Original Research

Prevalence of Autism Among Adolescents With Intellectual Disabilities

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Objective: To estimate the prevalence of autism in an epidemiologically-derived population of adolescents with intellectual disabilities (ID).

Method: The prevalence of autism was examined using the Autism Diagnostic Interview—Revised, with appropriate care taken in assessing lower functioning individuals and those with additional physical and sensory impairments. Individual assessment during psychological evaluation, and consensus classification of complex cases, involving clinicians experienced in the assessment of autism, contributed to the identification of autism.

Results: Overall, 28% of individuals, or 2.0 of the 7.1/1000 with ID in the target population (as we have previously identified in another study), were identified with autism. Autism rates did not differ significantly across severe ID (32.0%) and mild ID (24.1%); males predominated (2.3 males to 1 female), but less so for severe ID (2 males to 1 female, compared with 2.8 males to 1 female for mild ID). Socioeconomic status did not distinguish the groups with and without autism. Less than one-half of the adolescents who met diagnostic criteria for autism were previously diagnosed as such.

Conclusions: Our overall prevalence estimate for autism is in the higher range of estimates reported in previous studies of ID (more so for mild ID). This likely reflects the changes in diagnostic criteria for autism that have subsequently occurred. Discussion focuses on the identification of autism in the population with ID, and on the implications for service delivery and clinical training.

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Clinical Implications

- Autism is a common coexisting condition in the population with ID.
- The condition may remain unrecognized and (or) the symptoms of autism misattributed to other circumstances such as psychiatric disorder.
- Services for individuals with ID need to recognize, and adequately support, those with coexisting autism.

Limitations

- An observational measure standardized specifically for the assessment of autism (for example, the Autism Diagnostic Observation Schedule) was not included.
- Identifying the severity of the social-communicative impairment in individuals with ID, rather than identifying those who meet criteria for autism, is likely to have more practical relevance for identification of needs and service planning.
- The relatively low prevalence rate for mild ID might have contributed to the higher prevalence rate for autism in this study, although our autism rates for mild, relative to severe, ID are consistent with those derived from recent general population surveys.

Key Words: intellectual disabilities, autism, prevalence

consistent finding in general population studies of the prevalence of autism is that comorbidity with ID is common. Among those who meet formal diagnostic criteria for autistic disorder,¹ up to 75% have been estimated to be intellectually disabled, whether defined in terms of IQ and (or) level of adaptive skills.^{2,3} Details of these and more recent studies are summarized in Table 1. $^{2-8}$ While it is well-established that autism cooccurs with ID, relatively little is known about the frequency with which autism occurs in individuals with ID. Such data are important for planning community services appropriate to the particular needs of those with autism and ID; for example, outcomes for children with autism and ID are poorer than those for children with autism alone,⁹ a finding that may be related to the greater prevalence of psychiatric and behavioural disturbances in teenagers with autism and ID, compared with teenagers with ID alone.10-12

Only a handful of studies (outlined in Table 2^{13-21}) examined the prevalence of autism within the population with ID. Data derived from these earlier studies are limited by several factors. Notable among these are differing diagnostic criteria that reflect evolving conceptualizations of autism and ASD⁶ as well as the lack of standardized diagnostic methods that correspond to current definitions. Such factors might have contributed, for example, to the relatively low estimates for autism and ASD previously found in individuals with mild ID and to the challenge in detecting the various expressions of autism across the range of intellectual functioning. Existing prevalence rates for autism and ASD in individuals with ID may also be limited by the fact that study participants were derived largely from service (compared with population) studies, in which the more cognitively capable are particularly likely to be underrepresented.

Our study extends previous research by providing contemporary, population-based data on the prevalence of autism in individuals with ID using a standardized diagnostic tool. For this purpose, participants were assessed using the ADI-R,²² a standardized interview recommended for research purposes.²³ Our study was conducted within the context of a Canadian population survey of adolescents with ID.²⁴ This

ADI-R	Autism Diagnostic Interview—Revised
ADOS	Autism Diagnostic Observation Schedule
ASD	autism spectrum disorders
DSM	Diagnostic and Statistical Manual of Mental Disorders
ID	intellectual disabilities
SES	socioeconomic strata

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provided a unique opportunity not only to examine autism rates by sex and severity of ID but also to relate these to the same variables observed in the larger ID population.

