994; Scorgie & Sobsey 2000); bi-directional associations between family functioning and child development (e.g. Keogh *et al.* 2000); the impact of raising a child with

ID on fathers (e.g. Krauss 1993), siblings (e.g. Stoneman 2001), grandparents (e.g. Hastings 1997) and adoptive parents (e.g. Glidden & Pursley 1989); the situation of families from minority ethnic groups (e.g. Blacher *et al.* 1997; Fujiura & Yamaki 1997; Hatton *et al.* 2001; Hatton in press); and the identification of factors which may be associated with variations in outcomes. These have included: child characteristics such as challenging behaviour (e.g. Quine & Pahl 1985, 1991; Sloper *et al.* 1991; Blacher *et al.* 1997; Stores *et al.* 1998; Hastings 2003), gender (Frey *et al.* 1989), communication ability (Frey *et al.* 1989) and difficulty of caregiving (Gowen *et al.* 1989); ethnicity (e.g. Flynt & Wood 1989; Hatton *et al.* 2001); maternal age (e.g. Flynt & Wood 1989); socio-economic circumstances (e.g. Hatton *et al.* 2001); social support (e.g. Hatton *et al.* 2001); and coping strategies adopted by parents (e.g. Frey *et al.* 1989; Quine & Pahl 1991; Essex *et al.* 1999; Grant & Whittell 2000).

In 1999, the Social Survey Division of the Office for National Statistics (ONS) undertook a major study of the mental health of over 10 000 children and adolescents in the UK (Meltzer *et al.* 2000). The aim of the present paper is to present a secondary analysis of these data that focuses on the social and economic circumstances, mental health status, and self-assessed impact reported by mothers of children and adolescents with ID. Analyses investigating the prevalence of psychiatric disorders among children with ID, and the strengths and difficulties reported by the children themselves are presented in associated papers (Emerson 2001; Emerson 2003).

Subjects and methods

Secondary analysis was undertaken of data collected by the ONS survey of the *Mental Health of Children and Adolescents in Great Britain, 1999* (Meltzer *et al.* 2000). Relevant data files (ONSSSD 1999) were obtained from the Economic and Social Research Council (ESRC) Data Archive.

Sample

Full details of the sampling procedure are presented in Meltzer *et al.* (2000). Briefly, the ONS survey collected information on a multistage stratified random sample of 10 438 children between 5 and 15 years of age (83% of the target sample of 12 529

eligible children). The sample, stratified by region, age and sex, covered 475 postal code sectors in England, Scotland and Wales. Information was collected by interview with the child's primary carer (in 94% of cases the child's mother), and wherever possible for children aged 11 years or over, with the child themselves. Information was also collected by postal questionnaire from the child's teacher.

Information derived from fathers was excluded from further analysis since: (1) the vast majority of respondents (94%) were mothers; and (2) gender differences in responding to measures of stress and self-assessed impact may confound results (Seltzer *et al.* in press). This produced a final sample of 9726 mother-child dyads.

Definition of intellectual disability

The ONS survey did not include a specific measure of ID. As a result, it was necessary to combine survey items to operationally identify children who were likely to have ID. A child was defined as having ID if either: (1) their parents reported that their child had 'learning difficulties' and that they had been seriously concerned about their child's language development during the first 3 years of their life; or (2) the child attended a school for children with 'learning difficulties' (the term employed within UK educational services that is equivalent to ID or mental retardation). Children were subsequently excluded from this group if information collected from teachers indicated that any of the following three conditions were met: (1) the child was reported by teachers in mainstream schools to be of average ability in either reading, mathematics or spelling; (2) their developmental age (as estimated by their class teacher) was greater than 80% of their chronological age; (3) they were at least 7 years of age and had not progressed reached stage 3 (involvement of external professional support) in the process of the identification of special educational needs (DoE 1994).

The operational definition employed in the present study led to the identification of 245 children and adolescents aged 5–15 years as having ID (and 9481 children and adolescents as not having ID). This is equivalent to an overall age-specific prevalence rate for ID within the sample of 2.6%. The prevalence of ID in the sample varied as a function of gender, age and social deprivation (for details, see Emerson

2003) in a manner consistent with that reported in the epidemiological literature (e.g. Roeleveld *et al.* 1997; Larson *et al.* 2001).

Measures

Social functioning of the family

Measures collected by the ONS survey to assess the social functioning of the family included: the General Health Questionnaire (GHQ-12; Goldberg & Williams 1988) to estimate psychiatric morbidity among parental informants; the General Functioning Scale of the MacMaster Family Activity Device (FAD; Miller *et al.* 1985; Byles *et al.* 1988) to identify 'unhealthy' patterns of family functioning; and a nine-item scale exploring the use of reward- and punishment-based child management practices (Meltzer *et al.* 2000).

