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Mild mental retardation: psychosocial functioning in adulthood

B. MAUGHAN,[1] S. COLLISHAW AND A. PICKLES

From the MRC Child Psychiatry Unit and Social, Genetic and Developmental Psychiatry Research Centre, Institute of Psychiatry, London

ABSTRACT

Background. Evidence on the adult adaptation of individuals with mild mental retardation (MMR) is sparse, and knowledge of the factors associated with more and less successful functioning in MMR samples yet more limited.

Method. Prospective data from the National Child Development Study were used to examine social circumstances and psychosocial functioning in adulthood in individuals with MMR and in a non-retarded comparison group.

Results. For many individuals with MMR, living circumstances and social conditions in adulthood were poor and potential stressors high. Self-reports of psychological distress in adulthood were markedly elevated, but relative rates of psychiatric service use fell between childhood and adulthood, as reflected in attributable risks. Childhood family and social disadvantage accounted for some 20–30% of variations between MMR and non-retarded samples on a range of adult outcomes. Early social adversity also played a significant role in contributing to variations in functioning within the MMR sample.

Conclusions. MMR appears to be associated with substantial continuing impairment for many individuals.

INTRODUCTION

Current diagnostic criteria for mental retardation (World Health Organization, 1992; American Psychiatric Association, 1994) involve two elements: first, significantly below average intellectual functioning, and second, limitations in adaptive functioning – impairments in coping with common life demands, and in the skills required for personal independence. The inclusion of social adaptation as a defining criterion has long been a matter of debate, on both conceptual and methodological grounds (MacMillan *et al*. 1993). Developmental issues are among the key considerations here: adaptive capacities may change across development, varying with the demands and supports of differing environmental contexts. Indeed, in relation to mild mental retardation (MMR) some commentators have argued that associated impairments may be essentially time-limited, and confined to the years of schooling. As environmental demands become more varied and flexible with the transition to adulthood, and a wider range of social 'niches' becomes available, so adaptive problems are likely to decrease (Kushlick & Blunden, 1974; MacMillan, 1982).

Evaluating this possibility has proved difficult. In childhood, epidemiological studies have provided a clear picture of the functional impairments associated with MMR: increased rates of neurological abnormalities; speech, language and reading difficulties; and high rates of emotional and behaviour problems (see e.g. Birch *et al*. 1970; Rutter *et al*. 1970; Broman *et al*. 1987). Evidence on functioning in adulthood is much more limited. In terms of service use, rates of registration for special services are known to fall between childhood and adulthood

[1] Address for correspondence: Dr Barbara Maughan, MRC Child Psychiatry Unit, Institute of Psychiatry, De Crespigny Park, London SE5 8AF.

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(Scott, 1994), but it is also clear that many individuals not regarded as requiring additional support may still experience considerable difficulties in day-to-day functioning. More detailed assessments have primarily focused on previously institutionalized or specially educated samples (see Widaman *et al*. 1991, for a review), and very little is known about the later adaptation of young people educated in mainstream schools (Bruininks *et al*. 1990). This is likely to be an important gap. Many children with MMR are supported in mainstream schooling, and epidemiological studies suggest that, although less impaired than their special school counterparts, they too often face considerable difficulties. In the Isle of Wight epidemiological studies, for example, half of the 'mainstream' MMR group showed severe reading problems, and rates of neurological abnormality were twice as high, and behaviour problems four times higher, than in a non-retarded comparison group (Rutter *et al*. 1970). Any comprehensive picture of the adult functioning of individuals with MMR clearly needs to take account of this important group.

Although samples, methods and measures vary widely, a number of investigations have now concluded that around half of individuals with MMR are likely to show significant difficulties in coping in adult life (Weaver, 1946; Granat & Granat, 1978; Edgerton, 1984; Ross *et al*. 1985). The most comprehensive UK investigation to date derives from the Aberdeen surveys (Birch *et al*. 1970). The MMR sample included all children in a 5-year age-cohort placed in special schools in the city before age 16 ($N = 221$), along with a non-retarded comparison group individually matched for age, sex and childhood social class. A follow-up at age 22 painted a gloomy picture for many of the young people with MMR (Richardson & Koller, 1992, 1996). Although only 20% were receiving special services, much larger proportions faced problems at work (Richardson *et al*. 1988) and in their personal and social relationships (Koller *et al*. 1988*a*, *b*; Richardson *et al*. 1993), and over a third showed moderate to severe behaviour disturbances (Richardson *et al*. 1985*a*). Overall, only 27% were considered to be functioning adequately in all of these areas.

Our first aim in the present study was to provide further evidence on the social circumstances and adaptation of individuals with MMR in adult life, using data from the second of the British birth cohort studies, the National Child Development Study (NCDS). Although not designed as a study of mental retardation, NCDS allows for the identification of children with IQ levels in the MMR range, including those educated in both special and mainstream schools. The NCDS cohort has been tracked from birth to age 33, and the data-set includes indicators of many key aspects of adult functioning: cognitive competence (reading, writing and numeracy skills), independent living, occupational skills, and social and personal relationships. Emotional distress, behaviour problems and psychiatric disorder constitute further important outcome domains (Jacobson, 1982; Borthwick-Duffy & Eyman, 1990). In a recent review, Borthwick-Duffy (1994) noted that although there is a general consensus that people with mental retardation are at increased risk of emotional disorders, prevalence estimates vary widely, and few studies have reported comparisons with non-retarded controls. Based on a nationally representative birth cohort, NCDS also provides for assessments in this area.

In addition to information on patterns of functioning in adulthood, a second need is for more detailed exploration of factors that influence adult outcomes. Early social adversity may be of particular importance here. All epidemiological studies have noted strong overlaps between MMR and social disadvantage in childhood (Roeleveld *et al*. 1997), and more detailed reports have pointed to much increased risks of disrupted care-giving and distressed family circumstances among children with mild mental impairments (Richardson *et al*. 1985*b*). Although MMR is associated with identifiable pathological causes in a minority of cases (Simonoff *et al*. 1996), the two-group model of mental retardation, whereby mild impairments are regarded as primarily subcultural or familial, has largely stood the test of time. Perhaps surprisingly, however, there have been few attempts to examine how far any later difficulties faced by individuals with MMR are attributable to early social adversity, rather than to mental impairments *per se*. Thus, our second aim was to assess how far early adversity, along with other childhood risks, might account for variations in

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adult functioning between MMR and non-retarded samples.

