

# **Mental health disorders in adults with intellectual disabilities**

*Methods of assessment and prevalence of  
mental health disorders and problem behavior*

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## **Scientific environment**

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## Abbreviations

AAMR	American Association for Mental retardation
ABC	Aberrant Behavior Checklist
ADD	Assessment of Dual Diagnosis
APA	American Psychiatric Association
AD/HD	Attention deficit/hyperactivity disorder
CIDI	Composite International Diagnostic Interview
DASH-II	Diagnostic Assessment for the Severely Handicapped Scale-II
DBC-A	Developmental Behavior Checklist for Adults
DC-LD	DC-LD: Diagnostic Criteria for Psychiatric disorders for Use with Adults with Learning Disabilities/Mental Retardation
DSM-IV-TR	Diagnostic and Statistical Manual of Mental Disorders, 4 <sup>th</sup> edition – Text Revision
ICC	Intra-class correlation
ICD-10	International Classification of Diseases 10 <sup>th</sup> edition
ID	Intellectual disabilities
L-AID	Life Event Checklist for Adults with Intellectual Disability
OCD	Obsessive-compulsive disorder
P-AID	Psychopathology Checklists for Adults with Intellectual Disability
PAS-ADD	Psychiatric Assessment Schedule for Adults with a Developmental Disability
PIMRA	Psychopathology Instrument for Mentally Retarded Adults
RCP	Royal College of Psychiatrists
RSMB	Reiss Screen for Maladaptive Behavior
SCAN	Schedules of Clinical Assessment in Neuropsychiatry
SIB-R	Scale of Independent Behavior – Revised
WAIS-III	Weschler Intelligence Scale for Adults – third edition
WHO	World Health Organization
WISC-III	Weschler Intelligence Scale for Children – third edition

## Abstract

### Objective

The diagnostic manual '*DC-LD: Diagnostic criteria for use with adults with learning disabilities/mental retardation*' (DC-LD) was developed in an effort to increase the accuracy of diagnosis of mental disorders in adults with intellectual disability (ID), as the standard diagnostic criteria for mental disorders do not fully apply to people in this group. Currently, there is a need for assessment methods that incorporate these diagnostic criteria to gain more knowledge of the prevalence of specific mental disorders and problem behaviors. The first paper of this thesis investigates psychometric properties of the recently developed '*Psychopathology Checklists for Adults with Intellectual Disability*' (P-AID). In the second paper, prevalence rates and co-morbidity of mental disorders in a population sample of adults with ID using the P-AID were investigated. The main focus in the third paper was to investigate the relationship between level of ID and symptoms of specific mental disorders and problem behavior. In doing this, the effect of several other relevant factors regarding the association between level of ID and mental disorders were analyzed and discussed.

### Methods

There were 901 people registered with administratively defined intellectual disability who were eligible for the study. This comprises 0.27% of the total adult population in the investigated area of Rogaland and Sunnhordland, Norway. Information from 593 individuals was returned (66%). Staff members from group homes were used as informants. Mental disorders and problem behavior were screened for using the P-AID. The instrument comprises checklists for dementia, psychosis disorder, depression, mania, agoraphobia, social phobia, specific phobia, generalized anxiety and panic anxiety as well as eight types of problem behavior. The internal consistency and inter-rater reliability of the checklists were investigated, as was the factor solution of the P-AID. Comparisons of prevalence rates between studies were conducted using

chi-square analysis. The associations between the predictors and symptoms of mental and behavioral disorders were studied using a hierarchical linear regression model with forced entry.

## Results

**Reliability and validity of P-AID:** The overall findings in paper I indicate acceptable psychometric properties of the P-AID; reliability measures of the P-AID checklists were substantial with few exceptions. The inter-rater reliability was, however, affected by level of intellectual disability. The construct validity of the instrument was found to be strong because among other things, the factor structure of the P-AID corresponds to the conceptual structure of the DC-LD.

