



## Psychiatric disorders in adolescents and adults with autism and intellectual disability: A representative study in one county in Norway

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### ABSTRACT

Few studies assess psychiatric disorders in representative samples of individuals with autism and ID. Symptoms of autism and psychiatric disorders have been confounded. PAC, a conceptually analysed and validated screening instrument, was used.

*Aims:* Assess prevalence of psychiatric disorders in individuals with intellectual disability only (*ID-only*) and with combination of autism and ID (*autism*). Sixty-two (autism) and 132 (*ID-only*) participants were screened for psychiatric disorders with the Psychopathology in Autism Checklist (PAC); included general adjustment problems (*GAP*), and severe adjustment problems (*SGAP*) in one county in Norway. Psychosis, depression, anxiety, and OCD were addressed. Both *SGAP* and a high psychiatric disorder score were required to screen a psychiatric disorder. “Diagnostic overlap” was defined as more than one psychiatric disorder concurrent with autism.

Psychiatric disorders and *SGAP* were found to be high both in the autism (53.2%) and *ID-only* group (17.4%). More than 50% of the autism and approximately 20% of *ID-only* group had *SGAP*. The differences were significant. The autism–psychiatric disorder interaction was significant. The largest differences between the prevalence in the autism and the *ID-only* group were shown in individuals with anxiety. The majority of the individuals in both study groups were afflicted with more than one psychiatric disorder. About 60% were found to have more than one disorder. The individuals with more severe psychiatric symptoms had higher degrees of diagnostic overlap. Having an intellectual disability seem to imply high risk for developing adjustment problems, and it seems especially difficult for individuals with autism to master every-day challenges.

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## 1. Introduction

Individuals with autism spectrum disorders (ASD) are believed to be especially vulnerable to psychiatric problems (Bradley, Summers, & Wood, 2004; Clarke, Baxter, Perry, & Prasher, 1999; Ghaziuddin, 2005; Hutton, Goode, & Murphy, 2008; Morgan, Roy, & Chance, 2003; Tsakanikos, Costello, & Holt, 2006). There is, however, a large variability of prevalence of psychiatric disorders reported in studies of the group. The large variability reflects that there is a dearth of standardised criteria and instruments for assessment of psychiatric disorders in autism (Helverschou, Bakken, & Martinsen, 2008).

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There are conflicting findings related to whether individuals with autism and intellectual disability (ID) are more prone to develop psychiatric disorders compared to adults with ID-only. In one study, higher rates of psychiatric disorders were found in individuals with only ID (Tsakanikos et al., 2006). In contrast, other studies report higher rates in adults with both autism and ID (Bradley et al., 2004; Mouridsen, Rich, Isager, & Nedergaard, 2008; Morgan et al., 2003). Still others report only small differences between the groups (Melville et al., 2008).

To identify psychiatric problems in individuals with autism and ID is difficult. At least three problems are involved. Firstly, characteristics of autism overlap considerably with symptoms of the main psychiatric disorders: schizophrenia, affective disorders, anxiety disorders and OCD (Bakken, 2007; Clarke et al., 1999; Ghaziuddin, 2005; Helverschou et al., 2008; Long, Wood, & Holmes, 2000; McDougle, Kresch, & Posey, 2000; Rumsey, Rapoport, & Sceery, 1985). Secondly, psychiatric problems in individuals with autism and intellectual disability are shown in atypical ways; shown for example by self-injury, irritability, aggression, bizarre movements, and strange behaviour (Ghaziuddin, 2005; Hutton et al., 2008). Thirdly, individuals with autism have severe problems in communicating about their own condition. Even the more able have impaired ability to report own emotional problems. Furthermore, instruments designed to assess psychiatric disorders in people with ID are mostly unsuitable for people with autism (Matson & Nebel-Schwalm, 2007). These diagnostic obstacles increase the chance of misinterpreting the patient's symptoms. A psychiatric condition may both be overlooked and wrongly diagnosed (Bakken, 2007; Helverschou et al., 2008).