Finally, since many individuals with MMR do achieve satisfactory levels of adaptation in adulthood, we also need to know more about predictors of more and less successful outcomes within MMR samples. Here, current evidence is restricted to special school samples, and suggests that IQ level (Ross *et al*. 1985), family stability in childhood, and brain disorder (Richardson & Koller, 1992) are among the most important predictors of general adaptive functioning. Childhood behaviour problems – well-known to show continuities to a range of poor adult outcomes in non-retarded samples (see e.g. Robins, 1978; Zoccolillo *et al*. 1992) – have been examined in relation to later behavioural disturbance in individuals with MMR (Richardson *et al*. 1985*a*), but their effects on wider patterns of functioning have yet to be assessed. Therefore, our third aim was to examine the contributions of a range of childhood predictors in contributing to variations in adult functioning within an MMR sample.

METHOD

Samples

NCDS is a prospective study of all children in Britain born in 1 week (3–9 March) in 1958 – some 17000 in all. After the initial birth survey, childhood follow-ups took place at ages 7 (Davie *et al*. 1972), 11 (Wedge, 1969) and 16 years (Fogelman, 1983), and included a range of assessments: medical examinations and educational testing of the study child, interviews with parents, and data collection from teachers and schools. The adult contacts, at ages 23 and 33, involved interviews and questionnaires completed by the cohort members themselves (Ferri, 1993).

MMR status was defined on the basis of data from the 11 and 16 year-old contacts, using a two-stage approach. First, children were classified as falling into the mentally retarded range if they scored at or below 1·94 S.D. units below the mean (equivalent to IQ scores of $\leqslant 70$) on a standardized 80 item group-based general ability test administered to cohort members at age 11. The test was designed by the National Foundation for Educational Research, included alternate verbal and non-verbal items, and showed high reliability (Kuder-Richardson formula 0·94 (Douglas, 1964)). Secondly, as the test showed least discrimination at the extreme of the range, school placement data were used to exclude children with severe intellectual retardation from the MMR sample: all those reported as attending special schools or units for the severely retarded at ages 11 or 16 were excluded from the MMR category.

Of the 13473 children in the original birth cohort with the relevant test and school placement data, this approach identified 48 as severely retarded (a rate of 3·6 per 1000), 275 as falling into the MMR range (20·4 per 1000), and the remainder ($N = 13150$) as non-retarded. In a recent review of prevalence studies of MMR, Roeleveld *et al*. (1997) noted the wide range of prevalence estimates currently reported. They calculated a tentative average prevalence rate of 29·8 per 1000 for children in the 50–70 IQ range, slightly above Penrose's (1963) theoretical value of 22·7 per 1000 for mental retardation as a whole. The rate of MMR identified in the NCDS cohort fell well within the range reported in the more satisfactory epidemiological studies undertaken to date (Roeleveld *et al*. 1997).

Measures

Childhood

Birth circumstances

The Perinatal Mortality Survey (Butler & Bonham, 1963) included indicators of obstetric and perinatal complications (induced labour and foetal distress), together with the child's birthweight.

Social and family circumstances

Indicators of family size, social class, parental education and housing tenure were taken from the age 11 sweep, contemporaneously with the group definition measures. A binary indicator of periods spent in institutional or other substitute care up to age 16 was used to index family breakdown/severe parenting problems. For analyses within the MMR samples, these measures were combined to produce an eight-point social disadvantage index, including measures of childhood social class, family size, housing tenure and receptions into care, weighted according to their approximate power in predicting poor adult outcomes in the non-retarded comparison group.

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Sensory and neurological problems

Data from the medical examinations at each childhood sweep were used to derive indicators of any severe or handicapping sensory impairments, epilepsy, and minor and more severe neurological abnormalities.

School placement

School placement was recorded at each of the childhood sweeps. Special school placements were reported for children with sensory and physical as well as intellectual impairments, and for those with multiple difficulties. All of these types of provision were included in the special school category.

School attainments

Standardized reading comprehension and mathematics tests devised by the National Foundation for Educational Research were administered at age 11. Both showed high reliability (reading, Kuder-Richardson formula 0·82; maths, 0·92 (Fogelman, 1980)).

Behaviour problems

At age 11, standardized teacher behaviour ratings were made using the Bristol Social Adjustment Guides (BSAG, Stott, 1966), adapted for use in NCDS. Although now largely superseded, scores on the BSAG correlate highly ($r = 0{\cdot}92$) with the more widely used Rutter B scale (Yule, 1968). From a large pool of items, teachers were asked to endorse behavioural descriptors appropriate to each study child. Responses were then grouped to provide 12 syndrome scores, along with a total score. For the present analyses, syndrome scores were combined here to construct scales reflecting antisocial behaviour (including stealing, destructiveness and aggression), emotional problems (shy, withdrawn and depressed behaviours) and restlessness. Cut-offs as close as possible to the 90th percentile on the antisocial and the emotional factors, and the 95th percentile on the restlessness factor, were used to identify children showing high (problem) scores.

Psychiatric and other special service use in childhood

To avoid under-reporting from any individual data-source, parent, teacher and medical reports were combined to identify any contacts with child guidance, psychiatric and other specialist services up to age 16.

Court appearances

In a similar way, teacher and parent reports were combined to identify children who had appeared before the courts as a result of delinquency up to age 16.

Adult status and outcomes

Data from the cohort member interviews at age 33 were used to derive a range of measures of adult status and functioning, as follows.

Social class at age 33

Registrar General's occupational groupings: non-manual and skilled occupations were contrasted with semi-skilled/unskilled jobs. Subjects who had not participated in the labour market in the past 10 years were included in the second (unskilled) category. For women in stable marital/cohabiting relationships, social class was assigned according to their partner's occupational status.

Employment status at age 33

Two measures were derived: the first contrasting cohort members currently employed (including full-time, part-time and self-employment) with those who were unemployed and out of the labour market, the second contrasting the currently unemployed with the employed and those out of the labour market.

Employment history ages 23–33

Four measures were derived, covering the number of jobs of 1 month or longer, the number of periods of unemployment, the length of first period of unemployment and any dismissals.

