

Prevalence of autism in an urban population of adults with severe intellectual disabilities – a preliminary study

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Abstract

Background Research on the prevalence of autism in Iceland has indicated that one possible explanation of fewer autism cases in older age groups was due to an underestimation of autism in individuals with intellectual disabilities (IDs). The present study systematically searched for autism cases in the adult population of individuals with severe ID living in the city of Reykjavik, Iceland.

Methods Potential participants ($n = 256$) were recruited through the Regional Office for the Affairs of the Handicapped in Reykjavik. First, a screening tool for autism was applied, followed by the Childhood Autism Rating Scale and finally the Autism Diagnostic Interview-Revised (ADI-R).

Results The point prevalence of severe ID was 3.7/1000 (95% CI 3.2–4.1) with a male–female ratio of 1.2:1. Participation rate in the study was 46.5%. Participants were younger than non-participants and more often residents of group homes. The

prevalence of autism was 21% (25/119) (95% CI 14.7–29.2) with a male–female ratio of 1.8:1. Of the individuals with autism, 10/25 (40%) were verbal according to the ADI-R definition, and 18/25 (72%) had active epilepsy and/or other neurological conditions and handicaps.

Conclusion The study identified twice the number of autism cases than those previously recognised within the service system. Autism is a prevalent additional handicap in individuals with severe ID, which should always be considered in this population. There are indications that the estimated prevalence of autism found should be considered minimal.

Keywords adults, autism, prevalence, severe intellectual disability

Introduction

Intellectual disability (ID) or mental retardation is a heterogeneous group of disorders or conditions with varied causes and characterised by cognitive

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limitations because of organic brain dysfunction (Murphy *et al.* 1998). Cognitive abilities are measured with standardised intelligence tests with fixed mean and standard deviation. For the purpose of research, individuals with an IQ score below two standard deviations from the mean ($IQ < 70$) are considered to have ID (Murphy *et al.* 1998). Although an IQ below 70 is the most frequently used cut-point, evolving definitions of ID have led to broader inclusion (APA 1994). However, the results of standardised intellectual tests are not enough for a clinical diagnosis of ID, as a measure of adaptive behaviour and a clinical appraisal of these data and the developmental history is also required.

Controversy exists as to the prevalence of ID. The normal distribution forecasts that 1.92% of the population should test below IQ 70, which is the upper limit of ID according to the ICD-10 (WHO 1993), but epidemiological studies rarely confirm the prevalence of ID predicted by this model. However, the prevalence of severe ID ($IQ < 50$) seems relatively stable across geographical locations, age groups and time, or 3–4/1000 (Roeleveld *et al.* 1997; Leonard & Wen 2002).

There is a high prevalence of coexisting disabilities and disorders in ID, including sensory deficits, epilepsy, cerebral palsy, autism, and behavioural and psychiatric disorders (Murphy *et al.* 1998; Airaksinen *et al.* 2000; Strömme & Diseth 2000; de Bildt *et al.* 2005; Tobi *et al.* 2005). The number and severity of co-morbidities is closely related to the level of severity of ID, with those having an IQ below 50 being more affected.

Autism is a neurologically determined behavioural syndrome with multi-factorial aetiology and represents the more severe end of a spectrum of disorders of brain function (Tuchman & Rapin 2002). Autism is defined by three symptom domains: qualitative impairment in social interaction and communication as well as restricted, repetitive and stereotyped patterns of behaviour, interests and activities (WHO 1993). For the diagnosis of autism, autistic behaviours must be present to a certain degree in all three domains. In addition, deviant development has to be evident before the age of 36 months. In the case of atypical autism, a less severe symptomatology or a different pattern of symptom constellation is to be expected, and

onset prior to 36 months is not a requirement. The same applies to Asperger's syndrome, but by definition this diagnostic category is incompatible with ID (WHO 1993). Otherwise, definitions of autism spectrum disorders (ASDs) are independent of cognitive impairment.

During the last two decades there have been numerous accounts of increased frequency of autism, most often reported in the form of point prevalence. Instead of a prevalence of about 3–4/10 000 found for autism in earlier studies (e.g. Lotter 1966; Magnusson 1977), the prevalence of all ASDs seems to have stabilised at about 60/10 000 (e.g. Chakrabarti & Fombonne 2005; Fombonne *et al.* 2006; Gillberg *et al.* 2006; Ellefsen *et al.* 2007), although higher estimates have been reported (e.g. Honda *et al.* 2005; Baird *et al.* 2006).