Psychiatric disorders and strengths and difficulties of the child

The presence of psychiatric disorders among children and adolescents was identified through the use of the Development and Well Being Assessment (DAWBA; Goodman *et al.* 2000). This consists of two structured interviews (one undertaken with the child's primary carer and the other undertaken, for children aged 11 years or more, with the child themselves), a questionnaire used with the child's teacher and a computer-assisted diagnostic rating system that provides diagnoses against Diagnostic and Statistical Manual – IV and International Classification of Diseases, 10th Revision (ICD-10) criteria (Meltzer *et al.* 2000). The DAWBA has been shown to correlate highly with the Strengths and Difficulties Questionnaire (SDQ; Goodman 1997) and diagnoses contained in clinic records, to discriminate well between community-based and clinic-based samples of children, and to possess excellent levels of inter-rater agreement (Goodman *et al.* 2000; Fombonne *et al.* 2001).

Child and carer interviews and the postal questionnaire distributed to teachers also incorporated the extended versions of the SDQ (Goodman 1997, 1999; Goodman *et al.* 1998). This consists of 25 statements relating to specific strengths and difficulties faced by the child. The parent and child versions of the extended SDQ (Goodman 1999) also contain

items to assess the level of distress the problems cause for the child, the impact of the child's problems on different aspects of their lives and the level of difficulty presented by the child's problems for their family. The SDQ has been shown to correlate highly with the Rutter Child Scales (Goodman 1997), the Child Behavior Checklist (Goodman & Scott 1999) and the Child and Adolescent Burden Assessment (Goodman 1999), to have acceptable levels of test-retest reliability (Goodman 1999), and to discriminate well between community-based and clinic-based samples of children (Goodman *et al.* 1998, 1999).

Life events

The ONS survey included a 10-item measure of potentially stressful life events experienced by the child (Meltzer *et al.* 2000).

Results

Characteristics of the child

Information on selected characteristics of the sampled children is presented in Table 1.

As can be seen, children with ID were more likely to be male, have an ICD-10 diagnosis, have more than one ICD-10 diagnosis and to have a more general difficulties than children who do not have ID. Analyses of the interrelationships between child characteristics are provided in Emerson (2003).

Social and economic characteristics of families bringing up a child with intellectual disability

Information on the social and economic situation of the sampled children's families is presented in Table 2. On all indicators of socio-economic position,

Table 1 Selected characteristics of the child and adolescent participants with and without intellectual disability (ID): (NS) not significant; (d.f.) degree of freedom; (ICD-10) International Classification of Diseases, 10th Revision; and (SDQ) Strengths and Difficulties Questionnaire

Variable	Children with ID	Children without ID	Statistical significance
Age (years):			
5–10	54%	57%	
11–15	46%	43%	NS
Gender (boys)	72%	49%	$\chi^2 = 48.6$, d.f. = 1, $P < 0.001$
Ethnicity:			
White	94%	93%	
Black	3%	2%	
South Asian	2%	3%	
other	2%	2%	NS
Prevalence of ICD-10 psychiatric disorder:			
any disorder	38%	8%	$\chi^2 = 272.8$, d.f. = 1, $P < 0.001$
emotional disorder	10%	4%	$\chi^2 = 21.6$, d.f. = 1, $P < 0.001$
conduct disorder	25%	4%	$\chi^2 = 221.2$, d.f. = 1, $P < 0.001$
pervasive developmental disorder	7%	0%	$\chi^2 = 387.3$, d.f. = 1, $P < 0.001$
Number of ICD-10 diagnosed disorders:			
one	18%	6%	
two	16%	2%	
three or more	4%	1%	Mann–Whitney $z = 16.88$, $P < 0.001$
Mean SDQ Scores:			
total difficulties (parent)	16.6	8.1	Mann–Whitney $z = 17.34$, $P < 0.001$
total difficulties (child)	14.1	10.1	Mann–Whitney $z = 6.27$, $P < 0.001$
total difficulties (teacher)	15.3	6.1	Mann–Whitney $z = 14.31$, $P < 0.001$
prosocial behaviour (parent)	7.7	8.6	Mann–Whitney $z = 7.00$, $P < 0.001$
prosocial behaviour (child)	7.9	8.0	NS
prosocial behaviour (teacher)	5.2	7.4	Mann–Whitney $z = 9.20$, $P < 0.001$

E. Emerson • Mothers of children with ID

Table 2 Economic and social characteristics of the families of the child and adolescent participants with or without intellectual disability (ID): (NS) not significant; and (d.f.) degree of freedom