Receipt of benefits at age 33

Included reports of receipt by the cohort member or his/her partner of state benefits reflecting low family income (unemployment benefit, supplementary benefit/income support, family income supplement/family credit, one parent benefit, or housing benefit).

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Housing tenure at age 33

Owner-occupation was contrasted with all other tenure categories. Cohort members living in their parents' homes, or with other relatives, were classified as 'other'.

Non-independent living at age 33

Cohort members were treated as not living independently if they were unmarried and living with their parent(s)/family of origin. Those living with a marital/cohabiting partner but sharing accommodation with parents were classified as living independently on this measure.

Family life at age 33

Two measures were derived: whether cohort members were currently living with a partner; and ever fathered/mothered a child.

Disability in adulthood

Two measures were derived: self-reports of any longstanding illness or disability serious enough to limit daily life, and/or registration as disabled.

Literacy and numeracy skills

These were derived from cohort members reports of reading, writing, and numeracy problems in adulthood.

Relationship histories

Four measures were derived: whether the cohort member had ever lived as married with a partner for $\geqslant 1$ month; if so, their age at the start of their first partnership, and whether they had experienced a partnership breakdown; and if they had separated/divorced, whether they had formed a second or subsequent partnership.

Parenting histories

Two measures were derived: cohort members ages at the birth of their first child, and their number of children by age 33.

Social support

Six hypothetical scenarios were used to assess the availability of support from family, friends and other. We focused here on the three scenarios that tapped personal/emotional difficulties (an important change in your life, problems in relationships with a partner, and feeling down or depressed). In each case, summary measures were derived to index the availability of support from a friend, a parent or parent-in-law, and more than one person.

Psychological well-being and help-seeking for emotional problems

The Malaise Inventory (Rutter *et al*. 1970), a 24-item self completion scale, was used to assess affective symptomatology at age 33; interviewers were instructed to read the items for any subjects reporting marked reading difficulties. A total score of six or more has been shown to discriminate those with and without an interview diagnosis of depression (Rutter *et al*. 1976). Recent studies with both adolescent (Manikam *et al*. 1995) and adult samples (Lindsay *et al*. 1994) have confirmed the internal consistency of self-reports of anxiety and depressed mood among individuals with mild and moderate mental impairments. In addition, the adult interviews included self-reports of emotional difficulties and contacts with GPs or specialists over emotional problems between ages 23 and 33, and the CAGE (Mayfield *et al*. 1974), a brief screening questionnaire for alcohol problems, used in relation to both past and current drinking. Scores of two or more on the past version of the scale have been shown to provide a good indicator of alcohol problems in community samples (King, 1986).

Response rates and sample attrition

Complete data on the childhood measures selected for use in the analyses were available for 238/275 individuals in the MMR sample (86·5%) and 12033/13150 (91·5%) in the non-retarded comparison group. Of these, 122 (51·3%) and 8554 (71·1%) provided data at the age 33 follow-up. Occasional missing data on individual measures from the age 33 contact further reduced the numbers with complete data to 100 and 7205 respectively.

As these figures suggest, data losses over the period of the follow-up were significantly greater in the MMR than the comparison group. Known death rates did not differ significantly between the groups (3·2% and 1·7% respectively), but individuals with MMR were less likely to be traced in adulthood, and if traced, were also less likely to agree to participate. This pattern was not unexpected: in the 1946 British birth cohort, Wadsworth *et al*. (1992) found that childhood

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ability scores were among the strongest predictors of adult response rates. In NCDS, complete data cases also tended to underrepresent men, subjects from lower social class backgrounds in childhood, those who had spent periods in care, and those with childhood behaviour problems. In general, these factors appeared to affect response in both the MMR and comparison groups in similar ways; in some instances, however, there were suggestions that these additional factors had a rather greater impact on subject attrition within the MMR sample.

We used weights to tackle this sample attrition problem (Brick & Kalton, 1996; Dunn, 1997). Inverse probability weights were calculated from the predicted response probabilities derived from a logistic regression model of response to the cohort member interview at age 33. Two main criteria were used in selecting effects for inclusion in the weights: first, statistical significance within the logistic regression, and secondly, the extent to which the selected weighting scheme satisfactorily reproduced the means and prevalence rates of cases with complete childhood data on key variables at age 11. The prediction equation included effects of gender, parental education, childhood social class (no male head of household *versus* other, and classes IV and V *versus* other), general ability at age 11, teacher rated behaviour scores, reception into care and special school placement. To take account of possible differential impact of these factors in the MMR and comparison groups, interactions between each of these factors and MMR/comparison group status were also included. Finally, one rather extreme weight assigned to an individual subject was trimmed to that of the next lowest weight to improve precision of the estimates (Potter, 1988).

Statistical analysis

The weights were included throughout the analyses by the use of weighted likelihood estimation and the robust or sandwich parameter covariance matrix estimator of Huber (1967), as implemented in STATA (StataCorp, 1997). This approach is discussed and compared with other methods in Pickles *et al.* (1995). Tests for dichotomous outcomes were undertaken using logistic regression analyses, and those for continuous measures using multiple regression. The Tables show odds ratios (OR), 95% confidence intervals (CI) and associated significance levels for between-group comparisons on dichotomous measures, and means, standard deviations and F tests for comparisons on continuous measures. On two measures (age at partnership formation, and age at birth of first child), a minority of cohort members had not made the relevant role transitions by age 33. These measures were thus analysed using methods for censored regression and Wald z tests. The quoted significance levels are indicative only, as no corrections have been made for multiple testing or non-independence among tests.

RESULTS

Background

Table 1 provides an overview of the characteristics of the MMR and non-retarded samples at birth and in late childhood and adolescence. MMR was associated with low birth-weight in girls, with increased rates of neurological problems and epilepsy in boys, and with higher than expected levels of sensory handicap in children of both sexes. As numerous other studies have reported, MMR was much more common among children from lower social class backgrounds, and in large families. Parents of children in the MMR sample were less likely to have completed any post-compulsory education than those in the remainder of the cohort (12% *v.* 30%), and fewer families of children with MMR owned their own homes (24% *v.* 47%). The odds of family problems severe enough to necessitate the child's reception into care approached four times higher than those in the non-retarded sample.