All prevalence studies on autism or ASD describe male preponderance and in a review by Fombonne (2003) the male–female ratio ranged from 1.3:1 to 16:1 with a mean of 4.3. The male–female ratio is less pronounced when autism is associated with severe ID ($IQ < 50$) where this ratio approaches 2:1 or less (Nordin & Gillberg 1996; Fombonne 2003; de Bildt *et al.* 2005).

Most studies on the prevalence of ASD in children and adolescents with ID show higher estimates in the severe IQ range (e.g. Wing & Gould 1979; Nordin & Gillberg 1996; Steffenburg *et al.* 2003). Compared with research on children and adolescents with the double diagnosis of ID and ASD, data on adult populations are scarce (Bryson *et al.* 2008).

A population-based study on ASD in ID was conducted in the West Midlands, UK (Morgan *et al.* 2002). Youngsters and adults aged 16–65+ accessing services for individuals with ID were diagnosed with autism in two stages, a screening stage using the Scale of Pervasive Developmental Disorder in Mentally Retarded Persons (PDD-MRS) (Kraijer 1997) followed by a clinical stage. In total, 571 individuals were screened and 171 were diagnosed with ICD-10 childhood autism or atypical autism, or 30% of those screened. Of the group diagnosed with ASD, 88% had moderate to profound ID. The overall male–female ratio was 1.3:1.

Another population-based study in the UK examined psychiatric service use and psychiatric disorders in adults with ID (Bhaumik *et al.* 2008). All adults (aged 19 years or over) with administratively defined

ID in Leicestershire and Rutland were included ($n = 2711$). Of the total sample, 80.2% were classified in the moderate to profound ID range. Of the total sample, 8.8% were diagnosed with ASD (male–female ratio 2:1) of these 90.3% were classified in the moderate to profound ID range.

Studies on institutionalised populations with ID, usually heavily skewed towards severe impairment, have reported the highest estimates for autism and ASD (e.g. Kraijer 1997; La Malfa *et al.* 2004).

In a study on the prevalence of autism in Iceland, Magnusson & Saemundsen (2001) compared two cohorts, individuals born in 1974–83 and individuals born in 1984–93. The prevalence estimate (4.2/10 000) found for the older cohort was close to that typically reported in studies relying on Kanner's description of autism and published before 1985 (Wing 1993; Gillberg 1995; Bryson & Smith 1998), while the estimate for the younger cohort was considerably higher or 13.2/10 000. Even the latter figure was considered to be conservative, as this study was record-based and concentrated on autism and a narrow definition of atypical autism. These authors noted a 'second wave' of referrals in the younger cohort, that is, children who had already been diagnosed with ID and attended special schools but were then re-referred for possible autism. Thus, one possible explanation of lower prevalence in the older age group was undiagnosed autism in the population with ID.

Clinical diagnosis is frequently a prerequisite for receiving adequate services and treatment, so it is important for individuals with ID that ASD symptoms are recognised. Also, an estimate of the prevalence of ASD in individuals with ID is needed for the organisation and delivery of services. Finally, knowledge of the prevalence of autism in ID may alert professionals to the possibility of this dual diagnosis.

The present study was conceived as a partial test of the hypothesis of undiagnosed autism in adults with ID, using a three-stage methodology. As the main source of information was the records of the Regional Office for the Affairs of the Handicapped (ROAH) in Reykjavik, Iceland, and the quality of these records was unknown at the outset, the study also became a test of the feasibility of using the ROAH records as a basis for epidemiological research.

Methods

Population studied and ascertainment of intellectual disability

Services for the handicapped

The ROAH in Reykjavik is a governmental agency under the Ministry of Social Affairs and Social Security. The agency oversees and manages a number of special services for disabled and handicapped persons in the city of Reykjavik. The biggest single function is the management of residential services for persons with developmental disabilities. Other functions relate to counselling, support to parents of handicapped children, and vocational services. All persons diagnosed with IDs have the right to ROAH services, and all persons receiving services on the grounds of developmental disabilities are listed in the ROAH registers.

Diagnosis of intellectual disability

In order to be eligible for ROAH services, applicants must provide documentation concerning their disability. The most common documentation is a medical declaration. In cases of suspected or known ID the medical declaration is based on an examination by a physician and different sources of information, for example, etiological investigations, developmental and health history, standardised intellectual test results, diagnostic and classification systems, and service needs.

Because of the large age range of the sample, different diagnostic procedures were to be expected over time. In the ROAH records, there was inconsistent access to the sources of information which led to a diagnosis of ID and hence a medical declaration. All cases of doubtful documentation of ID were crosschecked with the records of the State Diagnostic and Counselling Centre (SDCC), a tertiary centre specialising in developmental disabilities (Jonsdottir *et al.* 2007). Excluded were all individuals who remained with doubtful documentation of ID or having cognitive test results in the 'normal' range ($IQ \geq 70$).