Variable	Children with ID	Children without ID	Statistical significance
Social class:			
I-II	30%	41%	Mann-Whitney $z = 4.73, P < 0.001$
III	37%	39%	
IV-V	33%	21%	
Jarman quintile:*			
1	27%	16%	Mann-Whitney $z = 4.30, P < 0.001$
2	25%	22%	
3	17%	21%	
4	16%	21%	
5	15%	20%	
Educational level of mother:			
graduate/professional qualification	10%	23%	$\chi^2 = 74.7, d.f. = 5, P < 0.001$
A-level	7%	10%	
GCSE grades A-C	20%	30%	
GCSE grades D-F	16%	12%	
none	42%	21%	
other	5%	3%	
Weekly household income (£):			
< 100	6%	5%	Mann-Whitney $z = 6.45, P < 0.001$
100-199	30%	17%	
200-299	24%	15%	
300-399	9%	13%	
400-499	10%	11%	
500-599	5%	11%	
600-770	9%	13%	
> 770	7%	17%	
Poverty [†]	44%	30%	
Type of accommodation:			
detached house/bungalow	14%	26%	$\chi^2 = 23.7, d.f. = 3, P < 0.001$
semi-detached house/bungalow	38%	39%	
terraced house/bungalow	39%	30%	
flat	9%	6%	
Tenure:			
owner	44%	69%	$\chi^2 = 80.6, d.f. = 2, P < 0.001$
social-sector tenant	50%	25%	
rents privately	6%	6%	
Marital status:			
married	60%	71%	$\chi^2 = 13.6, d.f. = 2, P < 0.001$
cohabiting	11%	8%	
lone parent	29%	21%	
Number of adults living in the household:			
1	21%	17%	NS
2	60%	67%	
3	14%	13%	
≥ 4	5%	3%	
Number of children living in the household			
1	20%	21%	NS
2	45%	46%	
3	20%	23%	
4	9%	8%	
≥ 5	5%	3%	

*An indicator of neighbourhood deprivation ranging from (1) the neighbourhoods which fall within the most deprived 20% in the UK and (5) the neighbourhoods which fall within the least deprived 20% in the UK.

[†]Net household income less than 60% of the national median.

families where the sampled child had ID were significantly more disadvantaged than families where the sampled child did not have ID.

Among families supporting a child with ID, lone mothers, when compared with mothers living with a partner: (1) were more likely to be living in poverty (86% versus 31%; $\chi^2 = 60.1$, d.f. = 1, $P < 0.001$); (2) lived in more socially deprived areas (38% versus 22% of mothers living in areas scoring in the 20% most deprived in the UK; Mann-Whitney $z = 3.06$, $P < 0.01$); (3) were less likely to be home owners (17% versus 55%; $\chi^2 = 30.0$, d.f. = 1, $P < 0.001$); and (4) were less likely to live in detached or semi-detached housing (39% versus 58%; $\chi^2 = 5.9$, d.f. = 1, $P < 0.05$).

Among families supporting a child with ID, mothers from minority ethnic groups: (1) lived in more socially deprived areas (67% versus 22% of mothers living in areas scoring in the 20% most deprived in the UK; Mann-Whitney $z = 3.48$, $P < 0.001$); and (2) were less likely to live in detached or semi-detached housing (13% versus 55%; $\chi^2 = 8.1$, d.f. = 1, $P < 0.01$).

Family functioning and the self-reported impact of child difficulties

Information on family functioning (from the FAD), child management practices and the self-reported impact of the sampled child's difficulties (from the SDQ and DAWBA) are presented in Table 3.

Items from the mothers' self-report of the social impact of their child's difficulties (see Table 3) were summed to create a Mother's Self-Assessed Social Impact Scale (MSASIS). This had good internal consistency for mothers of sampled children with ID (Cronbach's $\alpha = 0.72$) and without ID (Cronbach's $\alpha = 0.73$). Scores on the MSASIS were significantly greater for mothers of sampled children with ID than for mothers of sampled children without ID (Mann-Whitney $z = 16.79$, $P < 0.001$).

As can be seen in Table 3, an identical percentage of mothers of sampled children with ID (14%) reported that their child's difficulties had strengthened and weakened their relationships with their partners. In addition, a significant minority of mothers (11%) reported that their child's difficulties had strengthened the relationships between the child and their brothers and sisters. A series of exploratory bi-

variate analyses were undertaken to identify variables (listed in Table 5) associated with mother's reporting that their child's difficulties had either strengthened their relationships with their partners, or relationships between the sampled child and their siblings.

Strengthening of relationships with their partner was associated with having experienced no or only one potentially significant life event [odds ratio (OR) = 4.40; $\chi^2 = 7.14$, d.f. = 1, $P < 0.01$] and healthy family functioning (OR = 3.38; $\chi^2 = 4.28$, d.f. = 1, $P < 0.05$). There were trends for strengthening of relationships with their partner to be associated with having a younger child (age < 11 years) (OR = 2.99; $\chi^2 = 3.79$, d.f. = 1, $P = 0.051$) and not receiving family credit (OR = 2.18; $\chi^2 = 3.45$, d.f. = 1, $P = 0.063$).

Strengthening of relationships between the sampled child and their siblings was associated with the sampled child not having an ICD-10 diagnosis of conduct disorder (OR = 7.69; $\chi^2 = 9.44$, d.f. = 1, $P < 0.01$), not having two or more ICD-10 diagnoses (OR = 5.56; $\chi^2 = 6.06$, d.f. = 1, $P < 0.05$), and not having any ICD-10 diagnosis (OR = 3.75; $\chi^2 = 5.89$, d.f. = 1, $P < 0.05$).