By age 11, somewhat under a third of the children with MMR were placed in special schools, and rates of special schooling rose further (to 35·8% for boys and 28·3% for girls) by age 16. As expected, the special school subgroup included many of the most intellectually impaired children; at the same time, the data made clear that children from the full MMR ability range were also supported in mainstream schools. Mean reading levels and mathematics attainments in late childhood were severely depressed in the MMR samples: only 2% scored above the 25th percentile in mathematics, and 25% in reading. Finally, both girls

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Table 1. *Childhood characteristics*

	MMR		Comparison		Odds ratio (95% CI)	
	Boys ($N = 49$)† %	Girls ($N = 51$) %	Boys ($N = 3482$) %	Girls ($N = 3723$) %	Boys	Girls
Birth						
Low birth weight (< 2500 g)	7·2	19·4	6·8	8·1	1·1 (0·4–2·7)	2·7 (1·4–5·6)**
Foetal distress	14·4	4·2	9·9	7·8	1·5 (0·6–4·0)	0·5 (0·2–1·7)
Induced labour	13·3	14·3	13·3	13·1	1·0 (0·4–2·6)	1·1 (0·4–3·0)
Family background						
Social class IV or V	32·5	53·2	21·4	21·9	1·8 (0·9–3·4)	4·1 (2·2–7·5)***
Large family (⩾ 4 children)	57·1	62·2	28·7	28·6	3·3 (1·8–6·2)***	4·1 (2·2–7·6)***
Family disruption – ever placed in care by age 16	13·4	11·2	4·0	3·1	3·7 (1·3–10·2)*	4·0 (1·5–10·9)**
Medical conditions						
Moderate/severe sensory handicap	12·7	15·5	3·3	2·8	4·3 (1·6–11·7)**	6·5 (2·5–16·9)***
Epilepsy	7·9	3·6	0·7	1·0	12·2 (3·3–44·8)***	3·8 (0·5–28·8)
Neurological	8·3	1·4	1·4	1·0	6·6 (1·5–28·4)*	1·4 (0·2–10·4)
Behaviour problems age 11						
Antisocial	30·6	21·7	12·8	8·3	3·0 (1·5–6·2)**	3·1 (1·2–7·6)*
Hyperactive	14·9	11·4	5·7	2·8	2·9 (1·2–6·8)*	4·5 (1·9–10·6)**
Emotional	21·5	23·6	8·9	6·9	2·8 (1·4–5·7)**	4·1 (1·9–8·9)***
Psychiatric service contact by age 16	44·9	13·2	6·9	4·5	11·0 (5·8–20·8)***	3·2 (1·2–8·7)*
Schooling age 11						
Special schooling	31·2	23·9	0·8	0·6	52·9 (21·7–128·7)***	55·8 (19·1–162·9)***
Age 11 school attainment	Mean (±S.D.)	Mean (±S.D.)	Mean (±S.D.)	Mean (±S.D.)	F(df)	F(df)
Reading score	5·7 (±5·1)	5·3 (±4·2)	16·3 (±6·2)	16·3 (±5·7)	213·3 (1)***	240·8 (1)***
Maths score	2·4 (±3·8)	1·9 (±2·2)	17·5 (±10·3)	16·9 (±9·8)	159·5 (1)***	150·5 (1)***

* $P < 0{\cdot}05$; ** $P < 0{\cdot}01$; *** $P < 0{\cdot}001$.
† Unweighted *N*s. Weighted *N*s used in analyses: MMR, boys = 78, girls = 60; Comparison, boys = 3657, girls = 3509.

and boys in the MMR samples showed elevated rates of disruptive/antisocial behaviours, restlessness, and emotional problems. Children in special schools showed especially high rates of disruptive behaviours and of sensory/neurological difficulties. Rates of psychiatric service contact in childhood were high, especially among boys. More detailed tests showed that referrals for psychiatric help were more strongly associated with sensory and neurological problems than with behavioural disturbance in the MMR sample. Data on court appearances (available on slightly reduced numbers) suggested that boys were also at increased risk of officially adjudicated delinquency in their early and mid teens: 19% of boys with MMR, by contrast with only 10% in the comparison group, had appeared in court by age 16.

Social circumstances at age 33

Table 2 gives an initial overview of the groups' situations in adulthood. For many individuals with MMR, living circumstances and material conditions were poor. Among the men, a quarter were receiving benefits, and half were in lower class occupations. Unemployment was four times as common as in the comparison group, and home ownership only half as likely. Almost a quarter of men with MMR were living with their families of origin at age 33, and considerably lower proportions than in the remainder of the cohort were in marital or cohabiting relationships. One in six men with MMR reported that they suffered from a longstanding illness or disability, and one in 13 were registered disabled.

Rates of handicapping illness and disability were reported at similarly high levels among women with MMR, but official registrations for disability were much less common. Women in the MMR sample were more likely to have children in their early thirties than their peers, but somewhat less likely to be living with a partner at the time of interview. They themselves

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Table 2. *Circumstances at age* 33

	MMR		Comparison		Odds ratio (95% CI)	
	Men %	Women %	Men %	Women %	Men	Women
Class and material circumstances						
Class IV or V, or no work	49·4	60·0	16·3	21·2	5·0 (2·7–9·3)***	5·6 (3·0–10·3)***
Employed (FT, PT, or self)	68·5	38·6	92·1	68·7	0·2 (0·1–0·4)***	0·3 (0·2–0·5)***
Unemployed	19·9	1·8	5·3	2·2	4·4 (1·9–10·1)***	0·8 (0·1–5·9)
Receipt of benefits	27·5	48·1	9·7	16·4	3·5 (1·7–7·4)**	4·7 (2·5–8·9)***
Housing tenure: owner occupied house	38·2	41·7	73·3	74·0	0·2 (0·1–0·4)***	0·3 (0·1–0·5)***
Family circumstances at age 33						
Not living independently	23·9	3·8	9·0	4·7	3·2 (1·6–6·5)**	0·8 (0·2–3·5)
Currently living with a partner	61·8	74·7	80·4	82·6	0·4 (0·2–0·7)**	0·6 (0·3–1·2)
Has children	63·4	90·2	66·0	76·4	0·9 (0·5–1·7)	2·8 (1·2–6·9)*
Longstanding illness/disability						
Any limiting daily life	16·2	15·3	5·7	5·4	3·2 (1·3–8·0)*	3·1 (1·1–8·6)*
Registered disabled	7·4	1·3	1·1	0·6	7·4 (1·8–29·5}**	2·1 (0·3–16·1)

* $P < 0{\cdot}05$; ** $P < 0{\cdot}01$; *** $P < 0{\cdot}001$.

