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Access to services by children with intellectual disability and mental health problems: Population-based evidence from the UK

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Abstract

Background: Children with intellectual disability (ID) experience high levels of mental health problems that may require access to professional support. However, there is limited information about how frequently these children access services.

Method: A survey of mental health in children living in the United Kingdom (UK) by the Office of National Statistics in 2004 (N=7977) was used to examine levels of service access. Children with ID and mental health problems were compared to children with mental health problems (without ID), children with ID and no mental health problem, and typically developing children.

Results: Children with ID and mental health problems accessed specialist mental health services at higher rates than children with only ID, but at similar rates to children who only have mental health problems.

Conclusions: Overall, low levels of service access highlight likely high unmet need among children with ID, mental health problems and both conditions.

Keywords: Intellectual disability, mental health, service access, population sample

The reported prevalence of mental health problems among children with intellectual disability (ID) ranges from 30% to 50% (Einfeld, Ellis, & Emerson, 2011). This level of prevalence is significantly higher than in children who do not have ID (8-18%; Einfeld et al., 2011). Importantly, the prevalence of mental health problems among children with ID remains significantly higher than for other children, even after controlling for increased exposure to socioeconomic deprivation (Emerson, Einfeld & Stancliffe, 2010). Conduct problems and anxiety disorders are amongst the most prevalent mental health problems in this group of children (approximately 20% and 11% prevalence, respectively; Emerson & Hatton, 2007a).

Mental health problems in children with ID can start early in life. Emerson and Einfeld (2010) report higher rates of emotional and behaviour problems in two and three year old children with developmental delays living in the United Kingdom (UK) and Australia. In addition, mental health problems show considerable persistence in this population. In a unique longitudinal study, Einfeld and colleagues (2006) demonstrated that at 12 years of age 41% of Australian children with ID had clinically significant levels of mental health problems. By age 24, 31% of the same sample continued to have clinically significant levels of mental health problems (i.e. three quarters had long-term, persistent problems).

While robust population-based evidence on the prevalence of mental health problems in children with ID is emerging, data on service access and use are still relatively scarce. In an epidemiological survey of 578 Australian four- to 19-year olds identified to be representative of the administrative ID population in New South Wales and Victoria, only 10% of those with ID and a psychiatric diagnosis were in receipt of mental health services (Einfeld et al., 2006). In their study, Einfeld et al. identified mental health problems independently of administrative service use. This suggests that the small proportion of children in receipt of services could be due

to either low levels of identification of mental health problems or to low levels of mental health services available to this population. There are reports of low levels of service use from other countries. For example, Gothelf et al. (2008) found that about 21% of Israeli students with ID and mental health problems reported that they had received psychotherapeutic treatment and 25.3% reported receiving psychotropic medications.

In the UK, children with autism and ID who had high levels of behavioural and emotional problems were more likely to have recently accessed mental health services than those who did not have mental health problems (Salomone et al., 2014). However, the proportion of children with autism, ID and high levels of problems who had accessed recent mental health support was only in the range of 19-26%.

Population data on service access and use in children with ID and mental health problems are few. In addition, most studies have not included comparisons with children without ID and so questions about potential access inequalities have been addressed only rarely. Emerson and Hatton (2007b) using data from the Office of National Statistics (ONS: Green, McGinnity, Meltzer, Ford & Goodman, 2005) compared service access levels between children with ID and those without and found that overall 75% of children with ID had accessed some type of professional service in the previous six months. For most types of professional services, children with ID accessed them at higher rates compared to children without ID, except for specialist mental health services. While important, this existing evidence does not allow us to understand whether the presence of a mental health problem in addition to the ID might make a difference to service access levels, and indeed, access to specialist mental health services.

In the present study, we explored health care access among children with ID and mental health problems. We used data from a UK child population-representative survey (Green et al.,

2005). This data source is unique because the survey randomly identified children across British households, and identified mental health problems following an independent clinical interview without reference to any clinical diagnoses that may have already been present.