**Prevalence of mental disorders:** In our sample, 43% showed indices of either a mental disorder or problem behavior, whereas 35% of the sample showed indices of mental disorders. Problem behavior was present in 20% of the participants. Among those with mental disorders, anxiety disorder (16%) and depression (12%) were most common. Analysis of co-morbid disorders showed that 22% of the sample had one mental disorder or problem behavior diagnosis, 10% had two diagnoses and 12% had three or more diagnoses. This is similar to co-morbidity figures found in people with lifelong conditions of mental disorder.

**Association between level of ID and symptoms of mental disorders:** Level of ID contributed to the explained variance of symptoms of all disorders except mania, and was both linearly and curve-linearly related to symptoms of mental disorders dependent on the type of disorder that was considered. The factors age and negative life events were related to increased symptoms of one or more of the disorders. Some disorders were typically more prevalent in people with ID such as Down's syndrome and autism.

## Conclusion

The psychometric properties of the P-AID were found to be acceptable. Moreover, the P-AID provides a more detailed description of symptoms and possible diagnoses than the other available screening instruments. Although some revisions may be needed, these findings support the use of P-AID as a screening instrument in psychiatric epidemiological research and in the initial clinical assessment of mental disorders with adults with ID. Overall, mental disorders was found to be more common in adults with ID compared with adults in the general Norwegian population. However, not all disorders were more prevalent in this group. Adults with ID were shown to have similar burden of co-morbidity as other people with lifelong conditions of mental disorders. Level of ID was found to be independently associated with symptoms of mental disorders in adults with ID. The direction of the relationship varied in the different disorders. Symptom levels of psychopathology tended to peak between severe and moderate ID in most disorders.

## List of publications

Hove O, & Havik OE (2008). Psychometric properties of Psychopathology checklists for Adults with Intellectual Disability (P-AID) on a community sample of adults with intellectual disability. *Research in Developmental Disabilities, 29*, 467-82.

Hove O, & Havik OE (2008). Mental disorders and problem behavior in a community sample of adults with intellectual disability: three-month prevalence and comorbidity. *Journal of Mental Health Research in Intellectual Disabilities, 1*, 223-237.

Hove O, & Havik OE (2009). Developmental level and other factors associated with symptoms of mental disorders and problem behavior among adults with intellectual disability living in the community. *Social Psychiatry and Psychiatric Epidemiology*. [Epub ahead of print]

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# 1. GENERAL INTRODUCTION

## 1.1 Background

For the last 18 years, people with intellectual disabilities (ID) have been offered the standard health and social services in Norway. Prior to the five year decentralization of care for people with ID, which began in 1991, all care for people with ID was centralized to county authorities. The reform of care for people with ID was implemented as a result of a comprehensive critique of the living conditions for people with ID at the institutions (NOU, 1985:34). However, a recent evaluation by Norwegian Health authorities (Helsedirektoratet) concluded that the specialized health services in Norway lack quality, availability and competence when it comes to people with ID (Helsedirektoratet, 2007). Regarding mental health problems, Nøttestad and Linaker (1999) concluded that the «deinstitutionalization has not been shown to solve any problems connected with the mental health of people with ID» (s 528) in that the rate of mental health problems are equal to or higher than before the reformation started and the availability of specialized health services are lower than it was during the institution period despite the fact that specialist habilitation services were established at the county level following the reform. There is clearly a need for increased focus on the mental health needs and services for people with ID.

## 1.2 Definition and classification of ID

Intellectual disability is defined in the '*International Classification of Diseases, 10<sup>th</sup> edition*' (ICD-10) (World Health Organization (WHO), 1992) as a condition with delayed or disturbed development of intellectual and adaptive ability and functioning, with onset before age 18. A similar definition is listed in the '*Diagnostic and Statistical Manual of Mental Disorders, 4<sup>th</sup> edition – Text Revision*' (DSM-IV-TR) (American Psychiatric Association (APA), 2000). The person's intellectual ability is defined by the performance on standardized intelligence tests as '*Wechsler Intelligence Scale for Children – third edition*' (WISC-III) (Wechsler, 1991), '*Wechsler*

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*Intelligence Scale for Adults – third edition*’ (WAIS-III) (Wechsler, 1997) or ‘*Leiter International Performance Scale - Revised*’ (Leiter-R) (Roid & Miller, 1997).