Table 3. *Self-reported literacy and numeracy problems, age* 33

	MMR		Comparison		Odds ratio (95% CI)	
	Men %	Women %	Men %	Women %	Men	Women
Reading problems	38·7	33·0	4·5	2·1	13·4 (6·8–26·4)***	22·7 (11·1–46·3)***
Writing problems	45·5	34·4	11·9	5·8	6·2 (3·3–11·6)***	8·5 (4·3–16·7)***
Numeracy problems	17·0	8·5	1·7	2·5	11·9 (4·7–29·9)***	3·6 (1·4–9·6)*
Any literacy or numeracy problems since leaving school	55·0	43·7	13·3	8·0	8·0 (4·3–14·7)***	8·9 (4·7–16·7)***

* $P < 0{\cdot}05$; ** $P < 0{\cdot}01$; *** $P < 0{\cdot}001$.

were less likely to be in employment than other women, and their family social class (rated wherever appropriate on the basis of their partner's occupation) was if anything more depressed than that of men with MMR. Almost half of the women were receiving welfare benefits in their early thirties.

We undertook a series of analyses to assess how far these differences between the MMR and comparison groups were associated with variations in other childhood risks: low birthweight, sensory/neurological impairments, early social disadvantage (low social class, large family size, poor housing and receptions into care) and behaviour problems. Controls for these factors reduced, but failed to eliminate, the between-group differences. Among men, for example, controlling for childhood background factors reduced group differences in dependence on benefits by 41%, to an odds ratio of 2·1 (95% CI = 1·0–4·4, $P = 0{\cdot}05$). Among women, similar controls reduced group differences in housing tenure by 43%, moving the OR closer to the null value of 1 (OR = 0·44, CI = 0·22–0·89, $P = 0{\cdot}02$).

Within the MMR sample, variations in outcome also appeared to reflect some degree of continuity from childhood disadvantage. Receipt of welfare benefits and housing tenure showed no significant links with childhood general ability scores, early sensory/neurological problems or behavioural difficulties, but each point on the eight-point index of childhood disadvantage increased the odds of poor adult circumstances by $1\frac{1}{2}$ times. For women only, adult social status showed significant links ($P = 0{\cdot}05$) with tested ability levels in childhood; these associations were only marginally reduced by the inclusion of other childhood background factors.

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Table 4. *Partnership and parenting histories – age* 33

	MMR		Comparison		Odds ratio (95% CI)	
	Men %	Women %	Men %	Women %	Men	Women
Partnership histories						
Ever in a stable cohabitation	79·5	94·7	89·3	93·9	0·5 (0·2–1·0)*	1·2 (0·4–4·0)
Breakdown of relationship (ever)†	33·7	45·5	27·3	30·7	1·4 (0·7–2·7)	1·9 (1·0–3·6)
Multiple partnerships†	15·8	31·8	20·3	22·3	0·7 (0·3–1·7)	1·6 (0·8–3·4)
Mean age at first partner (years)†	(23·6)	(19·3)	(23·4)	(21·5)		
Parenting histories						
Teenage parent	6·4	39·5	3·0	12·1	2·2 (0·6–7·6)	4·7 (2·4–9·2)***
Number of live births ever						
0	36·6	9·8	34·0	23·6	1·0	1·0
1 or 2	43·5	46·9	52·5	57·5	0·8 (0·4–1·5)	2·0 (0·8–5·0)
⩾ 3	19·9	43·3	13·4	18·9	1·4 (0·5–3·5)	5·5 (2·1–14·5)**
Mean age at first child (years)‡	(24·0)	(20·7)	(25·9)	(24·1)		

* $P < 0{\cdot}05$; ** $P < 0{\cdot}01$; *** $P < 0{\cdot}001$.
† Of those ever in a relationship; ‡ of those who have had a child.

Literacy and numeracy skills in adulthood

Literacy and numeracy skills are of central importance to many aspects of adult functioning. In the non-retarded comparison group, around 10% of cohort members reported difficulties in these areas in adult life. As Table 3 shows, over 40% of women and more than half of the men with MMR reported problems of this kind. These self-ratings showed strong continuities with childhood reading and mathematical skills. MMR-comparison group differences in levels of adult literacy/numeracy problems were unrelated to childhood social background, behaviour, or sensory/neurological problems, but were reduced to non-significance by controls for age 11 general ability scores. Within the MMR sample, childhood reading and maths scores proved more important than measured general ability levels in accounting for variation in adult literacy and numeracy skills, and remained significant predictors of adult difficulties (reading, $P = 0{\cdot}02$; maths, $P = 0{\cdot}04$) in the presence of controls for sensory/neurological problems, childhood social disadvantage and behaviour problems.

Independent living, relationship and family formation

Table 4 gives details of patterns of marital/cohabiting relationships and family formation up to age 33. Here, findings varied in some important ways by gender. Among women, the great majority in both the MMR and comparison groups had established marital/cohabiting relationships by their early thirties, and most had had at least one child. The two groups differed markedly, however, in the timing of these early adult role transitions. Women in the MMR sample began their first partnerships over 2 years earlier than was the norm for women in the remainder of the cohort, and had their first child almost 5 years earlier; almost 40% became mothers in their teens. Censored regression analyses confirmed the highly significant differences between the groups in age at first partner ($z = -3{\cdot}52$, $P < 0{\cdot}001$) and age at first child ($z = -6{\cdot}04$, $P < 0{\cdot}001$). Group differences in age at first childbearing were reduced by 39% by controls for childhood social disadvantage and medical problems, and by a further 8% by the inclusion of childhood behaviour problems. Including all of these factors, however, the group differences remained highly significant ($P < 0{\cdot}001$). Within the MMR sample, variations in age of childbearing were significantly associated with early social disadvantage ($z = -2{\cdot}28$, $P = 0{\cdot}02$), though not with any of the other childhood factors examined. This pattern of early adult role transitions was much less marked for men with MMR, and no significant group differences in