Method

The Target Population With Intellectual Disabilities

Adolescents with autism were identified through an epidemiologic survey of ID. The methods employed for this larger study were provided in detail and previously published (Bradley et al 24). Briefly, individuals with ID aged 14 to 20 years were drawn from the population residing in the Niagara region in Ontario, (estimated total population 400 000). Consistent with the recommendations of the American Association on Mental Retardation,²⁵ and in recognition of the welldocumented discrepancy favouring level of measured intelligence over adaptive skills in individuals with autism,²⁶ ID was defined as IQ of 75 or below. Ethics approval was obtained from the Research Ethics Committee, Hamilton Psychiatric Hospital, Department of Psychiatry, Faculty of Health Sciences, McMaster University prior to initiating the study. Written informed consent was obtained from caretakers and legal guardians (usually parents) of all participants before scheduling any appointments. The study was conducted in several successive stages (Figure 1): comprehensive screening for adolescents with developmental or social problems, direct individual assessments of participants (first assessment) and indirect screening of nonparticipants to confirm ID, collection of background information on participants and nonparticipants, an estimate of prevalence for ID in the general population, and identification of autism within the target population with ID (second assessment; this study).

Prevalence of Intellectual Disabilities in the General Population

We identified 255 individuals as having ID (IQ \leq 75; based on a composite verbal and nonverbal IQ). Among these, 171 chose to participate (referred to as participants with ID; the remaining 84 were referred to as nonparticipants with ID). Thus participation rate was 67% (171/255). Participants and nonparticipants did not differ on age, sex, or IQ, although there were more nonparticipants in the lower social strata. Overall prevalence for ID was 7.18/1000. For mild ID (IQ = 50 to 75), prevalence was 3.54/1000, and for severe ID (IQ < 50), 3.64/1000. Our prevalence estimate for severe ID is similar to rates from previous studies conducted worldwide. Our estimate for mild ID parallels the lower rates found in Scandinavian countries and contrasts with the higher rates generally reported in the United States. Our results are similar to the Swedish studies in several other regards: our ratio of 1.3 males to 1.0 female, the greater contribution of severe ID to the overall prevalence rate for ID, and our finding of more males with mild ID and more females with severe ID. We

Investigator(s)	Location and age	Assessment approach and diagnostic criteria	Prevalence and other findings
Bryson et al ²	Nova Scotia; 20 800 children screened; aged	Behavioural questionnaires, ABC, psychometric data	Prevalence of autism ($n = 21$) = 10/10 000; Male:Female = 2.5:1
	6 to 14 years		Among the 21: 24% $IQ \ge 70$ 33% $IQ = 50$ to 69 42% $IQ \le 49$
Lotter ³	Middlesex, England; 78 000 children screened; aged 8 to 10 years, born between 1953 and 1955	Behavioural questionnaires, case notes, interviews	Prevalence of autism ($n = 35$) = 4.5/10 000; Male:Female = 2.6:1
			Among the 35: 15% IQ > 80 15% IQ 55 to 79 69% IQ < 55
Fombonne ⁴	3 French departments; 325 347 children screened; aged 6 to 16 years, born between 1976 and 1985	Clinical diagnosis by local child psychiatrist and review by experienced child psychiatrist ICD-10	Prevalence of autism (<i>n</i> = 174) = 5.35/10 000; 16.3/10 000 if other PDD included
			Among the 174: No MR = 12% Mild MR= 6.6% Moderate, proficient MR = 81%
Chakrabati and Fombonne ⁵	Midlands, England; 15 500 children screened; aged 2.5 to 6.5 years, between 1998 and 1999	Screening followed by ADI-R for children strongly suspected of having PDD	Prevalence of autistic disorder (<i>n</i> = 26) = 16.8/10 000; all PDD (<i>n</i> = 97) = 62.6/10 000
			Among the 26: Normal IQ = 31% Mild, moderate = 50% Severe, proficient = 19% Among the 97 (3 not tested) 25.8% had some degree of MR
Fombonne ⁶	Meta review of 32 epidemiologic studies (Table 1 page 367)	In review, author included for each study percentage with normal IQ	Normal IQ ranged from 0% to 55.8%; only 3 studies reported that more than one-half of the autism group had normal IQ
			Conclusion: Autism is associated with MR in about 70% of cases
Yeargin-Allsopp ⁷	Atlanta, Georgia; 289 456 children screened; aged 3 to 10 years	Review of records, expert review of cases	Prevalence of autism ($n = 987$) = 3.4/1000
		DSM-IV criteria	00% (<i>II</i> – 000, with iQ lest results) – MR (IQ ≥ 70)
Chakrabarti and Fombonne ⁸	Midlands, England; 10 903 children screened in 2002; aged 4 to 6 years (a follow-up from 2001 study ⁵)	ADI-R, psychometric tests and medical work-up in children with symptoms suggestive of PDD	Prevalence of autistic disorder ($n = 24$) = 22/10 000; other variants ($n = 40$) = 36.7/10 000; all PDD ($n = 64$) = 58.7/10 000
			Among the 24: 67% = MR 29% mild 38% moderate/severe
			Among the 64 (all PDDs): 29.8% = MR, which varied by disorder subtype (of those with PDD-NOS, MR = 12%)