The *Psychopathology in Autism Checklist (PAC)* is a carer-completed screening checklist, especially designed for identifying psychiatric disorders in adolescents and adults with autism and ID (Helverschou, Bakken, & Martinsen, 2009). Four main categories of psychiatric disorders were chosen to constitute PAC: psychosis, depression, anxiety disorder, and obsessive-compulsive disorder (OCD). The development of PAC was organised as a three-phase project; a conceptual study, a validation study, and a population study; the last presented here. The first main diagnostic problem – overlapping symptoms – was the focus of the conceptual analysis (Helverschou et al., 2008). Thus, the first step in the procedure of developing PAC was to establish indicators of psychiatric disorders that did not overlap with characteristics of autism. The second and third obstacles – atypical symptoms and impaired ability to report symptoms – were confronted in the PAC validation study (Helverschou et al., 2009). Cut-off points were defined for the scores corresponding to psychoses, depression, anxiety, and OCD. The validation study indicated that PAC discriminated between individuals with and without a psychiatric disorder and also, albeit imperfectly, between individuals diagnosed with different psychiatric disorders.

PAC includes a subscale assessing general adjustment problems (GAP), e.g. sleep disturbances, self-harm, irritability, passivity, and restlessness. Such adjustment problems are found in normally intelligent people with a psychiatric disorder (Gelder, Lopez-Ibor, & Andreasen, 2003) and also in people with an intellectual disability, who become mentally ill (Gustafsson & Sonnander, 2004, 2005). In the validation study, general adjustment problems were demonstrated in all the participants, but in higher degrees by individuals with psychiatric problems. A cut-off value of GAP was defined, that distinguished mentally ill individuals from individuals who were not suffering from any mental illness. GAP above this cut-off point were considered to reflect *severe* adjustment problems (SGAP). Use of the cut-off value revealed no SGAP in mentally healthy individuals, but a high prevalence of SGAP in mentally ill individuals (Helverschou et al., 2009).

The present paper presents a population-based study of psychiatric problems in individuals with autism and ID and in a representative sample of individuals with ID-only. The aims of the study were two-fold: (1) to estimate the prevalence of psychiatric disorders in adolescents and adults with autism and (2) to compare prevalence of psychiatric problems and severe adjustment problems in individuals with only an intellectual disability and individuals with both ID and autism.

## 2. Materials and methods

### 2.1. Participants

There are two groups of participants. *The autism group* includes all diagnosed and registered individuals with autism and intellectual disability from 14 years and up, known to the Autism team at the Nordlandssykehuset hospital in Nordland County, altogether 62 individuals during the data collection period in 2003–2004. The autism team is a special unit, which provide diagnostic assessment and follow up for children and adolescents with autism. The 62 individuals represent approximately 0.04% (4 of 10,000) of the general population of 250,000 individuals in Nordland County from 14 years and up (Statistical Yearbook for Norway, 2006). The 62 participants in the study group consisted of 45 males and 17 females, and the average age was 23.9 years (range 14–57 years). The diagnosis of autism had been clinically assessed by professionals in the Autism team according to ICD-10 criteria (World Health Organization, 1993), and all participants fulfilled the criteria for autistic disorder (AD) (i.e., deviances in communication, social interaction, and stereotypic and repetitive behaviour). The level of intellectual disability was also estimated by the special health services. Thirty-two participants had mild or moderate level of ID, and 30 had severe level of ID.

*The intellectual disability group, the ID group*, encompasses 132 adolescents and adults recruited through the local support teams for individuals with intellectual disability from 14 years and up with intellectual disability and no concurrent diagnosis of autism spectrum disorder, in five of the 44 municipalities in Nordland County. The participants represent the majority of individuals administratively defined and registered with ID (i.e., who received services from the municipality) in these municipalities (75.5% response rate) excluded those with autism, and are considered a representative sample of individuals with ID (Myrbakk & von Tetzchner, 2008). The 132 participants in the control group consisted of 65 males and 67

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