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Table 5. *Employment histories – ages 23–33*

	MMR		Comparison		Odds ratio (95% CI)	
	Men %	Women %	Men %	Women %	Men	Women
No jobs age 23–33	7·7	25·4	0·8	5·6	10·5 (2·6–41·7)**	5·7 (2·8–12·0)***
⩾ 5 jobs age 23–33	14·3	5·3	16·3	14·3	0·9 (0·3–2·2)	0·3 (0·1–1·1)
Any period of unemployment age 23–33	56·8	14·9	28·2	21·9	3·3 (1·8–6·2)***	0·6 (0·3–1·4)
Multiple periods of unemployment age 23–33	26·3	3·3	11·1	6·7	2·8 (1·4–5·9)**	0·5 (0·1–2·0)
1st period of employment:						
> 12 months†	31·0	12·8	25·6	28·3	1·3 (0·5–3·3)	0·4 (0·1–3·1)
Any sacking‡	3·8	0·0	4·0	1·4	1·0 (0·2–4·2)	—

* $P < 0{\cdot}05$; ** $P < 0{\cdot}01$; *** $P < 0{\cdot}001$.
† Of those ever unemployed; ‡ of those who have worked.

Table 6. *Social support*

	MMR		Comparison		Odds ratio (95% CI)	
	Men ($N = 40$)† %	Women ($N = 44$) %	Men ($N = 3309$) %	Women ($N = 3594$) %	Men	Women
Sources of support for:						
An important life change						
Friend	31·3	23·4	29·7	45·8	1·1 (0·5–2·2)	0·4 (0·2–0·7)**
Parent/in-law	81·4	61·1	63·5	72·3	2·5 (1·2–5·4)*	0·6 (0·3–1·1)
More than one person	81·8	68·2	76·6	86·8	1·4 (0·6–3·0)	0·3 (0·2–0·6)**
A relationship problem						
Friend	24·6	38·2	35·3	60·4	0·6 (0·3–1·3)	0·4 (0·2–0·8)**
Parent/in-law	68·0	49·1	52·8	54·6	1·9 (1·0–3·7)	0·8 (0·4–1·5)
More than one person	55·0	52·5	57·8	73·8	0·9 (0·5–1·8)	0·4 (0·2–0·7)**
Feeling down or depressed						
Friend	34·4	41·8	36·5	64·3	0·9 (0·4–1·9)	0·4 (0·2–0·8)**
Parent/in-law	51·2	45·2	37·5	46·4	1·7 (0·9–3·4)	1·0 (0·5–1·8)
More than one person	62·8	65·4	61·1	82·2	1·1 (0·5–2·1)	0·4 (0·2–0·8)**

* $P < 0{\cdot}05$; ** $P < 0{\cdot}01$.
† Unweighted *N*s. Weighted *N*s used in analyses: MMR, men = 64, women = 48; Comparison, men = 3461, women = 3378.

either age at first partnership or first child remained once the censored nature of the data had been taken into account. Instead, possibly more salient for the men was the lower overall rate of marriage/cohabitation in the MMR sample, and, as noted earlier (see Table 2), the much increased likelihood that men with MMR would be living alone with their family of origin in their early thirties. In this latter area, group differences were reduced by controls for childhood behaviour problems and social disadvantage, but still remained significant (OR = 2·6, CI = 1·1–5·7, $P = 0{\cdot}02$). Within the MMR sample, neither general ability levels nor any of the other childhood factors significantly predicted variations in independent living in the early thirties.

Employment histories

Table 5 shows indicators of employment histories between ages 23 and 33. For women, the only marked differences between the MMR and comparison groups arose in the proportions who had not worked at all outside the home during this period. These remained significant after controls for all childhood factors, and, with the exception of a significant ($P = 0{\cdot}03$) effect of childhood social disadvantage, showed few clear links with childhood background indicators within the MMR sample.

Among the men, one in twelve in the MMR sample had not worked at all between ages 23 and 33. Over half of this group (58%) were registered disabled. Even taking account of

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disability, however, men with MMR were still significantly more likely to have remained out of the labour market in their twenties and early thirties (OR = 7·8, CI = 2·6–23·8, $P = 0{\cdot}001$). Those in the job market had considerably increased risks of multiple periods of unemployment, but showed few other major employment problems on the measures available here. They were no more likely than men in the remainder of the cohort to have suffered long-term unemployment, to have made large numbers of job changes, or to have been dismissed from jobs. The increased vulnerability to repeated spells of unemployment in the MMR sample did suggest, however, that men with MMR faced greater difficulties in re-establishing themselves in work if they were made redundant or chose to leave a job. Group differences in rates of repeated unemployment were reduced by 34%, and to non-significance (OR = 1·9, CI = 0·9–3·9, $P = 0{\cdot}10$) when controlled for childhood social disadvantage, and for sensory/neurological and behavioural problems. Within the MMR sample, repeated unemployment was unrelated to general ability levels, but was significantly associated with early social adversity ($P = 0{\cdot}001$), and with lower levels of childhood behaviour problems ($P = 0{\cdot}04$). Once again, these findings gave little reason to assume that repeated unemployment reflected unsatisfactory performance in the workplace.

Social support

Table 6 shows responses to items from the social support questionnaire completed by cohort members at age 33. Within the non-retarded sample, responses varied consistently by gender, with more women than men reporting turning to a friend for support, and also having multiple sources of support available to them. Against that background, a consistent pattern of MMR-comparison group contrasts also emerged. Women with MMR were markedly less likely to report support from a friend than women in the remainder of the cohort, and they were also significantly less likely to feel that they had more than one person to turn to. Controls for childhood disadvantage and behaviour problems reduced these differences by up to 20%, but failed to eliminate them. For men, a quite different pattern emerged, with no group differences in support from friends, or in the availability of multiple sources of support. Instead, the main MMR-comparison group contrasts arose in relation to support from parents. This was reported at significantly higher levels by men in the MMR sample on one scenario (discussion of a major life change), and followed a similar though non-significant trend in the other two. As outlined earlier, men with MMR were much more likely to be living with their parents in adulthood; even among those living independently, however, group differences in reliance on parents remained at almost exactly similar levels.