Table 1 Population studies of autism, and other pervasive developmental disorders, and prevalence of ID in those

with ID			
Investigator(s)	Location and age	Assessment approach and diagnostic criteria	Prevalence and other findings
Wing and Gould ¹³	Camberwell, London, England; from a total population of 35 000; <15 years; <i>n</i> = 914	MRC HBS Autism and the triad of social impairments	Severity of social impairment gave more reliable associations with behavioural, psychological and medical variables than presence or absence of a history of typical autism
			11% autistic 40% socially impaired
Haracopos and Kelstrup ¹⁴	Institute for the Mentally Retarded, Denmark; aged	A specially-constructed combined observation and	25% of the group studied showed psychotic behaviours
	3.5 to 13.5 years; <i>n</i> = 392	interview scheme to identify psychotic behaviours	Among these, 6% in school for mild MR and 23% in school for severe MR
		Diagnosis of psychotic withdrawal and bizarre behaviour	
Shah, et al ¹⁵	London, England; adolescents and adults,	DAS adapted from the HBS (see above)	Among the adult population studied, 38% were impaired in social interaction, including 4% with autistic pattern of behaviour
	aged >10 years, // = 701	Triad of social impairments	
Gillberg et al ¹⁶	Goteborg, Sweden; aged 13 to 17 years, born with MR between 1966 and 1970; <i>n</i> = 149	Highly structured manual, medical records, observation, comprehensive diagnoses formulated by C Gillberg to identify psychotic disorder	83 (56%) mild ID and 66 (44%) severe ID
			64% with severe ID and 57% with mild MR were suffering from a handicapping psychiatric condition
			Autism-like psychotic behaviour occurred in >50% severe ID, and 14% mild ID
Lund ¹⁷	Sample from the Register	MRC HBS (revised 1982)	7.6% autistic psychosis (childhood autism)
	of the Danish National Service for the Mentally Retarded; aged >20 years; <i>n</i> = 302	ICD-8 to identify behavioural symptoms and psychiatric disorders	27% social withdrawal
		Wing's (1980) criteria for childhood autism broadened to include those with MR	
Deb and Prasad ¹⁸	Special schools Grampian, Scotland; aged 5 to 19 years; <i>n</i> = 767 children with MR	Questionnaire adapted from Bryson et al, ² individual assessment, information gathering Autistic disorder DSM-III-R	Among those with completed questionnaire (634/767), 14.3% with autistic disorder
			Among those with autistic disorder and ID: 8.9% IQ 70 to 80
			15.6 % IQ 50 to 69 15.6% IQ 35 to 49 38.8% IQ < 35
Nordin and Gillberg ¹⁹	Swedish Habilitation Services, Malmöhus County, Sweden; from a total population of 16 645; preschool to school-age; n = 177 children with MR, with and without motor disability, from a total population of 16 645	DSM-111-R and CARS Autistic disorder, autistic-like condition, ASD not otherwise specified	8.9% with autistic disorder: 5.3% mild ID 13.6% severe ID
			19.8% with ASD: 12.3% mild ID 29.5% severe ID