Classification of intellectual disability

Actual measures of intellectual functioning were only accessible for part of those diagnosed with ID,

thus precluding the use of the ICD-10 sub-classification. Instead two categories were retained, that is, severe ID with IQ below 50, and mild ID with IQ in the 50–69 range. Potential participants were only classified with severe ID if there was access to intellectual or developmental measures (including measures of adaptive behaviours), or when an evaluation of information about aetiology, developmental history and description of the intensity of service needs clearly supported such a classification. All others were classified with mild ID. As individuals with mild ID represented only 20% of the total group with ID, it was decided to limit the study on autism to those with severe ID.

Description of the population with severe intellectual disability

For the 1 of January 2000 the records of ROAH in Reykjavík listed the names and personal identification numbers of 256 individuals aged 18 to 67 years who had been classified with severe ID, 139 males and 117 females. Fifty-four individuals living in three residential facilities outside the city boundaries were registered as residents of Reykjavík. These were included in the sample described above. Of the total group with severe ID, 11 had a diagnosis of autism. All of these individuals had been diagnosed in childhood by an interdisciplinary team at the Department of Child and Adolescent Psychiatry, Landspítali University Hospital, or as adults by a clinical expert using the Autism Diagnostic Interview-Revised (ADI-R) (five cases). Two individuals who were considered autistic but without a formal diagnosis were excluded as they did not participate in the study.

Measures

A screening instrument developed by Bryson and colleagues, henceforth termed the 'Bryson scale', is a questionnaire, which was originally developed as a screening instrument in an epidemiological study of autism and based on DSM-III-R (Bryson *et al.* 1988). It contains 19 items reflecting the three symptom domains that define autism, scored on a 3-point scale (0, 1, 2). The Bryson scale had previously been translated into Icelandic (Magnusson & Gunnarsdottir 1994), and was the only instrument

available in Iceland at the time that could sensibly be used for intellectually handicapped populations. As the scale was intended for children and adolescents, it was necessary to change the wording slightly, and three items pertaining specifically to childhood were excluded (items no. 4, 12, 15). In the original research by Bryson and colleagues, a cut-off of 16 points provided the best balance of sensitivity and specificity. Deb & Prasad (1994) used a cut-off of 10 points for school-aged children in order to minimise false negatives in the screening stage of their study. In view of the use of fewer items (16 instead of 19), an arbitrary decision of an 8-point cut-off was made in order to prevent missing out on persons with autistic symptoms of impairing magnitude. In a separate study the alpha coefficient was 0.88 for this modified version of the Bryson scale (Hjaltestad & Gunnarsdottir 2000).

The Childhood Autism Rating Scale (CARS; Schopler *et al.* 1988) consists of 15 items scored on a 7-point scale. All items contribute equally to a total score. The recommended cut-off on the CARS is 30 points, as listed in the manual. However, previous research on the CARS had suggested that autistic symptoms, as measured by this instrument, became milder with increasing age, both for adolescents and adults (Mesibov *et al.* 1989). In light of these results, we decided on a lower cut-off, or 26 points. A preliminary study on the reliability and validity of an Icelandic translation of the CARS had been conducted previously (Einarsdottir & Haraldsdottir 1992). The CARS was used in the present study as an interview on current behaviours. In a separate study the alpha coefficient for the CARS was 0.93, and the correlation between the modified version of the Bryson scale and the CARS was 0.59 (Hjaltestad & Gunnarsdottir 2000).

The ADI-R is a widely studied investigator-based interview (Lord *et al.* 1994; Lord *et al.* 1997; Rutter *et al.* 2003). For a diagnosis of autism, cut-offs must be reached or exceeded in all three ICD-10/DSM-IV symptom domains: impaired social interaction, impaired communication, and stereotyped and repetitive actions. For the examination of symptom constellation, there are two sets of algorithms: (1) a diagnostic algorithm where abnormal behaviour at the age of 4–5 years and abnormal behaviours 'ever' present weigh heavily in the overall appraisal of autistic symptoms; and (2) an algorithm based on

current behaviours alone. The algorithm of current behaviours includes fewer items than the diagnostic algorithm, and thus portrays a less severe overall picture of autistic symptoms. An Icelandic translation of the ADI-R was used (see Saemundsen *et al.* 2003). The ADI-R classifies language abilities into two categories, verbal and non-verbal. Being verbal according to the ADI-R consists of the 'functional use of spontaneous, echoed, or stereotyped language that, on a daily basis, involves phrases of three words or more that at least sometimes include a verb and is comprehensible to other people' (Rutter *et al.* 2003, p. 8).