Our first research aim was to examine the associations between service access and the presence of a mental health problem and/ or ID. To do this, we considered children with both ID and mental health problems, children who only had either ID or mental health problems, and children who had none of these conditions (control group). This design allowed us to compare levels of service access firstly between typically developing children and children with a diagnosable condition. We anticipated that children with a diagnosable condition would access any type of professional service at a higher rate, because of their higher level of need. Additionally, this design allowed us to examine service access rates when children had one diagnosable condition compared to having two. With regard to specialist mental health services, we anticipated that children with a mental health problem and ID would access this service at higher levels compared to children who only had ID. Similarly, we anticipated that children with ID and mental health problems would access specialist mental health services at levels higher to those of children with just mental health problems.

Our second aim was to examine factors associated with professional service use across the population of British children and, in particular, whether the presence of ID and/ or mental health problem would still be significantly associated with accessing professional services, after accounting for possible associations with socio-economic indicators and maternal mental health.

Materials and methods

The present study is a secondary analysis of data from 7,977 children (aged five to 16 years old) who participated in a 2004 UK survey on psychiatric morbidity (Green et al., 2005). The UK Department of Health and the Scottish Executive Health Department commissioned the survey, which the UK ONS conducted. Using Child Benefit Records, the survey identified children who were representative of the UK population of 5-16 year-olds living in private households. At the time of the study, Child Benefit was a universal, non-means tested benefit with near-universal coverage in the UK. The sampling method used in the survey involved identifying a random group of age-appropriate children from each of the 426 UK postal sectors, resulting in a target sample of 10,496 whom the ONS could trace and approach for interview. Following refusals, difficulties with language and ability to contact, the ONS conducted 7,977 valid interviews, which represents 76% of the target sample (Green et al., 2005). Primary caregivers, typically mothers (95%), completed the interviews and interviewers then asked teachers to provide further information.

Participants

Among the 7,977 children included in the survey, we identified children with ID and a clinician-assigned psychiatric diagnosis (mental health problem, see below). The identification of ID followed previous work by Emerson and Hatton (2007a). Emerson and Hatton designated children as having ID if: (a) their carer reported the child had ID and their teacher indicated that the child either had a difficulty in reading, maths and spelling or a developmental quotient (teacher estimated developmental age divided by chronological age) two or more standard deviations below average; (b) their teacher reported they had difficulties in reading, maths and spelling, and they had a developmental quotient two or more standard deviations below average;

or (c) their carer reported the child had ID and they had been concerned about their language development in the first three years of life. Mental health problems (the presence of an International Classification of Disease (ICD)-10 based psychiatric diagnosis) were identified following a standardised clinical interview (Goodman, Ford, Richards, Gatward & Meltzer, 2000; see below for a full description) that was conducted by trained interviewers and rated by trained clinicians.

Using these classifications, 165 children were identified with ID, 104 children were identified with ID and a mental health problem (ID/MH); 634 children with a mental health problem (without ID), and 7,047 children did not have ID or mental health problems. We included the latter group as a control group that would indicate population norms with reference to socio-demographic characteristics and service access levels. Children in the control and ID groups were on average ten years old, whereas in the groups with a mental health problem the children were slightly older (11 years-old). Compared to the control group (50% boys), there were significantly more boys in the three other groups, with the highest rate in the dual diagnosis group of ID and mental health problems (71% boys). There were high levels of socio-economic adversity in the three clinical groups. The highest level of adverse socio-economic circumstances was in the ID/MH group: income poverty (48%), parental unemployment (49%), low maternal education (58%) and single parent status (14%). In addition, the presence of ID and/or a mental health problem was associated with high levels of exposure to negative life events (ranging from 57% to 69% exposed to a list of child-related life events). Table 1 presents demographic information for the sample and statistical comparisons.

Measures

Mental health problems. We defined mental health problems as the presence of any ICD-10 diagnosis. ONS researchers had assigned ICD-10 diagnoses using the Developmental and Well-Being Assessment (DAWBA: Goodman et al., 2000). The DAWBA can identify psychiatric disorders in community samples and involves a combination of structured and open-ended information. Trained interviewers obtained information from the parent, child (if 11 years or older) and, if available, the child's teacher. Experienced clinicians reviewed the structured and open-ended information and considered appropriate diagnoses using ICD-10 criteria (Green et al., 2005). The DAWBA can reliably discriminate clinical cases among community populations (Goodman et al., 2000).