Adaptive functioning refers to the person’s ability to independent function and ability to cope with typical life demands as measured by standardized adaptive behavior rating scales such as the ‘*Scale of Independent Behavior – Revised*’ (SIB-R) (Bruininks, Woodcock, Weatherman, & Hill, 1996). Cut-off for a diagnosis of ID is set to approximately two standard deviations below the general population mean in both intellectual ability and adaptive functioning. A diagnosis of ID is subdivided into four ID-levels: mild (IQ=69-50), moderate (IQ=49-35), severe (IQ=34-20) and profound (IQ<20).

### **Prevalence of ID**

According the American Association for Intellectual and Developmental Disabilities (AAIDD: formerly American Association for Mental Retardation (AAMR)), the theoretical prevalence of ID is about 3% when using a classification scheme based on the normal distribution of IQ scores (AAMR, 2002). The reliance on intelligence test performance in diagnosing ID has been criticized as a person’s IQ level does not necessarily correspond to her/his support needs (AAMR, 2002). In line with a more functional approach, AAMR suggests that the population prevalence of ID is about 1%. However, the prevalence of ID is highly dependent on definition, methods and study population (APA, 2000); this is especially true for the mild ID group (AAMR, 2002). Changes in the assessment of level of severity of ID have been suggested that take this criticism into consideration. In its most recent revision, AAMR suggests that ID-level may be defined in terms of support intensity needed, IQ range or levels, special education needs, environmental assessments, etiology-risk factors systems, levels of adaptive behavior, mental health measures, or funding levels benefits categories (AAMR, 2002)

### **Administratively defined ID**

People with ID receiving social and health services are registered with Norwegian Health Authorities. According to figures from this registry, about 0.45% of the total population (both children and adults) receive some type of service due to their ID

(Helsedirektoratet, 2007). This group has been labeled as “administratively defined ID”. There is uncertainty about whether all the people in the registry actually qualify for a diagnosis of ID because the definition of the category has been unclear. Another problem with this registry is that it does not have information about who made the diagnosis. It is, however, likely that this group includes most of the people with profound to moderate ID. About 1/4 of the group tend to receive a diagnosis of mild ID when evaluated by health care staff using ICD-10 guidelines for Mental Retardation (ICD-10-MR) (WHO, 1996) or DSM-IV-TR guidelines (Holden & Gitlesen, 2006; Hove, 2007).

### 1.3 Mental disorders in adults with intellectual disabilities

During the last decades, the difficulties of providing adequate mental health treatment for adults with intellectual disabilities have been focused on. Historically, health personnel have shown various attitudes toward mental health problems in individuals with ID. Signs of mental disorders in people with ID have been regarded as problem behavior or as artifacts of the developmental or social delay inherent in ID (Reiss, Levitan, & Szyszko, 1982). According to Borthwick-Duffy (1994), some authors have also argued that people with intellectual disabilities do not develop mental disorders. Others have argued that the emotional problem of people with ID are of a different nature – typically of a biological rather than psychosocial origin - than for those without ID (Szymanski & Grossman, 1984). Today, however, it is generally acknowledged that adults with intellectual disabilities have the same type of mental disorders and the same severity of symptoms as adults in the general population (Borthwick-Duffy, 1994; Fletcher, Loschen, Stavrakaki, & First, 2007).

#### **1.3.1 Prevalence of mental disorders in adults with intellectual disabilities**

Several studies of prevalence of mental disorders in adults with ID exist. The prevalence estimates have, however, varied considerably. In a review of studies investigating prevalence, Whitaker and Read (2006) identified 14 studies addressing prevalence of mental disorders in people with ID in which all four levels of ID were