Table 2

continued

Table 2 continued				
Investigator(s)	Location and age	Assessment approach and diagnostic criteria	Prevalence and other findings	
Stromme and Diseth ²⁰	Akershus County, Norway; aged 8 to 13 years; $n = 178$ children with MR from total population of 30 037	Semi-structured parent interview, Clinical Child Interview, review of charts and previous psychiatric examinations	8% with PDD (16% of whom had hyperkinesis)	
			37% of total population with MR had a psychiatric diagnosis	
		ICD-10		
de Bildt et al ²¹	Friesland Province, Netherlands; aged 4 to 18 years; <i>n</i> = 825 children and adolescents known to MR facilities	Screening with PDD-MRS, ABC, and assessment with ADI-R, ADOS, DSM-IV-TR	7.8 to 19.8%, depending on instrument and concept of PDD; 16.7% (DSM-IV-TR) considered best estimate (based on multiple informants and time points)	
			Estimate of autistic disorder using ADI-R was 16.8% for combined levels of ID: 11.3 % mild ID 21.5% severe, profound ID	
ABC = Autism Behaviour Checklist; CARS = Childhood Autism Rating Scale; DAS = Disability Assessment Schedule; MR = mental retardation;				

MRC HBS = Medical Research Council Handicap Behaviour and Skills Schedule; PDD = pervasive developmental disorders;

concluded that the low prevalence rate of mild ID in our study was linked to the policies of integration in Ontario over the previous 3 decades; policies that may have made individuals with mild ID less visible. The reader is referred to Bradley et al²⁴ for further details of these finding and the stages 1 to 3 outlined above.

Identification of Autism Within the Target Population

During a second visit, all participants were assessed for autism using the ADI-R.²² This structured interview, administered to primary caregivers (usually the parents), elicits detailed descriptions of the behaviours diagnostic of autism according to DSM-IV¹ and ICD- 10^{27} criteria. The interview focuses on current behaviour and early developmental milestones (at and prior to age 4 and 5 years). Individual behavioural items are rated on a 0-to-3 scale, with 1 to 3 representing increasingly atypical behaviour. The ADI-R provides an algorithm with cut-off scores for autism, including a total score and subscores for each of the 3 domains of impairment (in language–communication, social–play, and behavioural inflexibility).

While the ADI-R was shown to accurately distinguish autism from other developmental disorders, even in adolescents with ID, its ability to differentiate among the most severely intellectually-disabled individuals remains challenging.^{28–30} Thus care was taken to ensure that for each individual the items considered were developmentally or otherwise appropriate (notably, that mental age, either currently or at age 4 to 5

years, was within the range expected for each behaviour assessed). For example, a 15-year-old with a current mental age of 3 years would not be expected to have shown imaginative play at 4 to 5 years. By implication, for those with profound ID (composite IQ < 35; n = 37/154 or 24% of ID participants), some of whom also had sensory and (or) motor impairments, some ADI-R items were excluded. As recommended by Lord (personal communication, November 1997), subscale and total scores for the autism algorithm items were treated as absolute rather than as ratios of the number of items administered (that is, scores were not corrected for excluded items), thus raising the threshold for an autism diagnosis in this more impaired subgroup. Score sheets revised accordingly for profoundly physically and (or) cognitively impaired individuals are available from the authors.