Service use. The ONS survey questioned parents about services they had accessed in the past 12 months because of concern about their child's emotion, behaviour or concentration. This part of the survey was semi-structured and resulted in the identification of 11 sources of support. These sources of support could be formal or informal with the former referring to specialist and non-specialist services (Green et al., 2005). For the current analysis, we categorised sources of help according to whether they needed a referral and their degree of specialisation. The categories developed were:

- Primary care, comprising general practitioners and teachers. These are services available to everyone in the UK and people can access them without a referral from a health or social service practitioner
- Social work/education services, comprising social work and special education services. Families access these services via a referral from a professional or a test for eligibility

- Mental health services, comprising child, adolescent or adult mental health services. These services provide specialist mental health input and are typically accessed via referral from a professional

We also considered an overall category of professional help, comprising all the categories detailed above *plus* specialist physical health services (typically paediatrics). A non-professional support category summarised all support accessed from non-professionals, comprising family or friends, telephone helplines, self-help groups, and the Internet.

Socioeconomic adversity. We created a composite variable to provide an index for family socio-economic adversity. This variable included income poverty (family income above or below 60% of the national median equivalised income), maternal education (low educational qualifications [left school at 16 or earlier] vs. higher level), the family's economic activity (neither parent in paid employment vs. at least one parent in paid employment) and family negative life events (none vs. one or more negative life events). Negative life events (separation, financial crisis, problems with the police/courts, death in the family, death of close friend, child in serious accident, child close friendship ended) were included to capture adverse circumstances experienced by the child in the year prior to the interview. The resulting composite contained four variables. The composite score was converted to a dichotomous variable to indicate families experiencing low socio-economic adversity (0 or 1 adversity indicators present) and families experiencing high adversity (2 or more adversity indicators present). We considered family composition as a separate variable (single parent status vs. other).

Maternal mental health. To account for any potential associations between maternal psychological well-being and levels of service access for the child, we controlled for likely maternal emotional disorder and positive maternal mental health. The ONS survey assessed

maternal mental health using the 12-item General Health Questionnaire (GHQ-12: Goldberg & Williams, 1988). ONS surveys have included the GHQ-12 as a unidimensional assessment of psychological well-being and suggested that a score of three or above is indicative of a likely emotional disorder (Green et al., 2005; Meltzer, Gatward, Goodman & Ford, 2000). We also estimated positive mental health using GHQ-12 items 1, 3, 4, 7, 8, and 12, which Hu, Stewart-Brown, Twigg, and Weich (2007) identified as discriminating well between positive and negative mental health. Internal consistency in the ONS sample was .877 for the total GHQ-12 composite and .759 for positive mental health. We used a median split to identify mothers with high positive mental health vs those with low positive mental health (Totsika, Hastings, Emerson, Lancaster & Berridge, 2011), and the clinical cut-off of 3+ for the GHQ-12 as a whole to indicate likely emotional disorder.

Results

Levels of service contact

Table 2 shows the rate of service contact for the four study groups. As expected, all types of service contact were at the lowest levels among the control group. Statistical comparisons indicated that levels of service access were higher in the three clinical groups compared to the control group. In light of this, we examined separately pairwise differences between children with ID/MH and those with ID only, and children with ID/MH and those with MH only.

Comparing service access levels between ID/MH children and those with MH only, there were no significant differences in non-professional support accessed (36.5% and 34.9% respectively, $\chi^2 = 3.93$, $p = .05$), in all professional services accessed (76.9% and 67.2%, respectively, $\chi^2 = .11$, $p = .739$), or contact with specialist mental health services (27.9% and

23.5%, respectively, $\chi^2 = .94$, p = .333). It is noteworthy that less than a third of children with a mental health problem (with or without ID) accessed any specialist mental health service. Significant differences between the ID/MH and MH only groups were seen for use of social services and education services ($\chi^2 = 10.068$, p = .002), and primary care ($\chi^2 = 6.76$, p = .009). Children with ID/MH accessed social services and specialist education services at significantly higher rates (40.4%) compared to children who had mental health problems but no ID (25.4%). Similarly, children with ID/MH accessed primary care from general practitioners and teachers significantly more frequently (72.1%) compared to children who had mental health problems and no ID (58.7%).