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included. In these studies, prevalence rates for overall mental disorder varied from about 4% to 46%. In seven of the 14 studies included, the prevalence rate was between 10% and 20% (Borthwick-Duffy & Eyman, 1990; Deb, Thomas, & Bright, 2001a; Eaton & Menolascino, 1982; Farmer, Rohde, & Sack, 1993; Jacobson, 1982, 1990; Rojahn, Borthwick-Duffy, & Jacobson, 1993) and in five of the studies, the rates were 28% or higher (Cooper, 1997; Corbett, 1979; Gostason, 1985; Iverson & Fox, 1989; Lund, 1985). A prevalence estimate above 90% has also been reported (Linaker & Nitter, 1990). Due to the variation in previous prevalence estimates and methodological limitations, some authors have argued that prevalence estimates are actually unknown in adults with ID (Cooper, Smiley, Morrison, Williamson, & Allan, 2007; Smiley, et al., 2007). Among the methodological limitations that have been pointed out is the use of small, restricted or biased samples, poorly defined or limited assessment, or the diagnostic criteria (Cooper, Smiley, Morrison, Williamson, et al., 2007; Whitaker & Read, 2006). Other problems have also been noted such as failure to report type of prevalence (Whitaker & Read, 2006) or reporting all-age or collapsed prevalence figures without describing which subgroups are included (Cooper, Smiley, Morrison, Williamson, et al., 2007).

In another review of epidemiology of mental health problems in adults with ID, the point prevalence of mental health problems was suggested to lie between 30% and 50% when problem behavior is included (Smiley, 2005). The most recent study of prevalence found that the point prevalence of total mental disorders, including psychoses, affective and anxiety disorders, obsessive-compulsive disorder (OCD), organic disorders, alcohol and substance use disorders, pica, sleep disorder and attention deficit hyperactive disorder (ADHD), personality disorders and problem behavior, was 37% (Cooper, et al., 2007) with an incidence of 16% (Smiley, et al., 2007). The generalizability of these findings is uncertain as this is the only study based on the diagnostic system '*DC-LD: Diagnostic Criteria for Psychiatric disorders for Use with Adults with Learning Disabilities/Mental Retardation*' (DC-LD), developed by the Royal College of Psychiatrists (RCP) (2001). The present project addresses the replication of the Cooper et al. study by investigating the prevalence of mental disorders and problem behavior using the same diagnostic framework as Cooper et al.

did. The present study also seeks to extend current knowledge by investigating the presence of co-morbid mental disorders in this group in addition to their ID.

### **1.3.2 Factors associated with mental disorders**

Several clinical and socio-demographic factors that are related to mental ill-health in the general population may also be related to mental ill-health in adults with ID. In addition, factors associated with ID may also be associated with mental health disorders co-morbid with the ID. These factors should be addressed in scientific and clinical work on this group. Factors such as age, gender, autism, level of ID, autism, epilepsy, physical illness, negative life-events, etc. have been studied in relationship to mental disorders in adults with ID. Yet, conclusive evidence regarding the association of these factors with mental disorders hardly exists. Regarding age, studies have found age to be unrelated to total prevalence of mental disorder (Cooper, et al., 2007), although some have found higher (Cooper, 1997) or reduced prevalence (Day, 1985) in older ages. As with age, most studies on gender have not found a consistent relationship to total prevalence (Borthwick-Duffy & Eyman, 1990; Jacobson, 1982). Epilepsy is a frequent condition in people with ID and known to be associated with increased risk of mental disorders in the general population. In people with ID, the association with epilepsy does show conflicting results, even when the same screening tools are employed (Espie, et al., 2003; Taylor, Hatton, Dixon, & Douglas, 2004). Regarding the relationship between physical ill-health and mental disorders, some researchers have found positive correlations (Deb, et al., 2001a), other has found negative correlations (Cooper, et al., 2007) and some have found no correlation (Moss, Goldberg, Patel, & Wilkin, 1993). In contrast to the findings above, negative life events have repeatedly been found to correlate with mental disorders in adults with ID (Esbensen & Benson, 2006; Hamilton, Sutherland, & Iacono, 2005; Hastings, Hatton, Taylor, & Maddison, 2004). A recent study found no relation, however, between negative life events experienced the preceding 12 months and new episodes (incidence) of mental disorders (Smiley, et al., 2007). These conflicting results highlight the need for an exploratory and descriptive approach in the study of factors associated with mental disorders in epidemiologic research in this population.