Mental health of mothers

Information on the self-reported psychological impact of the child's difficulties (from the DAWBA) and the GHQ-12 are presented in Table 4.

Items from the mothers' self-report of the psychological impact of their child's difficulties (see Table 4) were summed to create a Mother's Self-Assessed Psychological Impact Scale (MSAPIS). This had excellent internal consistency for mothers of sampled children with ID (Cronbach's $\alpha = 0.83$) and without ID (Cronbach's $\alpha = 0.85$). Scores on the MSAPIS were significantly greater for mothers of sampled children with ID than for mothers of sampled children without ID (Mann-Whitney $z = 20.78$, $P < 0.001$).

A series of multivariate analyses (forward stepwise logistic regression: $P_{(\text{variable entry})} < 0.05$, $P_{(\text{variable removal})} < 0.1$) were employed to identify variables associated with: (1) the 'caseness' on the GHQ-12 (score > 2); (2) an above-median score on the MSASIS; (3) an above-median score on the MSAPIS; and (4) 'unhealthy' family functioning on the FAD (score > 2). Candidate predictor variables are listed in Table 5. All predictor variables were in binary format, thus allowing for the calculation of corrected

E. Emerson • Mothers of children with ID

Table 3 Family functioning and mothers' self-assessment of the social impact of the difficulties of the sampled child or adolescent with or without intellectual disability (ID): (NS) not significant; (d.f.) degree of freedom; and (SDQ) Strengths and Difficulties Questionnaire

Variable	Children with ID	Children without ID	Statistical significance
Family functioning: [*] unhealthy	29%	18%	$\chi^2 = 18.5$, d.f. = 1, $P < 0.001$
Child management practices (mean score): punishment	11.7	11.2	Mann-Whitney $z = 2.89$, $P < 0.01$
reward	10.2	10.1	NS
Mean SDQ impact score: mother self-report	6.9	1.6	Mann-Whitney $z = 20.57$, $P < 0.001$
child self-report	3.3	1.5	Mann-Whitney $z = 5.60$, $P < 0.001$
teacher self-report	5.9	1.4	Mann-Whitney $z = 17.59$, $P < 0.001$
<i>Mother self-report items (percentage of all mothers)</i>			
Child's difficulties have made relationship with partner: stronger	14%	2%	NS
more strained	14%	3%	
no difference	72%	95%	
Child's difficulties contributed to break up with previous partner: to a great extent	21%	5%	Mann-Whitney $z = 3.81$, $P < 0.001$
to some extent	10%	8%	
not at all	69%	87%	
Child's difficulties have made my relationships with other children: stronger	11%	2%	Mann-Whitney $z = 4.61$, $P < 0.001$
more strained	19%	3%	
no difference	70%	95%	
Child's difficulties have made their relationships with their brothers and sisters: stronger	11%	2%	Mann-Whitney $z = 4.29$, $P < 0.001$
more strained	20%	4%	
no difference	69%	94%	
Child's difficulties have caused me problems with other members of my family: yes	19%	4%	$\chi^2 = 159.3$, d.f. = 1, $P < 0.001$
Child's difficulties have caused me problems with my friends: yes	11%	2%	$\chi^2 = 134.0$, d.f. = 1, $P < 0.001$
Child's difficulties have disrupted my own leisure and social activities: to a great extent	18%	2%	Mann-Whitney $z = 20.68$, $P < 0.001$
to some extent	24%	5%	
not at all	58%	93%	
Child's difficulties have disrupted leisure and social activities with my child: to a great extent	17%	2%	Mann-Whitney $z = 20.18$, $P < 0.001$
to some extent	22%	4%	
not at all	61%	95%	
Others disapprove of or avoid me because of my child's difficulties: yes	25%	3%	$\chi^2 = 302.5$, d.f. = 1, $P < 0.001$

*Classification on the GFS-FAD.

E. Emerson • Mothers of children with ID

Table 4 Mothers' mental health assessed using the General Health Questionnaire (GHQ-12) and the self-assessed psychological impact of the difficulties of the sampled child or adolescent with or without intellectual disability (ID): (d.f.) degree of freedom; and (SDQ) Strengths and Difficulties Questionnaire

Variable	Children with ID	Children without ID	Statistical significance
GHQ-12:			
mean score	2.6	1.8	Mann-Whitney $z = 4.89, P < 0.001$
percentage 'unhealthy' (score > 2)	35%	25%	$\chi^2 = 13.9, d.f. = 1, P < 0.001$
<i>Mother self-report items (percentage of all)</i>			
I am embarrassed about my child's difficulties:			
yes	20%	4%	$\chi^2 = 149.9, d.f. = 1, P < 0.001$
Child's problems have made me worried:			
to a great extent	36%	5%	Mann-Whitney $z = 19.61, P < 0.001$
to some extent	34%	15%	
not at all	31%	80%	
Child's problems have made me depressed:			
to a great extent	14%	2%	Mann-Whitney $z = 17.93, P < 0.001$
to some extent	30%	7%	
not at all	56%	91%	
Child's problems have made me tired:			
to a great extent	24%	4%	Mann-Whitney $z = 20.17, P < 0.001$
to some extent	31%	8%	
not at all	45%	88%	
Child's problems have made me physically ill:			
to a great extent	7%	1%	Mann-Whitney $z = 13.93, P < 0.001$
to some extent	13%	2%	
not at all	80%	97%	
I have seen a doctor because of difficulties coping with my child:			
yes	22%	4%	$\chi^2 = 207.8, d.f. = 1, P < 0.001$