Comparing service access levels between children with ID/MH and those with ID and no mental health problem, there were significant differences for all types of services accessed. In all cases, children with ID/MH accessed support and services at significantly higher levels compared to children with ID only: non-professional help ($\chi^2 = 15.19$, p <.001); primary care ($\chi^2 = 18.38$, p <.001); Social services and education services ($\chi^2 = 17.08$, p <.001); mental health services ($\chi^2 = 28.54$, p <.001); and all professional services ($\chi^2 = 20.56$, p <.001).

Factors associated with accessing professional services

We used multivariate logistic regression models to examine the contribution of each potential predictor of service use in the population of British children. A separate model was fitted for each type of service used (Table 3). The aim of these analyses was to examine the association between service use and the presence of ID and a mental health problem, after accounting for a range of family and demographic characteristics (Table 1) that are potentially associated with service use. As mentioned, we aimed to control for maternal mental health (emotional disorder and positive mental health) for its potential to relate to child service access

(through maternal service access). The correlation coefficient for the measures of maternal emotional disorder and maternal positive mental health was -.58, suggesting that the association between these two constructs was not high enough to prevent them being entered in the models together. Further collinearity tests indicated that there were no problems with multi-collinearity in the models. We also controlled for socio-economic adversity and family status (Durà-Vilà & Hodes, 2009).

Presence of ID and mental health problems. Controlling for child age, gender, maternal mental health, socio-economic adversity and single family status, the presence of ID was associated with significantly higher odds of accessing all types of professional services: Odds ratio (OR) for primary care: 4.44 (95% CI: 3.24, 6.07); for social/education services: 4.79 (95% CI: 3.30, 6.96); and for specialist mental health services: 1.89 (95% CI: 1.19, 3.02). The presence of a mental health problem was also significantly associated with higher odds of accessing professional services: OR for primary care was 6.68 (95% CI: 5.55, 6.07); for social/education services was 9.06 (95% CI: 7.03, 11.66); and for specialist mental health services was 22.11 (95% CI 16.11, 30.34). Overall, the presence of ID and the presence of a diagnosable mental health problem were significantly and independently associated with increased access to all three professional services, after accounting for any effects of deprivation, maternal mental health, child gender and age.

Socioeconomic position. Interestingly, accessing any of the three types of professional services was not associated with increased socio-economic adversity. The other indicator of socio-economic position was single parent family. Living in a single parent family was not associated with accessing primary care or specialist mental health services but was associated with accessing social/ education services (OR: 1.35, 95% CI: 1.02, 1.93): single parent families

were more likely to access social services or specialist education services for concerns regarding their child's developmental outcomes.

Summary. Examining the variables associated with specialist mental health service access, child age, socio-economic adversity, single parent status, and maternal positive mental health were not identified as significant correlates. The presence of ID and the presence of a mental health problem were significant correlates. The only other variable associated with higher odds of access to specialist mental health services was child male gender.

Discussion

We examined available UK population-representative data for information about service access by those children who have ID and mental health problems. As hypothesised, children with either mental health problems or ID, or both conditions accessed all types of service more frequently than a control group of children. Overall, children with ID/ MH presented with the highest levels of service access. Contrary to our hypothesis, however, the ID/ MH group accessed specialist mental health services at a similar rate as children who only had a mental health problem. The overall rates of access to services were low (less than a third of all children with a mental health problem whether or not they had ID), suggesting potentially high levels of unmet need. Compared to children who only had ID, children with co-morbid ID and mental health problems accessed all types of services more frequently, potentially suggesting that complications arising from comorbid conditions are being addressed by increased service access in a UK context. This finding reinforces data from Canada showing that children with ID and challenging behaviour access the highest number of services (Lunsky et al., 2014). The higher frequency of specialist mental health service access in comorbid conditions compared to ID only

groups suggests that contrary to a diagnostic overshadowing hypothesis, in practice clinicians are able to recognise psychological problems in children with ID.

Examined under an inequality lens (Emerson & Hatton, 2014) we would have expected service access to specialist mental health services to be lower for children with ID. We actually hypothesised that children with increased complexity (ID+/MH) would access specialist mental health services at a significantly higher rate than their peers with only mental health problems. The non-significant difference in accessing specialist mental health services between the MH and ID/MH group would suggest prima facie that there is no evidence of inequality in accessing specialist mental health services. However, this non-significant difference suggests lack of differentiation according to level or complexity of need, and thus a potential mismatch between need and access.