### **Assessment of psychosocial phenomenon**

Compared with the general population, assessments of psychosocial phenomena as life events may need adjustment for the special needs of people with ID. Moving to a new household or getting new neighbors may be a more demanding life experience for a person with ID than for people in the general population. It may also be that other factors than those typically found in the general population are more relevant risk factors for adults with ID. Little is known, for instance, about the coherence of the social care provided by the municipalities even though structured and predictable everyday support is often assumed to be fundamental to the social and psychological functioning for individuals with ID. The sampling of psychosocial factors as life events and coherence of social care may often rely on third party informants. As far as we know, no report has previously been made regarding the reliability of life event checklists for people with ID. In the present study, reliability of two recently developed checklists - Life event Checklist for Adults with Intellectual Disability (L-AID) and Coherence of Social care for Adults with Intellectual Disability (C-AID) - is investigated.

### **1.3.3 Relationship between level of ID and mental disorders**

Intellectual abilities below the population average are associated with increased risk for developing psychoses disorders (Woodberry, Giuliano, & Seidman, 2008). Low childhood intelligence has been found to increase the risk of adult depression and anxiety (Koenen, et al., 2009). Whether there is a general relationship between lower intellectual abilities and ill-health is, however, more controversial. Evidence from the literature on people with ID is unclear. As argued by Whitaker and Read (2006), no methodological sound study on mental disorders in adults with ID has sampled the entire range of ID. Usually, only a limited range of people with mild intellectual disability is included. Another important point is that previous studies have reported conflicting results regarding the relationship between level of ID and composite indexes of mental disorders. Positive correlations between level of ID and mental disorders have been found (Cooper, et al., 2007; Borthwick-Duffy & Eyman, 1990; Iverson & Fox, 1989), negative correlations have been found (Gillberg, Persson,

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Grufman, & Themner, 1986; Holden & Gitlesen, 2004; Rutter, 1970) and no relationship between level of ID and mental disorders has been reported (McQueen, Spence, Garner, Pereira, & Winsor, 1987).

Reviewers of epidemiology of mental disorders in adults with ID argue that further research should consider specific mental disorders rather than composite indexes of mental disorders when assessing the relationship between level of ID and mental disorder (Borthwick-Duffy, 1994; Smiley, 2005). A few studies have investigated the relationship between level of ID and presence of a specific mental disorder. However, these studies have also reported conflicting results. Some have argued that prevalence of mental disorders may peak at the moderate level of ID for depression, anxiety and psychosis (Holden & Gitlesen, 2004). Others have found that adults with mild/moderate ID show more symptoms of psychosis and depression than those with severe/profound ID (Myrbakk & von Tetzchner, 2008a), but no differences in anxiety, mania and obsessive compulsive disorder. In contrast to Holden and Gitlesen (2004), Myrbakk and von Tetzchner (2008a) found no relationship between level of ID and depression when using ‘*Mini Psychiatric Assessment Schedule for Adults with a Developmental Disability*’ (Mini PAS-ADD) (Prosser, Moss, Costello, Simpson, & Patel, 1997). No relationship between level of ID and psychosis has been reported (Cooper, et al., 2007). Thus, the relationship between level of ID and psychosis is unclear. Level of ID has been found to be unrelated to dementia in older adults with ID (Strydom, Hassiotis, King, & Livingston, 2009), yet Temple, Jozvai, Konstantares, & Hewitt (2001) found fewer cases of dementia in people with higher cognitive function in a sample of people with ID and Downs syndrome.

Except for Cooper et al. (2007), none of the studies mentioned above controlled for other factors that might explain the observed effects of ID diagnosis of mental disorders. In the present study, we examine the effect of biological factors such as age, gender, autism, genetic syndrome, epilepsy and cerebral palsy as well as psychosocial factors such as negative life events and coherence of the social care provided by community staff members. As biological factors may be considered more fixed compared to the more reactive and fluctuating psychosocial factors, these factors may

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be grouped separately when studying associations with mental disorders. Further, the former studies examining the relationship between level of ID and mental disorders employed linear terms in the analyses. The review of findings indicates that one should test if the association between level of ID and symptoms of specific mental disorders could be non-linear. As a consequence, both the linear and the curve-linear term of ID-level were included in the present study.