ORs for all significant associations. Interval or ordinal-level variables were converted to binary format by employing a median split. Analyses were undertaken on mothers of sampled children with ID and separately for mothers of sampled children without ID. The results are given in Tables 6 and 7. They are also summarized graphically for all statistically significant associations in which the corrected OR is greater or equal to 2.0 in Figs 1 and 2. Eight children with ID and 155 children without ID were excluded from these analyses because of missing data on one or more variables.

The corrected ORs given in the tables and figures are measures of effect size which assess the contribution of one variable while controlling for the effects of other variables in the equation. As such, they can point to associations which are socially or clinically significant, as opposed to being merely statistically

significant. This is particularly important when undertaking research with large samples. Corrected ORs may be combined multiplicatively to assess the impact of combinations of variables. Thus, for example, the odds of the mother of a sampled child who has ID screening positive for having an adverse mental health status are increased by 189 times ($2.63 \times 2.84 \times 2.90 \times 2.30 \times 3.79$) if the mother receives family credit, their child has experienced a greater number of life events, is a boy and part of an 'unhealthy' family, and she reports higher self-assessed social impact of their child's difficulties (when compared with mothers who show none of these characteristics; see Table 6 and Fig. 1). Similarly, the odds of mothers in general screening positive for having an adverse mental health status are increased 1.7 times (70%) if the mother is a lone parent, is not a home owner and lives in poverty

Table 5 Candidate predictor variables: (ICD-10) International Classification of Diseases, 10th Revision; and (ID) intellectual disability

Socio-economic circumstances:	
educational level of mother (none or GCSE D-F versus higher)	
home owner (yes/no)	
housing type (detached or semi-detached versus terraced or flat)	
poverty (net household income <60% of national median)	
receipt of family credit (yes/no)	
Household composition:	
lone parent (yes/no)	
number of adults living in the household (1-2 versus ≥3)	
number of children living in the household (1-2 versus ≥3)	
Characteristics of the sampled child:	
age group (5-10 or 11-15 years)	
gender (boy/girl)	
ID (yes/no)	
physical disability (yes/no)	
any ICD-10 diagnosis (yes/no)	
more than one ICD-10 diagnosis (yes/no)	
ICD-10 diagnosis of conduct disorder (yes/no)	
ICD-10 diagnosis of emotional disorder (yes/no)	
ICD-10 diagnosis of pervasive developmental disorder (yes/no)	
Family functioning :	
use of reward-based child management practices (Y-score >10)	
use of punishment-based child management practices (Y-score >11)	
'healthy' family functioning (Y-score >2)	
Number of potentially stressful life events experienced by sampled child (none versus one or more)	
Mother's self-assessed impact of sampled child's difficulties:	
psychological (Y-score >3)	
social (Y-score >4)	

(1.26 × 1.21 × 1.19) (when compared with mothers who show none of these characteristics; see Table 7).

These results identify a number of direct associations between the assessed mental health status of the sampled child's mother and: (1) indicators of deprivation (e.g. receipt of family credit); (2) the number of potentially stressful life events experienced by the child (and presumably the family); (3) the mother's self-assessed social impact of the sampled child's difficulties; (4) family functioning; and (5) the gender of the sampled child.

Among mothers in general (Table 6, Fig. 2), having a child with ID marginally reduced the odds of

screening positive for having an adverse mental health status (once all other variables were taken into account). However, having a child with ID did increase the odds of scoring high on self-assessed psychological and social impact (again, once all other variables were taken into account).

Given the association between maternal distress, and both socio-economic status and the emotional and behavioural difficulties of children with ID, an additional series of exploratory analyses were undertaken. These indicated that socio-economic status appeared to moderate the association between maternal distress, and the emotional and behavioural difficulties of children with ID. Thus, for example, the presence of an ICD-10 diagnosis was significantly associated with maternal caseness on the GHQ-12 only for families not living in poverty [not poverty OR = 3.2; $\chi^2 = 7.7$, d.f. = 1, $P < 0.01$; poverty OR = 1.6; $\chi^2 = 1.0$, d.f. = 1, not significant (NS)] and only for families living in less-deprived neighbourhoods (not deprived neighbourhood OR = 3.0; $\chi^2 = 6.2$, d.f. = 1, $P < 0.05$; deprived neighbourhood OR = 2.0; $\chi^2 = 2.9$, d.f. = 1, NS).