It is concerning that between 72% and 76% of children with mental health problems (with and without ID) had not accessed specialist mental health services in the past 12 months, suggesting low levels of mental health service access in general. Some methodological limitations of the current study may go some way in explaining this trend. It is possible that DAWBA generated diagnoses (based on symptoms in the last month) could have identified children awaiting service-based diagnosis or referral. Another possibility is that the current data might under-represent contact as information about service use relied primarily on parents' retrospective recall and this can be vulnerable to biases (Shivram et al., 2009). The current study could not verify service use, investigate the frequency and duration of service contact, nor the purpose of service access (i.e., whether this was for support with mental health). However, even accounting for these methodological limitations, the gap in service access is so wide for the

population of children with mental health problems (with or without ID), that it is very likely to demonstrate high levels of unmet need in the UK.

Looking at the data across all professional services, a substantial proportion of children with ID did not access professional services. These low levels of service access are consistent with findings from other studies and other countries (Einfeld et al., 2006; Gothelf et al., 2008; Salomone et al., 2014). Children with ID had most contact with primary care services (i.e., general practitioners and teachers), but still between 30% and 50% of children with ID with or without mental health problems, respectively, had not accessed primary care at all in the previous 12 months. With regard to more specialist input accessed via referral, access to social services and specialist education services was also at low levels for children with ID (40% if they also had mental health problems and 18% if they did not). This may reflect how well families of these children cope. However, we would expect that specialist education services would address these children's learning difficulties rather than their mental health problems.

One of the limitations of the current study was the lack of formal test data in the ascertainment of ID status. The definition of ID used might have incorporated borderline cases, with such children unlikely to reach ID service eligibility criteria. This may be one of the factors that leads overall service access levels for children with ID as a whole to appear relatively low. In other studies, higher levels of overall service access have been reported and this may be due to the severity of disability and the co-morbid medical and neuro-developmental problems of samples considered (Doran et al, 2012; Larson, Russ, Kahn & Halfon, 2011; Schieve et al, 2012) or the time point of measurement (Barron, Molosankwe, Romeo & Hassiotis, 2013). However, it is noteworthy that disability severity is not consistently associated with increased service use (Lunsky et al., 2014).

The strength of the DAWBA was that it allowed diagnosis independent of reported service use. In the present analysis, the DAWBA would have been completed almost exclusively by parent report and this is consistent with how the DAWBA can be used. Although the DAWBA often includes a self-report for adolescents, it is unlikely adolescents with ID would have been interviewed or contributed self-reports at the same rate as adolescents without ID. Mental health problems may present slightly differently in ID and there is an adapted version of the Diagnostic Statistical Manual available (Diagnostic Manual- ID; Fletcher, Loschen, Stavrakaki & First, 2007) for use with people with ID as well as additional guidance on using the World Health Organisation International Classification of Dieases-10. These adaptations are not incorporated into the DAWBA, so it is possible that the DAWBA will tend to either over or under estimate the presence of mental health problems in children and adolescents with ID. Therefore, some caution in interpretation is needed.

Controlling for any other effects, having ID or having mental health problems were still significantly associated with accessing professional services. When considering particular demographic characteristics systematically related to accessing professional services, male gender was the only variable associated with service use across the three types of services. Maternal emotional disorder was significantly associated with increased access to social/educational service and primary care, though, interestingly, not to specialist mental health services, suggesting that possible mental health problems of the mother do not independently relate to mental health service use for the child.

Interestingly, the lack of association between adversity and any type of service access contrasts with findings from other countries on adults with ID (with regard to primary care; Balogh, Ouellette-Kuntz, Brownell and Colantonio, 2013) and adolescents with ID (Amone-

P'Olack et al., 2010). When we substituted income poverty for adversity in the logistic regression models in an additional exploratory analysis, the results were identical for specialist mental health and social/educational services (i.e., income poverty did not increase the odds of service access), but suggested an association with reduced access to primary care (OR. 84, 95% CI: .72, .98), similar to the Balogh et al. study.