Procedures

The present study was conducted in three stages: a screening stage using the Bryson scale, an intermediary stage applying the CARS, and a diagnostic stage based on the ADI-R. The original plan was to screen for ASD in the whole ID range, and thus a need was felt for an intermediary stage to reduce the number of participants entering the diagnostic stage.

As a part of their BA thesis, two psychology students carried out the screening and part of the intermediary stage (Hjaltestad & Gunnarsdottir 2000). All those eligible received a letter of introduction addressed to the individual, where the purpose of the study was explained and in which the recipient was asked to participate. Attached to the introductory letter was the Bryson scale with directions for completion, and a form for informed consent.

Usually, the legal guardians or staff at residential facilities (after having gained permission from the former) responded to the letter of introduction. If there was no response, the residential facilities or legal guardians were contacted once by telephone in order to clarify whether there was an interest in participating in the study or in providing additional information on the study or its procedures. All participants, or their legal guardians, signed a letter of informed consent.

After informed consent and a completed questionnaire had been received by ROAH, all participants scoring 8 points or higher on the Bryson scale were contacted again. In a separate study the psychology students had been trained in the applica-

tion of CARS as an interview of current behaviours and had established reliability with experienced clinicians. When a CARS total score reached 26 or higher the individuals moved to the third stage where the ADI-R was applied by experienced clinicians. Residential staff members who knew the individual well were the respondents in most cases. Thus, they had limited access to developmental history, so only the algorithm for current behaviours on the ADI-R was scored.

Experienced clinicians (ES and PM) reviewed the records of those previously diagnosed with autism in order to verify their diagnoses but these individuals did not undergo another assessment within the study. These clinicians also reviewed all data on new cases found in the study and decided on autism diagnosis.

Calculation of the 95% confidence interval (CI) for an estimate of the prevalence of ID was based on a method proposed by Wilson (Newcombe & Altman 2003), and the same method was used to calculate the 95% CI for percent prevalence of ASD. Chi-square was used for categorical data.

The study was reported to the Data Protection Authority, and the National Bioethics Committee approved the procedures of the study.

Results

On the first of January 2000 the total number of inhabitants in Reykjavik aged 18–67 years was 70 007. The number of individuals recorded with severe ID at ROAH in the beginning of the same year was 256, or a point prevalence of 3.7/1000 (95% CI 3.2–4.1) with a male–female ratio of 1.2:1. Fifty-eight individuals had Down's syndrome (DS) with a prevalence of 0.83/1000 (95% CI 0.64–1.08).

Participation was low as only 119 of 256 individuals with severe ID participated, or 46.5%. Selective attrition by gender was not observed (males 66, females 53; ratio 1.2:1). However, significant differences between participants and non-participants were found, both regarding distribution of age groups ($\chi^2 = 22.29$; $P < 0.001$) as well as residency ($\chi^2 = 36.25$; $P < 0.001$). Participants were younger than non-participants, and were more often residents of group homes, while the non-participants

were more often living with their parents or living independently with support.

Eleven cases of autism were previously known to ROAH. Fourteen additional cases were found in the study. With the total of 25 cases of autism, the prevalence was 21% (25/119; 95% CI 14.7–29.2), 16 males and nine females (ratio 1.8:1). Seventeen were diagnosed with autism (ICD-10 F84.0) and eight with atypical autism (ICD-10 F84.1). The mean age of autism cases was 32.56 (SD = 10.92; range 19–63); a majority lived in group homes (22) and three lived with parents. Ten (40%) were verbal according to the ADI-R definition. Fifteen (60%) had been diagnosed with epilepsy at some point in their lives (male–female ratio 2.8:1). Active epilepsy and/or other neurological conditions and handicaps were present in 18/25 of the autism cases, including sensory impairment (four), cerebral palsy (five) and DS (three). Twenty (80%) of the autistic group received psychotropic drugs (antiepileptic drugs included).

Discussion

The prevalence of severe ID (IQ < 50) in our geographically defined cohort of 18- to 67-year-old adults ($n = 256$) fits well estimates predicted by a review of the literature, or 3–4/1000 (Roeleveld *et al.* 1997). The proportion of individuals with DS was 22.7%. The prevalence of autism found was 21% and the male–female ratio was in line with what is to be expected of autistic populations in the severe IQ range.