Across all three scenarios, MMR-comparison group contrasts in patterns of social support seemed relatively independent of childhood background factors. Neither early disadvantage nor behaviour problems seemed implicated in between-group differences for either sex, and the childhood factors showed few clear links with variations in availability of support within the MMR sample.

Adult psychiatric morbidity and service use

Women in the MMR sample reported strikingly high levels of depressed mood at the time of the adult interviews, with over half scoring above a cut-point on the Malaise Inventory suggesting clinically significant disorder (Table 7). Malaise scores were also much elevated among the men. By contrast, self-reported rates of help-seeking for emotional problems in the previous 10 years showed only minor group differences, and rates of alcohol problems (as indexed by high scores on the CAGE) were closely similar in the two samples. For both women and men, MMR-comparison group differences in Malaise scores were reduced (by 35% and 42% respectively) by the addition of controls for childhood adversity, sensory/neurological impairments and behaviour problems. Taking all of these factors into account, however, the group differences remained highly significant.

To enhance the power of the within-group analyses, predictors of high Malaise scores and past help-seeking within the MMR samples were examined for men and women combined. Taking account of mean differences between the sexes, high scores on the Malaise Inventory showed some links with childhood sensory and neurological problems (OR = 3·1, CI = 1·0–9·6, $P = 0{\cdot}05$) and social disadvantage (OR = 1·4,

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Table 7. *Psychiatric morbidity – age* 33

	MMR		Comparison		Odds ratio (95% CI)	
	Men %	Women %	Men %	Women %	Men	Women
High Malaise score (⩾ 6)	29·7	51·1	9·0	15·9	4·3 (2·1–8·7)***	5·5 (3·0–10·3)***
Emotional problems ages 23–33						
None	56·7	36·6	53·2	37·5	1·0	1·0
Some, but no help-seeking	30·7	17·0	33·3	33·0	0·9 (0·4–1·8)	0·5 (0·2–1·2)
Consulted GP	7·9	34·2	8·0	19·5	0·9 (0·3–2·5)	1·8 (0·9–3·7)
Consulted specialist	4·6	12·3	5·5	10·0	0·8 (0·2–2·6)	1·3 (0·4–4·0)
High CAGE score	18·1	10·4	16·4	7·7	1·1 (0·5–2·4)	1·4 (0·6–3·4)
Total Malaise score: mean (±S.D.)	3·6 (±3·6)	5·8 (±4·5)	2·0 (±2·7)	2·8 (±3·2)	$F = 25·7$ (1)***	$F = 52·5$ (1)***

*** $P < 0·001$.

CI = 1·0–2·0, $P = 0·07$), but not with general ability levels or childhood behaviour ratings. Women with MMR were considerably more likely than men to report consulting GPs and/or specialists over emotional problems in the previous 10 years (OR = 6·1, CI = 2·2–16·5, $P < 0·001$). Taking these gender differences into account, only childhood behaviour problems showed any associations with help-seeking ($P = 0·07$).

The data on service contacts also made it possible to examine attributable fractions for service use associated with MMR across the cohort as a whole. As shown in Table 1, rates of psychiatric and other specialist service contacts were much elevated in the MMR sample in childhood, especially among boys; based on these data, the percentage of childhood service use attributable to MMR was 11·1% for boys and 3·4% for girls. In adulthood, service use among men with MMR was much reduced. Among women, rates of contact increased over those reported in childhood, but to a lesser extent than for women in the comparison group. Service use attributable fractions thus fell between childhood and adulthood for both sexes.

Special and mainstream schooling

Finally, in view of the widespread debates on the advantages and disadvantages of mainstream schooling for children with mild mental impairments (see e.g. Howlin, 1994), it seemed important to attempt some assessment of the extent to which adult outcomes within the MMR sample varied according to the type of school cohort members had attended. As it was clear that special schools had admitted some of the most severely impaired children within the MMR sample, the analyses were all controlled for intake differences between the two school sectors in terms of cohort members' measured ability in childhood, social background and behaviour problems, and sensory/neurological handicaps.

On the majority of the outcome measures any initial bivariate differences in adult outcomes between mainstream and specially educated groups were reduced to non-significance ($P > 0·2$) by controls for intake variations between the two school sectors. Some marginal associations with school placement did, however, remain on three indicators: housing tenure ($P = 0·10$), earlier age at first child among women ($P = 0·09$), and Malaise scores ($P = 0·04$). In each case, young people placed in special schools had fared less well than their peers in mainstream schooling.

DISCUSSION

Mental retardation has been identified as a much under-researched area in relation to the size of the clinical burden involved (Medical Research Council, 1993). Recent estimates suggest that some 1·6 million people in the UK are likely to be affected, the great majority showing mild mental impairments comparable with those examined here. Among the many aspects of this field requiring fuller attention, developmental studies, and especially those tracing longer-term patterns of adaptive functioning, have been especially sparse.

Against that background, this study was designed to capitalize on data collected in the course of the National Child Development Study to characterize key aspects of adult functioning

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in MMR samples, and to provide some initial pointers to the childhood influences that might be involved. Before discussing the findings, it is important to consider both the strengths and the limitations of the NCDS database for a study of this kind. On the positive side, it allowed for the identification of a relatively sizeable sample of children functioning intellectually within the MMR range, and provided markers of their adaptation in a range of aspects of adult functioning. Almost all previous follow-up studies have focused on specially educated or referred samples, and few have included non-retarded comparison groups. NCDS offered the major advantage of providing data on the important group of mainstream-educated children with MMR and of allowing for comparisons with non-retarded samples throughout the analyses.

Alongside these strengths, two main limitations must also be borne in mind in interpreting the findings. First, individual IQ tests were not available within the data-set, and we relied instead on results from a group-based general ability test to distinguish the MMR and non-retarded comparison groups, and on educational placement records to exclude those with severe impairments. More refined approaches to group definition would undoubtedly have been desirable. In practice, however, the rate of MMR identified using this approach (20·4 children per 1000) fell well within the range of estimates reported in the more satisfactory epidemiological studies undertaken to date (Roeleveld *et al*. 1997) and the childhood correlates of MMR closely paralleled those identified by previous investigations. The second limitation concerned loss of data. Subject attrition, along with the requirement for complete data on measures from a number of study sweeps, and from different reporters, considerably reduced the numbers available for the main analyses, particularly among members of the MMR sample. We identified a series of factors that differentiated complete from incomplete data cases: cognitive ability, male gender, family disruption and disadvantage in childhood, restricted parental education, and childhood behaviour problems. These variables affected the availability of data in the MMR and comparison groups in broadly similar ways. Nonetheless, the weights used to take account of sample attrition were constructed to allow not only for main effects of these factors, but also for possible variations in their impact between the two main study groups.