Current data suggest significant apparent unmet need for children with ID, children with mental health problems and children with both conditions in the UK. Future research needs to focus on examining barriers to service use. Apart from the often cited focus on intra-family factors, like deprivation and adversity, potential external barriers need to be examined, including regional availability of specialist services, and the effectiveness of measures for gatekeeping access to secondary care used in primary care.

Evidence in the present study was based on data collected about ten years ago (Green et al., 2005). Since then, there has been an emphasis on providing more specialised services for children with ID who have mental health problems. Unfortunately, there has been no update to the ONS survey, despite it being the most comprehensive survey of mental health in the population of British children (Hollins et al., 2014). It is, therefore, unknown whether recent policy changes have increased service access for children with increased complexity (i.e., those with ID who also have mental health problems), or simply diverted children with ID towards specialised teams and professionals instead of mainstream child mental health services. Consequently, it will be important to collect new data about service access in large, representative samples of the population in future research endeavours.

References

Amone-P'Olak, K., Ormel, J., Oldehinkel, A. J., Reijneveld, S. A., Verhulst, F. C., Burger, H. (2010). Socioeconomic position predicts specialty mental health service use independent of clinical severity: The TRAILS study. *Journal of the American Academy of Child & Adolescent Psychiatry, 49*, 647-655. doi: 10.1016/j.jaac.2010.03.007

Balogh, R. S., Ouellette-Kuntz, H., Brownell, M. & Colantonio, A. (2013). Factors associated with hospitalisations for ambulatory care-sensitive conditions among persons with an intellectual disability: a publicly insured population perspective. *Journal of Intellectual Disability Research, 57*, 226-239. doi: 10.1111/j.1365-2788.2011.01528.x

Barron, D. A., Molosankwe, I., Romeo, R. & Hassiotis, A. (2013). Urban adolescents with intellectual disability and challenging behaviour: costs and characteristics during transition to adult services. *Health and Social Care in the Community, 21*, 283-292. doi: 10.1111/hsc.12015

Doran, C. M., Einfeld, S. L., Madden, R. H., Otim, M., Horstead, S. K., Ellis, L. A. & Emerson, E. (2012). How much does intellectual disability really cost? First estimates for Australia. *Journal of Intellectual and Developmental Disability, 37*, 42-49. doi: 10.3109/13668250.2011.648609

Durà-Vilà, G. & Hodes, M. (2009). Ethnic variation in service utilisation among children with intellectual disability. *Journal of Intellectual Disability Research, 53*, 939-948. doi: 10.1111/j.1365-2788.2009.01214.x

Einfeld, S. L., Ellis, L. A. & Emerson, E. (2011). Comorbidity of intellectual disability and mental disorder in children and adolescents. A systematic review. *Journal of Intellectual and Developmental Disabilities, 36*, 137-43. doi: 10.1080/13668250.2011.572548

Einfeld, S. L., Piccinin, A. M., Mackinnon, A., Hofer, S. M., Taffe, J., Gray, K. M., Bontempo, D. E., Hoffman, L. R., Parmenter, T., Tonge, B. J. (2006). Psychopathology in young people with intellectual disability. *Journal of the American Medical Association, 296*, 1981-1989. doi: 10.1001/jama.296.16.1981

Emerson, E., & Einfeld, S. (2010). Emotional and behavioural difficulties in young children with and without developmental delay: a bi-national perspective. *Journal of Child Psychology and Psychiatry, 51*, 583-593. doi: 10.1111/j.1469-7610.2009.02179.x.

Emerson, E., Einfeld, S., Stancliffe, R. J. (2010). The mental health of young children with intellectual disabilities or borderline intellectual functioning. *Social Psychiatry and Psychiatric Epidemiology, 45*, 579-587. doi: 10.1007/s00127-009-0100-y

Emerson, E., & Hatton, C. (2014). *Health inequalities and people with intellectual disability.* New York, USA: Cambridge University Press

Emerson, E., & Hatton, C. (2007a). Mental health of children and adolescents with intellectual disabilities in Britain. The *British Journal of Psychiatry, 191,* 493-499. doi: 10.1192/bjp.bp.107.038729

Emerson, E. & Hatton, C. (2007b). *The mental health of children and adolescents with learning disabilities in Britain. Report for the Institute for Health Research and the Foundation for People with Learning Disabilities.* Lancaster, UK: Lancaster University.