In an epidemiological study on Dutch children and adolescents the prevalence of 26% was suggested as the best estimate for ASD in a group with IQ ≤ 50 (de Bildt *et al.* 2005). Another recent study on adolescents reported 32% with ASD in a sample with severe ID (Bryson *et al.* 2008). A study on adults (age range 16–65+) in the UK with 88% of the participants in the severe ID range suggested 30% as the estimate for autism and atypical autism (Morgan *et al.* 2002). Another population-based study in the UK on psychiatric service use in adults with ID reported a much lower figure for ASD or 8.8% (Bhaumik *et al.* 2008). In the study on Dutch children and adolescents (de Bildt *et al.* 2005) the ADI-R estimate for autism in the severe range was

considerably lower than what was considered to be the best estimate (21.5% vs. 26%). In comparison, the present study used the ADI-R algorithm for current behaviours, which underestimates autistic symptoms relative to the diagnostic algorithm. Such underestimation may become further exaggerated, as autistic symptoms tend to get milder with increasing age (Seltzer *et al.* 2003). However, an underestimation of autism in the present study is not likely to originate from that level, as there was no individual who received the ADI-R who was not diagnosed with autism. Thus, adding a screening stage in this group may have resulted in missing cases.

Lifetime prevalence of epilepsy in the autistic group of the present study was high in relation to studies on the cumulative risk of epilepsy in young adults with moderate to profound ID (35%) (Airaksinen *et al.* 2000) but within the range reported in studies on severely impaired adult populations with autism (Mouridsen *et al.* 1999; Danielsson *et al.* 2005; Melville *et al.* 2008).

It is noteworthy; that of the 25 individuals with autism in the present study three had DS. In the total sample with severe ID there were 58 individuals with DS but 30 in the sample, which took part in the study. Given that the prevalence of autism and ASD in DS ranges from 5% to 16% (Reilly 2009), the number of individuals with DS and autism found in the present study should range from 1.5 to 4.8.

The attrition in our cohort is of concern, and selective in respect to the fact that the participants were younger than the non-participants. In addition, participants were more likely to live in group homes than non-participants, who were more likely to live independently with support or with their parents, which might suggest a selective attrition towards the upper end of the distribution below IQ 50. We are not in a position to draw conclusions in this respect as we did not have access to IQ sub-classifications of the participants. However, it can be argued that the selective attrition, from the point of view of residency, might predispose to a more autistic sample. Nevertheless, we found 14 new cases of autism, which doubled the number of individuals known to have autism in this population.

In the present study, an invitation to participate was sent directly to each potential participant, and

not to the parents/legal guardians of the individuals or to the directors of each type of residency. We figured that the letter would eventually come to the attention of parents or caregivers. However, this procedure created ambiguity concerning the responsibility for responding to the request for participation. Parents frequently felt that caregivers were in a better position to provide information regarding possible autistic behaviours. A repeated misunderstanding of caregivers was that it was unnecessary to take part in the project if the individual concerned was not autistic.

Besides, the above methodological shortcomings, there are issues to be resolved for future research on the prevalence of ID and autism in adults in Iceland. For instance, in the ROAH records ID classification was sometimes lacking, which of course, was directly related to the absence of IQ measures, especially in the oldest age groups. Also, it is possible that there may be reluctance to attach ID classification to persons using the services for the handicapped, thus emphasising that individual needs based on impaired functioning are more important than ICD diagnoses. Even though access to services for the handicapped is mainly through medical declarations, there is no existing protocol for the content of such declarations, which undermines their role as a source for epidemiological research.

This preliminary study on the prevalence of autism in a geographically defined adult population with severe ID aged 18 to 67 years reported an estimated 21%. However, the case-finding procedures and the research literature suggest that the number of autism cases in our sample may be underestimated. Nevertheless, the results provide further support for the hypothesis that there are many undiagnosed cases of autism in the adult Icelandic population with ID. Concerns of parents or caregivers regarding possible autism should be taken seriously and formally tested. Further studies on autism in individuals with ID should include the mild ID level. The concept that adults with ID may gain something from an additional diagnosis of autism needs to be explained to stakeholders, and at the same time, that the risk of such diagnosis is minimal. Medical declarations are apparently an unreliable source of data for epidemiological research, and the records of the regional offices for

the affairs of the handicapped seem limited. Further studies should concentrate on the younger age groups which are likely to have been in contact with the SDCC, and thus to have received a reliable interdisciplinary diagnosis of ID, which may also provide a basis for sub-classification of cognitive abilities. In addition, multiple sources of information should be used, that is, the records of the regional offices for the handicapped, social services providing services for the handicapped, special services within the educational system, and finally governmental and independent service providers.

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