Discussion

The ONS survey of the *Mental Health of Children and Adolescents in Great Britain, 1999* collected information on a multistage stratified random sample of 10 438 children between 5 and 15 years of age across England, Scotland and Wales (Meltzer *et al.* 2000). Secondary analysis of data on 9726 mother-child dyads indicated that: (1) families supporting a child with ID were significantly economically disadvantaged when compared with families supporting a child who did not have ID; (2) mothers of sampled children with ID, when compared with mothers of sampled children who did not have ID, reported that their child's difficulties resulted in greater social and psychological impact; (3) having a child with ID marginally reduced the odds of mothers screening positively for having mental health problems (once all other variables were taken into account); and (4) among mothers of children with ID, mental health problems were associated with the child's difficulties having a greater social impact, having a boy, the child experiencing more than one potentially stressful life event, receipt of means-tested welfare benefits and 'unhealthy' family functioning.

Table 6 Results of logistic regression analyses of the mothers of the sampled child or adolescent with intellectual disability ($n = 237$): (GHQ-12) General Health Questionnaire; (d.f.) degree of freedom; and (ICD-10) International Classification of Diseases, 10th Revision

Dependent and predictor variables	Corrected odds ratio	P-value
<i>Mothers' GHQ-12 category (unhealthy)</i>		
Nagelkerke $R^2 = 0.301$; model $\chi^2 = 58.6$, d.f. = 5, $P < 0.001$		
(Greater) self-assessed social impact	3.79	<0.001
Gender of sampled child (boy)	2.90	0.005
More than one potentially significant life event	2.84	0.001
Receipt of family credit	2.63	0.054
Unhealthy family functioning	2.30	0.011
<i>Mothers' self-assessed social impact of sampled child's difficulties (greater)</i>		
Nagelkerke $R^2 = 0.469$; model $\chi^2 = 102.7$, d.f. = 4, $P < 0.001$		
(Greater) self-assessed psychological impact	8.70	<0.001
More than one ICD-10 diagnosis	4.23	0.011
ICD-10 diagnosis of conduct disorder	2.71	0.023
Sampled child also has a physical disability	2.37	0.013
<i>Mothers' self-assessed psychological impact of sampled child's difficulties (greater)</i>		
Nagelkerke $R^2 = 0.452$; model $\chi^2 = 98.1$, d.f. = 4, $P < 0.001$		
ICD-10 diagnosis of pervasive developmental disorder	15.01	0.020
(Greater) self-assessed social impact	10.53	<0.001
More than one potentially significant life event	3.47	<0.001
Poverty	2.06	0.031
<i>Family functioning (unhealthy)</i>		
Nagelkerke $R^2 = 0.079$; model $\chi^2 = 13.5$, d.f. = 2, $P = 0.001$		
(Greater) self-assessed social impact	2.08	0.016
More than one potentially significant life event	2.01	0.020

The external validity of these results is determined in large part by the sampling strategy employed by the ONS. The use of high-response-rate, multistage, stratified, random samples of over 10 000 children and families across three countries is uncommon in the family research in the field of ID (Seltzer *et al.* in press).

The main threat to the external validity of these results is presented by the necessity to use an operational definition of ID that has not been independently validated. However, as reported elsewhere, the validity of this operational definition is supported by the following observations: (1) the use of the definition resulted in an overall prevalence rate that is consistent with the existing epidemiological literature; (2) the observed prevalence rates varied as a function of age, gender and social deprivation in a manner consistent with the existing epidemiological literature; and (3) the use of the definition resulted in prevalence rates for psychiatric disorders among children and adolescents which are highly

consistent with the existing literature (Emerson 2003).

Three aspects of these results will be discussed below: (1) the socio-economic situation of families raising a child with ID; (2) the association between raising a child with ID and the mental health status of mothers; and (3) factors associated with negative psychological outcomes for mothers of children with ID.

The data presented are consistent with the results of previous studies in suggesting that families supporting children with ID are at increased risk of socio-economic disadvantage, and that this may be particularly so for lone mothers and mothers from minority ethnic groups (Beresford 1995; Fujiura & Yamaki 1997; Fujiura 1998; Hatton *et al.* 2001). In the UK in 1999, 86% of lone mothers bringing up a child with ID were doing so under conditions of poverty. Similar socio-economic inequalities have been reported for the families of children with a range of disabilities (Gordon *et al.* 2000) and are likely to

E. Emerson • Mothers of children with ID

Table 7 Results of logistic regression analyses undertaken on the total sample of mothers ($n = 9563$): (GHQ-12) General Health Questionnaire; (ICD-10) International Classification of Diseases, 10th Revision; (d.f.) degree of freedom; and (ID) intellectual disability