Fletcher, R., Loschen, E., Stavrakaki, C. & First, M. (2007). *Diagnostic Manual- Intellectual Disability (DM-ID): A clinical guide for diagnosis of mental disorders in persons with intellectual disability.* Kingston, NY: NADD Press.

Goldberg, D. & Williams, P. (1988). General Health Questionnaire. Windsor, UK: NFER-Nelson Publishing.

Goodman, R., Ford, T., Richards, H., Gatward, R. & Meltzer, H. (2000). The Development and Well-being Assessment: Description of initial validation of an integrated assessment of child and adolescent psychopathology. *Journal of Child Psychology and Psychiatry and Allied Disciplines, 41*, 645-655. doi: 10.1111/j.1469-7610.2000.tb02345.x

Gothelf, D., Goraly, O., Avni, S., Stawski, M., Hartmann, I., Basel-Vanagaite, L. & Apter, A. (2008). Psychiatric morbidity with focus on obsessive-compulsive disorder in an Israeli cohort of

adolescents with mild to moderate mental retardation. *Journal of Neural Transmission, 115,* 929-936. doi: 10.1007/s00702-008-0037-4

Green, H., McGinnity, A., Meltzer, H., Ford, T. & Goodman, R. (2005). Mental health of children and young people in Great Britain 2004. Hampshire, UK: Pulgrave MacMillan.

Hollins, S., Chapman, V., Jayesinghe, N., Roycroft, G., Rough, E., Davies, F., … Wilson, R. (2014). Recognising the importance of physical health in mental health and intellectual disabilities. Achieving parity of outcomes. London, UK: British Medical Association.

Hu, Y., Stewart-Brown, S. L., Twigg, L. & Weich, S. (2007). Can the 12-item General Health Questionnaire be used to measure positive mental health? *Psychological Medicine, 37,* 1005-1013. doi: 10.1017/S0033291707009993

Larson, K., Russ, S., A., Kahn, R. S. & Halfon, N. (2011). Patterns of comorbidity, functioning and service use for US children with ADHD, 2007. *Pediatrics, 127*; 462-470. doi: 10.1542/peds.2010-0165

Lunsky, Y., Tint, A., Robinson, S., Gordeyko, M. & Ouellette-Kuntz, H. (2014). System-wide information about family carers of adults with intellectual/ developmental disabilities- A scoping review of the literature. *Journal of Policy and Practice in Intellectual disabilities, 11,* 8-18. doi: 10.1111/jppi.12068

Meltzer, H., Gatward, R., Goodman, R., & Ford, T. (2000). *The mental health of children and adolescents in Great Britain.* London, UK: The Stationary Office.

Office for National Statistics Social Survey Division, Mental Health of Children and Adolescents in Great Britain, 2004 (computer file). Colchester, Essex: The Data Archive (distributer), 5 March 2011. SN: 5269.

Salomone, E., Kutlu, B., Derbyshire, K., Mccloy, C., Hastings, R. P., Howlin, P., & Charman, T. (2014). Emotional and behavioral problems in children and young people with autism spectrum disorder in specialist autism schools. *Research in Autism Spectrum Disorders, 8,* 661-668. doi: 10.1016/j.rasd.2014.03.004

Schieve, L. A., Gonzalez, V., Boulet, S. L., Visser, S. N., Rice, C. E., Van Naarden Braun, K., & Boyle, C. A. (2012). Concurrent medical conditions and health care use and needs among children with learning and behavioral developmental disabilities, National Health Interview Survey, 2006-1010. *Research in Developmental Disabilities, 33,* 467-476. doi: 10.1016/j.ridd.2011.10.008

Shivram, R., Bankart, J., Meltzer, H., Ford, T., Vostanis, P. & Goodman, R. (2009). Service utilization by children with conduct disorders: findings from the 2004 Great Britain child mental health survey. *European Child and Adolescent Psychiatry, 18,* 555-563. doi: 10.1007/s00787-009-0012-0

Totsika, V., Hastings, R. P., Emerson, E., Berridge, D. M., & Lancaster, G. A. (2011). Behavior problems at five years of age and maternal mental health in autism and intellectual disability. *Journal of Abnormal Child Psychology, 39,* 1137-1147. doi: 10.1007/s10802-011-9534-2