All ADI-Rs were administered by one of 2 people, both of whom met recommended research reliability criteria for scoring the ADI-R algorithm items (more than 90%). Following the recommendations of Lord et al,³⁰ cases were designated as autistic only when the individual scored above the ADI-R cut-offs for each of the 3 subdomains and total score. The following steps were taken to ensure agreement regarding the identification of autism. First, interviews were audiotaped and agreement in scoring between the 2 interviewers was monitored at regular intervals to optimize the probability that reliability was maintained throughout the duration of the study. In addition, 2 individuals

PDD-MRS = pervasive developmental disorders in mentally retarded persons

Figure 1 Outline of study design



FSIQ = Full Scale IQ (intelligence quotient); WAIS-R = Wechsler Adult Intelligence Scale—Revised; WISC-R = Wechsler Intelligence Scale for Children—Revised

independently reviewed and scored the audiotapes of all individuals with sensory and (or) motor impairment, and (or) profound ID (n = 37), and those for whom at least one of the ADI-R subdomain scores or total score was within one point of the cut-off range for autism (n = 42, for a total of 79/154 or 53%). Among the 79 cases, including the most difficult and equivocal in our ID population, disagreements in whether the combined ADI-R criteria had been met occurred in only 3 cases (4%) with 2 raters, and 19 cases (24%) with 3 raters. These were resolved through consensus. In addition, a retrospective review of assessments for episodic psychiatric disorders (including direct observation of each individual) was conducted on 36 ADI-R positive and 36 negative autism cases³¹ to compare ADI-R outcomes with clinical impressions. Cases were classified as autism, probable autism, and uncertain, based on clinical impressions, with reference to

DSM-IV criteria and to developmental level (IQ and scores from the Vineland Adaptive Behaviour Scales³²), but blind to ADI-R data (Figure 1).

Data Analyses

Prevalence and related descriptive data on age, SES, and sex are expressed in terms of frequency counts and percentages, with associated CIs, as appropriate. To ensure sufficient data for every cell, the SES were reduced from 5 to 3 by collapsing Hollingshead's 2 upper (1 and 2) and lower (4 and 5) categories.²⁴ Group comparisons by sex and severity of ID were conducted using chi-square tests.

Results

Age was excluded from all analyses, as the groups with autism-ID and (without autism) ID did not differ



Figure 2 Intellectually-disabled participants and nonparticipants, with and without autism

significantly in mean age, nor did age interact with sex (mean age ranged from 16.4 to 17.0 years; all *P* values were greater than 0.05). Parental SES did not reliably distinguish participants with autism–ID from those with ID alone (*P* > 0.05), nor was SES related to IQ in either group (all *P* values were greater than 0.05). However, among the entire group with IDs, nonparticipants differed significantly from participants by being less frequently represented the uppermost of the SES, $\chi^2 = 4.92$, df 1, *P* < 0.05.²⁴

Prevalence of Autism

Among those who agreed to participate, 171 had a composite IQ of 75 or less (Figure 2). ADI-R data were not available in 11 cases, and were indeterminate in an additional 6 cases, thus reducing the ID population to 154. Of these, 43 (13 females and 30 males) or 27.9% met ADI-R criteria for autism (20.8% to 34.9% with 95%CI); that is, their total ADI-R scores and their subscale scores for each of the 3 domains of impairment (communication, socialization, and behavioural inflexibility) exceeded the cut-off scores diagnostic of autism. Males predominated, with a ratio of 2.3 to 1 female, particularly for those with mild ID (2.8 to 1, compared with 2 to 1 for severe ID).

able to participate in the second assessment stage of the study. Scrutiny of available data on these individuals failed to reveal any feature (that is, age, sex, IQ, rates of epilepsy, or other associated medical conditions) that distinguished them from the larger group of participants with IDs, or that might be systematically associated with autism. The 6 participants indeterminate ADI-R diagnoses were with multihandicapped, with various motor and (or) sensory impairments and profound ID, thus precluding administration of most ADI-R items. The frequency of both males (4/6) and blindness (4 designated as legally blind, the remaining 2 were only responsive to bright colours and [or] lights) increases the likelihood of greater prevalence of autism in this group.^{33,34} Assuming at least equal representation to that observed in the larger population of ID participants, 3.1/11 with no ADI-R data and 1.7/6 indeterminate ADI-R cases would be expected to have autism. Thus, among the entire participant population with ID (n = 171), 48 cases or 28.2% (95%CI, 21.2% to 35.2%) are estimated to have autism. Placed in the context of the larger general population from which the ID population was ascertained, 7.2/1000 were