Dependent and predictor variables	Corrected odds ratio	P-value
<i>Mothers GHQ-12 category (unhealthy)</i>		
Nagelkerke $R^2 = 0.146$; model $\chi^2 = 995.9$, d.f. = 10, $P < 0.001$		
(Greater) self-assessed psychological impact	2.31	<0.001
Unhealthy family functioning	2.27	<0.000
More than one potentially significant life event	1.67	<0.001
(Greater) self-assessed social impact	1.57	<0.001
Sampled child <i>not</i> having ID	1.40	0.027
Sampled child has an ICD-10 diagnosis of emotional disorder	1.38	0.006
Lone parent	1.26	0.001
Not a home owner	1.21	0.003
Poverty	1.19	0.010
Older child	1.16	0.003
<i>Mothers self-assessed social impact of sampled child's difficulties (greater)</i>		
Nagelkerke $R^2 = 0.508$; model $\chi^2 = 3051.0$, d.f. = 11, $P < 0.001$		
(Greater) self-assessed psychological impact	27.78	<0.001
Sampled child has an ICD-10 diagnosis	3.99	<0.001
Sampled child <i>has</i> ID	2.21	<0.001
Unhealthy family functioning	2.02	<0.001
Sampled child has an ICD-10 diagnosis of emotional disorder	1.57	0.024
Sampled child has a physical disability	1.56	<0.001
More than one potentially significant life event	1.46	<0.001
(Lower) level of mother's educational attainment	1.33	0.002
More than two children living in the household	1.31	0.002
(Greater use of) punishment in child management	1.30	0.002
Gender of sampled child (boy)	1.26	0.006
<i>Mothers self-assessed psychological impact of sampled child's difficulties (greater)</i>		
Nagelkerke $R^2 = 0.548$; model $\chi^2 = 3053.8$, d.f. = 11, $P < 0.001$		
(Greater) self-assessed social impact	28.57	<0.001
Sampled child has an ICD-10 diagnosis	4.48	<0.001
Sampled child has more than one ICD-10 diagnosis	3.19	<0.001
Sampled child <i>has</i> ID	2.43	<0.001
Sampled child does <i>not</i> have an ICD-10 diagnosis of emotional disorder	1.87	0.002
Sampled child has a physical disability	1.68	<0.001
Poverty	1.52	<0.001
Unhealthy family functioning	1.51	<0.001
(Greater use of) punishment in child management	1.49	<0.001
More than one potentially significant life event	1.28	0.008
More than two children living in the household	1.28	0.010
<i>Family functioning (unhealthy)</i>		
Nagelkerke $R^2 = 0.100$; model $\chi^2 = 611.7$, d.f. = 10, $P < 0.001$		
(Greater) self-assessed social impact	2.02	<0.001
(Lower) level of mother's educational attainment	1.60	<0.001
(Less use of) reward in child management	1.52	<0.001
(Greater) self-assessed psychological impact	1.45	<0.001
(Greater use of) punishment in child management	1.43	<0.001
Sampled child has an ICD-10 diagnosis of conduct disorder	1.42	0.002
(Lower) income	1.32	<0.001
Three or more adults living in the household	1.27	0.001
(Not a) home owner	1.19	0.009
Older child	1.17	0.007

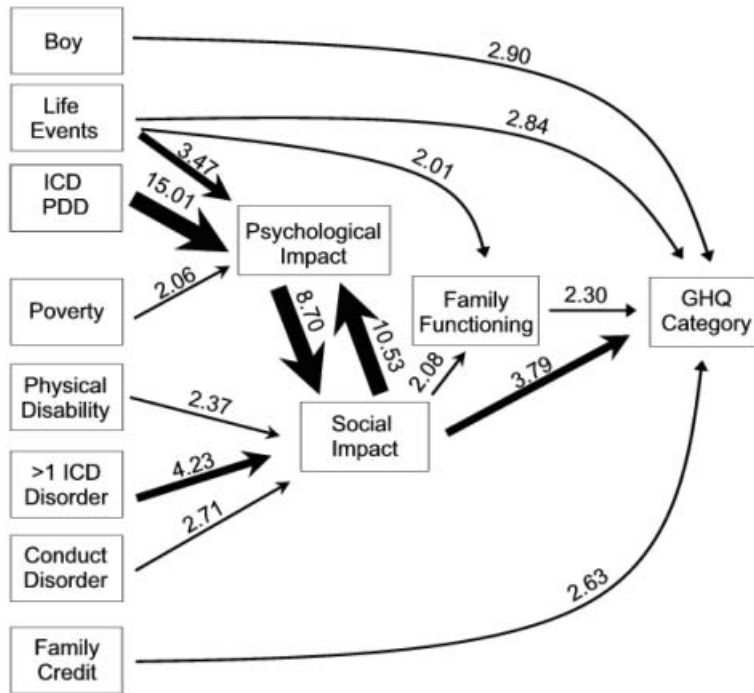


Figure 1 Results of the logistic regression analyses of the mothers of the sampled child with intellectual disability ($n = 237$): (ICD-10) International Classification of Diseases, 10th Revision; (PDD) pervasive developmental disorder; and (GHQ) General Health Questionnaire.