Table 1. Socio-demographic profile of children with intellectual disability (ID), children with a mental health problem (MH), those with both conditions (ID/MH) and a control group

	Control group	**ID**	**MH**	**ID/MH**	**Overall comparison[1]**
N	7674	165	634	104	
Child male	3558 (50.3%)	104 (63.0%)	375 (59.1%)	74 (71.2%)	43.811, p<.001
Child age	10.46 (3.41)	10.12 (3.22)	11.44 (3.30)	10.96 (2.88)	52.37, p<.001
Socio-economic adversity[2]	1689 (26.4%)	62 (46.3%)	243(43.8%)	39 (48.8%)	240.05, p<.001
Family poverty	1689 (26.4%)	62 (46.3%)	243 (43.6%)	39 (48.4%)	114.35, p<.001
Neither parent working	926 (13.4%)	46 (31.1%)	183 (29.2%)	48 (48.5%)	224.49, p<.001
Child experienced one or more negative life event	3093 (44.7%)	81 (56.6%)	429 (69.2%)	64 (68.8%)	159.66, p<.001
No/low maternal education	2040 (29.5%)	75 (51.4%)	305 (49.3%)	53 (58.2%)	158.58, p<.001

Single parent	567 (8.1%)	19 (11.5%)	74 (11.7%)	15 (14.4%)	15.80, p<.001
Maternal emotional disorder	1378 (20.0%)	43 (29.7%)	292 (47.4%)	34 (38.2%)	259.65, p<.001
Maternal positive mental health	12.06 (1.90)	11.91 (2.14)	10.95 (2.93)	11.04 (2.29)	132.55, p<.001

[1]Group comparison for binary variables was conducted using Chi Square tests. Comparison for non-binary variables was conducted using Kruskal Wallis tests.
[2]Adversity is a composite of family income poverty, parental unemployment, child negative life events and maternal education.

Table 2. Levels of service access amongst the study groups.

	Control group	ID	MH	ID/MH	Overall comparison[1]
N	7674	634	165	104	
Primary care	1057 (14.9%)	75 (45.5%)	372 (58.7%)	75 (72.1%)	956.35, p<.001
General practitioner, teacher					
Social / Education services	161 (2.3%)	29 (17.6%)	161 (25.4%)	42 (40.4%)	1008.68, p<.001
Social service,, special educational services					
Specialist mental health	72 (1.0%)	8 (4.8%)	149 (23.5%)	29 (27.9%)	1146.44, p<.001
Specialist child and/or adult mental health services					
All professional help	1158 (16.4%)	81 (49.1%)	426 (67.2%)	80 (76.9%)	1143.00, p<.001
The three service types above plus specialist physical health					
Non-professional help	693 (9.8%)	26 (15.8%)	221 (34.9%)	38 (36.5%)	399.75, p<.001
Family/friends, helpline, self-help groups, Internet					

[1]Group comparison conducted using chi-square tests.

Table 3. Multivariate logistic regression models for professional service access in full sample (N=7,977)

	Primary care model	**Social / Education service model**	**Specialist mental health service model**
	Odds ratio (95% CIs)	Odds ratio (95% CIs)	Odds ratio (95% CIs)
Age	0.98 (.96-.99)	1.01 (.98-1.05)	1.01 (.97-1.06)
Intellectual Disability	**4.44 (3.24-6.07)**	**4.79 (3.30-6.96)**	**1.89 (1.18-3.02)**
Mental health problem (ICD-10)	**6.68 (5.55-8.03)**	**9.06 (7.03-11.66)**	**22.11 (16.11-30.34)**
High adversity	1.04 (.90-1.20)	1.26 (.96-1.65)	1.01 (.73-1.40)
Single parent	1.10 (.94-1.29)	**1.35 (1.02-1.77)**	0.62 (.78-1.53)
Maternal emotional disorder	**1.63 (1.37-1.94)**	**1.41 (1.03-1.93)**	1.43 (.97-2.09)
Maternal positive mental health	.99 (.95-1.02)	**0.93 (.87-.99)**	.95 (.89-1.02)
Male gender	**1.51 (1.34-1.72)**	**1.50 (1.18-1.92)**	**1.51 (1.12-2.04)**

Note: CIs = Confidence Intervals; Bold font highlights significant results (p<.05).