In the case of the 11 participants with no ADI-R data (6 females and 5 males, of whom 5 had severe and 6 had mild

ID), their caretakers could not be contacted or were unavail-

Table 3 Number in each group by gender and severity of ID				
	Severe ID		Mild ID	
	Males	Females	Males	Females
Autism–ID	16	8	14	5
ID alone	21	30	39	21
Totals	37	38	53	26

identified with ID,²⁴ of which 2.0 are estimated to have autism.

Previous Diagnosis of Autism

Among the entire 43 ADIR– positive autism cases identified here, a total of 20 (47%; 3 females and 17 males) were diagnosed previously as such (12/20), or described as autistic-like, or as having autistic features (8/20). Among the remaining ID participants, one of the 11 with no ADI-R data was previously diagnosed with autism (a male with severe ID), and one of the 111 designated by us as nonautistic had been described as having autistic features (a female with severe ID).

Clinical Impressions

Among 36 ADI-R positive autism cases seen for a direct observation by one of us, 24 (67%) were classified as autism, 9 (25%) as probable autism, and 3 (8%) as uncertain; conversely, of 36 ADI-R negative autism cases, 32 (89%) were classified as nonautism and 4 (4%) as uncertain. The ADI-R autism group as a whole also had significantly more episodic (for example, mood and adjustment³¹) and nonepisodic (for example, inattentive, hyperactive, and impulsive³⁵) disorders and other psychopathology.¹⁰

Group Comparisons by Sex and Severity of ID

ID was derived from composite verbal and nonverbal IQs, and categorized as mild (IQ = 50 to 75) or severe (IQ < 50). The frequency of autism did not differ from those with mild ID (24.1%) and severe ID (32.0%; P > 0.05). However, a 3-way frequency analysis, conducted on the distribution of cases in autism and nonautism groups by sex and severity of ID, yielded 2 significant 2-way interactions: group by sex, $\chi^2 =$ 4.15, df 1, P < 0.04, and sex by severity of ID, $\chi^2 = 5.94$, df 1, P < 0.01. Males predominated in the autism–ID group (30 to 13 males to 2.3 to 1 female) but not in the ID alone group (60 to 51 males to 1.2 to 1 female). In addition, for both groups combined (autism and nonautism), males were disproportionately represented relative to females, among those with mild ID (n = 53/79 [67.1%]) males and 26/79 [32.9%] females; $\chi^2 = 9.2$, df 1, P < 0.01), whereas the proportion of males and females with severe ID did not differ (n = 37/75 [49.3%])males and 38/75 [50.7%] females; P > 0.05). However, as can be seen in Table 3, this pattern of similar proportions of males and females for severe ID is accounted for by the group with ID alone; in the autism group, males were also disproportionately represented among those with severe ID.

Exploratory chi-square tests were thus conducted on the nonsignificant 3-way interaction of group by sex and severity of ID. Of particular interest, these analyses revealed that in those with severe ID, males were more likely to have autism than their female counterparts ($\chi^2 = 4.24$, P < 0.05), who did not differ in the frequency of autism from either males or females with mild ID (all *P* values were greater than 0.05; Table 2): among those with severe ID, 1 in 2.3 males were ADI-R positive for autism, compared with 1 in 4.8 females; the latter outcome (ratio) approximated that of both males and females with mild ID (1 in 3.8 and 1 in 5.2, respectively).