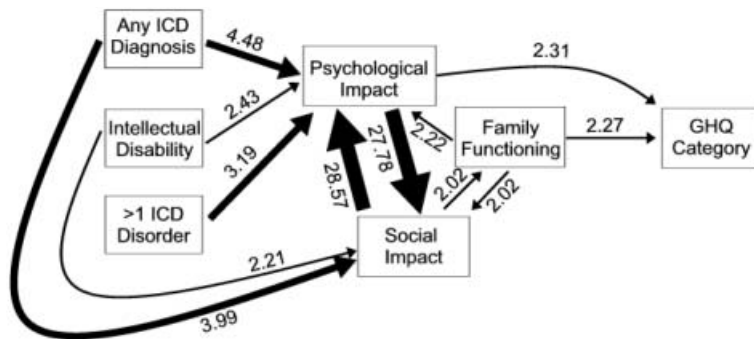


Figure 2 Results of the logistic regression analyses of the total sample of mothers ($n = 9563$): (ICD-10) International Classification of Diseases, 10th Revision; and (GHQ) General Health Questionnaire.

reflect the operation of a number of factors including the association between socio-economic deprivation and the incidence of less severe forms of ID (Roeleveld *et al.* 1997), and the direct and indirect economic impact of raising a child with ID (Beresford 1995; Hatton *et al.* 2001). As discussed below, socio-economic deprivation was associated within the present study with poorer psychological outcomes for mothers in general and for mothers of children with ID. These observations make a strong case for targeting interventions at reducing poverty among children with ID and their families (FPLD 2003).

The use of a large, well-constructed, population-based sample makes it possible to assess the unique contribution made by having a child with ID to the self-reported psychological distress and mental health status of mothers (Table 7, Fig. 2). In the results presented above, having a child with ID marginally reduced the odds of screening positive for having an adverse mental health status (once other relevant variables were taken into account). Among mothers in general, possible psychiatric morbidity was associated with self-assessed psychological and social impact of the child's difficulties, 'unhealthy' family

functioning, exposure to more potentially stressful life events, emotional disorders in the sampled child and indicators of socio-economic deprivation. However, having a child with ID was associated with an increased probability of the child's mother scoring highly on self-assessed psychological and social impact (again, once other relevant variables were taken into account).

This pattern of results suggests that, as would be predicted from the existing literature, mothers of children with ID do experience considerable levels of psychological distress and social disruption as a result of social deprivation, and their child's emotional and behavioural difficulties (Crnic *et al.* 1983; Ramey *et al.* 1989; Baker *et al.* 1997; Blacher & Hatton 2001; Seltzer *et al.* in press). However, once these factors have been taken into account, that their child has ID appears to be moderately protective of possible psychiatric morbidity. It is not possible within the present data to identify the possible mechanisms underlying this association.

Among mothers of children with ID, psychiatric/behavioural problems exhibited by the child were strongly associated with the level of the mother's self-assessed psychological distress and social impact (cf. Quine & Pahl 1985, 1991; Sloper *et al.* 1991; Blacher *et al.* 1997; Stores *et al.* 1998; Hastings 2003). Possible psychiatric morbidity among mothers of children with ID was associated with, in order of predictive importance, the social impact of the child's difficulties, child gender (cf. Frey *et al.* 1989), exposure to more than one potentially stressful life event, economic deprivation (cf. Hatton *et al.* 2001) and 'unhealthy' family functioning. However, it is interesting to note that the frequently observed association between child emotional and behavioural difficulties and maternal distress appears to be moderated by socio-economic status, i.e. this association only reached the level of statistical significance among families who were not living in poverty or who were not living in more deprived neighbourhoods.

Taken together, these observations are consistent with the view that the apparent effect of ID on maternal stress may be mediated by the effects of behavioural disturbance/psychopathology, to which children with ID are at significantly increased risk (Linna *et al.* 1999; Dykens 2000; Stromme & Diseth 2000; Emerson 2003). However, it is clear that mod-

els of understanding maternal distress also need to address a range of contextual factors including poverty, family functioning, exposure to potentially stressful life events and variables such as maternal coping strategies which it was not possible to assess within the present study.

Finally, it is important to avoid the over-generalizing from the commonly reported association between raising a child with ID, maternal psychological distress and social disruption. Only a minority of mothers reported that their child's difficulties had made them to any extent depressed or physically ill. Similarly, only a minority of mothers reported that their child's difficulties had disrupted their social and leisure activities, or had had an adverse effect on relationships within the family. Indeed, mothers were just as likely to report that their child's difficulties had strengthened their relationship with their partner as they were to report that it had weakened their relationship. Exploratory analyses indicated that maternal reports of strengthening of relationships with their partner was associated with having experienced fewer potentially stressful life events, healthy family functioning, having a younger child and not receiving means-tested welfare benefits.

Future research clearly needs to address the complexity of outcomes associated with raising a child with ID, the range of variables which are associated with variation in outcomes, and to place these analyses within the general social and economic context of caring.

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