Our first aim was to contrast the MMR and comparison samples on a range of measures of adult status and functioning. With few exceptions, individuals with MMR appeared to be facing considerably elevated rates of difficulty. For many, living circumstances and social conditions in adulthood were poor, and potential stressors high. Many of the women had married and begun childbearing at very young ages; by their early thirties they were markedly more likely to be caring for large families than the majority of their peers, and to be reliant on welfare benefits to supplement or maintain their incomes. In terms of social support, most women in the cohort saw friends as key resources at times of emotional or relationship problems. Women with MMR were significantly less likely to report supports of this kind, and their levels of emotional distress at the time of the adult interviews were exceptionally high.

For men, outcome profiles differed in some important ways, most obviously in relation to indicators of independent living. Almost a quarter of the men with MMR were living with their parents in their early thirties, and regardless of living situation, men in the MMR sample were more likely than others to see their parents as key sources of social support. On the measures available in NCDS, overt labour market difficulties in the MMR sample were confined to two main areas: men with MMR were more likely to have faced multiple periods of unemployment than their peers in their twenties and early thirties, and a small but higher proportion had remained completely out of the labour market throughout this period. Finally, like their female counterparts, men with MMR showed much increased risks of psychiatric morbidity in adulthood.

Mild mental retardation is widely characterized as cultural/familial in origin, with social disadvantage and genetic factors assumed to play key contributory roles. The strong overlaps between MMR and social adversity in childhood raise important questions about the basis for problems in adult functioning, and the extent to which poor adult outcomes might be attributable to socially disadvantaged conditions in early life. Comparisons between MMR and non-

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retarded samples in NCDS suggested that factors of this kind played a non-trivial, but by no means predominant, role. Taking account of the higher rates of sensory and neurological problems within the MMR sample, measures of childhood social disadvantage (low social class, large family size, poor housing circumstances and family breakdown) accounted for some 20–30% of differences between the MMR and non-retarded groups across a range of adult outcome measures. The main exceptions were indicators of adult social support in both sexes, and lack of independent living among the men, both of which seemed relatively unrelated to early disadvantage.

Probably the most striking aspect of the findings concerned the high rates of emotional distress reported by both men and women with MMR in adult life. A considerable body of evidence suggests that adults with mental retardation are at increased risk of emotional disorders (Borthwick-Duffy, 1994). To date, however, few studies have been able to provide direct comparisons with similar assessments in non-retarded samples. Our results suggest that in both relative and absolute terms, individuals with MMR are likely to experience high rates of affective symptomatology in adulthood. So far as we could ascertain, these findings are unlikely to reflect methodological artefacts. Other investigators (Lindsay *et al.* 1994; Manikam *et al.* 1995) have shown that adolescents and adults with mild–moderate mental impairments are able to provide consistent reports of feelings of depression and anxiety on self-report instruments similar to the Malaise Inventory, and Malaise scores showed no systematic relationships with variations in intellectual ability within the MMR sample studied here. The high rates of emotional distress reported also stood in marked contrast to cohort members' reports of alcohol problems, which were in no sense elevated in the MMR sample.

To date, the mechanisms underlying increased risks for psychiatric disorder among individuals with MMR remain little understood; brain pathology, early family adversity, feelings of inadequacy in educational and social roles, intrinsic associations between cognitive and behavioural/emotional functioning, and genetic factors are among the most widely-canvassed possibilities (Simonoff *et al.* 1996). Our findings suggest that sensory/neurological problems, along with early adversity, played significant roles in both between and within-group differences, but nonetheless accounted for only modest proportions of the risks observed. Perhaps surprisingly, continuities from teacher-rated behaviour problems in childhood showed little impact in the within-group analyses of current symptomatology. To an extent, this may have reflected methodological limitations: the BSAG teacher ratings, although widely used at the time of the childhood studies, undoubtedly provided less sensitive indicators of childhood behaviour problems than more recently developed assessment tools. More generally, however, it seems clear that more detailed studies of the factors that contribute to the greatly elevated risks of emotional distress among young adults with mild mental impairments are greatly needed.

Measures of service use highlighted other issues. Between group differences in reports of contacts with health and psychiatric services were much reduced between childhood and adulthood, but with little indication that levels of distress had moderated in parallel ways. In childhood, attributable risks for service use associated with MMR were considerably elevated; similar estimates in adulthood showed barely any increased risk among women and lower than expected rates among men. These contrasts need to be seen against the background of levels of contact with psychiatric and health services at different developmental periods in the cohort as a whole. By age 11, for example, under 5% of girls in the comparison group had been referred to child guidance or other psychiatric services, but in early adulthood some 10% of women reported referral to a specialist for mental health problems and much larger proportions had consulted their GPs. Among men, rates of specialist referral were higher in childhood and were maintained at broadly similar rates in adult life. Within the MMR samples, the findings followed very different trends, suggesting that relative rates of access to service use declined across development. We can only speculate on reasons for this pattern. Under-reporting of service contacts by individuals with MMR cannot, of course, be excluded. In addition, however, it seems likely that referrals from teachers and others constituted an important avenue for access to services in childhood; lack

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of comparable 'third party' initiators of service contact in adulthood may have contributed in no small way to the relatively low levels of help-seeking reported in adult life.

As noted at the outset, a number of commentators have argued that the school years may prove the most demanding for individuals with MMR, and that problems in adaptive functioning may decrease as environmental demands become more flexible in adult life. Our findings suggest a different, and in many ways less optimistic, conclusion. For many individuals with MMR, the demands of the school years seem likely to be replaced by other stressors in adulthood, new challenges presenting themselves at each new life-stage. From a theoretical perspective, our findings argue the need for more detailed studies of the developmental pathways involved here. From a practice viewpoint, appropriate and accessible supportive services in adulthood would appear to be urgent needs for many individuals with MMR.

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