Discussion

In the present study, 28.2% (95%CI, 21.2% to 35.2%) of the participant population with ID were identified with autism. Given our prevalence rate of 7.18/1000 for ID, this provides an estimate of 2.0 individuals with autism and ID per 1000 of the general population. Nonparticipants congregated in the lower SES,²⁴ but were otherwise comparable (that is, in age, sex ratio, and estimated IQ) to the participants. Previous work would suggest that our estimated prevalence of autism, based on the ADI-R, most likely includes some cases on the broader autistic spectrum (that is, with atypical autism or pervasive developmental disorder not otherwise specified), although primarily those with autistic disorder.^{28,30} Our estimate of 28.2% is in the higher range of rates for autism reported in previous studies of populations with ID. Indeed, our estimate more closely approximates Nordin and Gillberg's¹⁹ 19.8% for ASD, compared with autism. Assuming relatively complete ascertainment through the registry system in Sweden, their relatively low rates most likely reflect diagnostic criteria based on a more restricted conceptualization of autism than that represented in the ADI-R^{23,36} or more recent DSM criteria.⁶

In contrast, Wing et al's^{13,15} estimate of 40%, derived largely from those with severe ID, includes a broad spectrum

showing the triad of autistic impairments (in social reciprocity, communication, and imagination and behavioural flexibility). The precise mapping of their autistic triad onto current diagnostic criteria remains unclear, although presumably a large proportion of the 40% would meet current criteria for autism, and most, but not necessarily all, of the remainder would meet the more inclusive criteria for ASD. Recognition that autism exists within a spectrum of related conditions has emphasized the arbitrariness of categorical boundaries (that is, between autistic disorder and its variants). This said, to advance our understanding of the etiologies of autism and to plan appropriately for service needs, it will be important to extend the work of Wing et al^{13,15} by providing prevalence data on the entire spectrum of autistic disorders in individuals with IDs. Clearly, their estimate (40%) would suggest that substantially more than 28.2% of the ID population will benefit from services designed for the needs of individuals with autism.

Otherwise, the main difference between ours and earlier reports is that we did not find that autism predominates in individuals with severe (compared with mild) ID. In earlier studies,¹⁹ autism was reported to be more than twice as common in those with severe ID (13.6%) than mild ID (5.3%), and the same was the case for the more inclusive ASD 29.5% and 12.3%, respectively (see Haracopos and Kelstrup¹⁴ for an even larger discrepancy). In contrast, and consistent with general population surveys,^{8,37} we found that autism was more equally distributed among those with severe ID (32%) and mild ID (24.1%). Our relatively high rate for mild ID most likely reflects a combination of revised diagnostic criteria for autism and our increased awareness of, and ability to detect, its various manifestations in more capable individuals. However, while our overall population prevalence estimate for ID $(7.18/1000)^{24}$ is comparable with those reported over the past 50 years, 38-40 our rate for mild ID (3.54/1000) was more similar to the lower rates generally found in Scandinavian studies. We attribute this to mild ID currently being less visible in individuals, consequent to the successful integration policies operating in Canada over the last several decades. Individuals with mild ID in the school system may not be identified unless presenting with behavioural difficulties (Bradley et al²⁴ and Sonnander et al⁴¹). This may serve both to reduce ascertainment of potential cases of mild ID and to increase the likelihood that those identified have autism, given the higher rate of behaviour disturbance in the latter. It bears emphasizing that our autism rates for mild, relative to severe, ID parallel those derived from recent general population surveys.^{8,37}

Consistent with a large volume of literature on autism,^{42–46} we found that autism predominates in males, particularly in those with mild ID (2.8 to 1 female, compared with 2 to 1 for severe ID). Such findings have been taken as evidence that whereas

risk for autism is less in females, when affected, females are more likely than males to be severely intellectually impaired.⁴⁷⁻⁴⁹ Preliminary findings from the present study suggest a different picture. Unlike previous research, we examined rates of autism by sex and severity of ID relative to the same variables in the larger ID population. Our main finding is that, to the extent that females are more likely than males to have severe (compared with mild) ID, this is not specific to those with autism but rather common to females with ID. Moreover, in our study it was males, not females, with severe ID who were disproportionately likely to have autism (1 in 2.3, compared with 1 in 4.8, respectively). Autism was relatively underrepresented not only in females, regardless of ID status (1 in 5), but also in males with mild ID (1 in 3.8, compared with 1 in 2.3 for males with severe ID). While the small number of females with autism precludes firm conclusions, evidence that risk for autism is particularly high in males with severe ID may have important implications for research on genetic and other biologic etiological mechanisms in autism. They suggest that either the mechanisms themselves, or their expression, may vary with severity of ID and sex. This issue could be explored in studies of familial risk for ASD (and its lesser variants) by examining both the sex and cognitive status of affected members.⁵⁰

One limitation of our study is that we did not use an observational measure, such as the ADOS.⁵¹ standardized specifically for the assessment of autism. The validity of autism diagnoses is optimized when both the ADI-R and ADOS are used in combination with expert clinical judgment.²⁸ However, we were able to compare ADI diagnoses with clinical impressions about coexisting autism from the subsequent assessments for episodic psychiatric disorders in autism and nonautism groups. There was complete agreement for autism in 67% of cases and for nonautism in 89% of cases, even though these psychiatric assessments (which included direct observation of each individual) were not focused on autistic behaviours but rather on baseline behaviours, prior to the onset of any new psychiatric disorder.31 The ADI-R autism group had significantly greater prevalence of episodic³¹ and nonepisodic³⁵ psychiatric disorders and other psychopathology.¹⁰ Our data point to the need for systematic evaluation of autism as a developmental condition, including a detailed developmental history of early behaviours, conducted separately from any assessment for psychiatric disorder; otherwise, not only may the diagnosis of autism be missed but symptoms of autism may be misattributed to symptoms of psychiatric disorder, in particular psychosis.⁵²⁻⁵⁴ Interpretation of direct observational measures may be complicated by the frequent presence of this additional psychopathology, particularly in older individuals with autism or ASD.

Finally, in our study less than one-half of the adolescents who met ADI-R criteria for autism were previously diagnosed. This underdiagnosis of autism is of considerable concern. Lack of identification is likely to result in unmet needs, contributing to the higher prevalence of behavioural and psychiatric disturbance found in individuals with ID and autism, compared with individuals with ID alone.^{10,11} As noted above, undiagnosed autism in individuals with ID may also result in misdiagnoses of adult psychiatric disorders. Our finding that autism occurs in 28.2% of those with intellectual impairment, only one-half of whom were previously diagnosed, underscores the importance of training professionals and other care providers in the detection and diagnosis, treatment, and care of this sizeable population.

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Résumé : La prévalence de l'autisme chez les adolescents souffrant de déficiences intellectuelles

Objectif : Estimer la prévalence de l'autisme dans une population épidémiologique d'adolescents souffrant de déficiences intellectuelles (DI).

Méthode : La prévalence de l'autisme a été examinée à l'aide de l'entrevue diagnostique de l'autisme révisée (ADI-R), en prenant soin d'évaluer les personnes au fonctionnement moindre et celles ayant des incapacités physiques et sensorielles additionnelles. L'évaluation individuelle durant l'évaluation psychologique, et la classification par consensus des cas complexes, faisant appel à des cliniciens ayant l'expérience de l'évaluation de l'autisme, ont contribué à l'identification de l'autisme.

Résultats : En tout, 28 % des personnes ou 2,0 des 7,1/1000 souffrant de DI dans la population cible (comme nous l'avons précédemment identifiée dans une autre étude) ont été identifiées souffrir d'autisme. Les taux d'autisme ne différaient pas significativement entre les DI graves (32,0 %) et les DI bénignes (24,1 %); les hommes prédominaient (2,3 hommes pour 1 femme), mais moins pour les DI graves (2 hommes pour 1 femme, comparé à 2,8 hommes pour 1 femme pour les DI bénignes). Le statut socioéconomique ne distinguait pas les groupes avec et sans autisme. Moins de la moitié des adolescents qui satisfaisaient aux critères diagnostiques de l'autisme avaient précédemment reçu ce diagnostic.

Conclusions : Notre estimation globale de la prévalence de l'autisme est dans la portion supérieure des estimations déclarées dans des études précédentes des DI (encore plus pour les DI bénignes). Ceci reflète probablement les changements des critères diagnostiques de l'autisme qui sont survenus subséquemment. La discussion met l'accent sur l'identification de l'autisme dans une population souffrant de DI, et sur les implications pour la prestation de services et la formation clinique.