## 1.4 Mental health classifications for adults with ID

Several authors have argued that there is a lack of accurate psychiatric diagnosis in adults with ID (Dagnan, 2007; Sturmey, 2007). This has been given particular attention because accurate diagnosis is the most important tool for research and is assumed to be a basis for effective treatment (Szymanski, et al., 1998).

### **Problems in diagnosing mental disorders in people with ID**

Several phenomena associated with a diagnosis of ID may affect accurate assessment of mental disorders when done in accordance with the standard diagnostic systems in ICD-10 and DSM-IV. Some phenomena are related to cognitive aspects of the ID, such as unsophisticated communication and poor presentation of own experience and symptomatology. Other characteristics of the behavioral aspects of the ID may complicate diagnosis: the presence of bizarre behavior in response to minor stressors may be misdiagnosed as a mental disorder or high levels of unusual behavior can make it difficult to recognize the onset of a new disorder (Sovner, 1986). Other difficulties arise from the possibility that developmentally appropriate phenomenon may be misdiagnosed as mental disorders (Hurley, 1996) or in situations where the person may have learned to hide her/his disability (Edgerton, 1967, as cited in Sturmey, 2007). Additional diagnostic challenges may arise from provocative practice of care givers, inaccurate third party information and referrals for assessment and treatment that are primarily initiated by care givers rather than the person with ID her-/himself. People presenting with long-term and severe problem behavior who take multiple psychotropic medications may have a mixture of symptoms and signs that are extremely difficult to fit into the framework of the standard classification scheme

(Sturmeay, 2007).

### **Limitations of standard diagnostic manuals**

There are several limitations of the present standard diagnostic manuals that may infer with diagnostic reliability. Firstly, many of the standard diagnostic criteria in DSM-IV or ICD-10 rely on verbal items and/or descriptions of emotional, behavioral or psychological events that are difficult to understand or describe for some people with ID. Diagnoses are often based on third-party information and the interpretation of overt behavior expressed by the person being assessed because of the person's lack of verbal skills. Secondly, the standard criteria are not developed for use with third-party information (e.g. care giver's observations) and as a result the utility of these criteria is reduced. Thirdly, several diagnostic categories in the standard manuals have an extensive use of sub-categorization, assuming the presence of detailed and reliable information on the psychopathology that may not exist for people with ID (Cooper, Melville, & Einfeld, 2003). Finally, it is not clarified how problem behavior, which is commonly shown by people with ID, should be classified within the ICD-10 or DSM-IV-TR scheme.

In response to the difficulties with the standard diagnostic criteria outlined above, a variety of modifications of the standard diagnostic systems have been proposed for people with ID (Cain, et al., 2003; Clarke & Gomez, 1999; Davis, Judd, & Herrman, 1997; Marston, Perry, & Roy, 1997; Moss, et al., 1997; Ross & Oliver, 2003; Szymanski & King, 1999). The use of behavioral equivalents for verbal descriptions in this group has also been discussed and applied (Charlot, 2005; RCP, 2001). The most recent modification to ICD-10 criteria is the DC-LD manual (RCP, 2001). In contrast to other modifications that often are developed ad hoc (Cooper, et al., 2003), the system suggested by RCP is based on a comprehensive and systematic review of the existing literature with explicit references to the ICD-10 systems.

## **1.4.1 Methods of assessment of mental disorders in adults with ID**

### **Lack of 'gold standard' assessment**

Establishing reliable and valid diagnoses of mental disorders has shown to be a

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difficult matter in the general population (Aboraya, Rankin, France, El-Missiry, & John, 2005). One way of improving reliability and validity of mental disorders is to use operationalized methods as part of the clinical assessment (Aboraya, et al., 2005). Thus, the ‘gold standard’ of clinical assessment of mental disorders in the general population combines clinical judgment by a trained professional in psychology or psychiatry with a standardized diagnostic interview covering all categories of mental disorders (e.g. the ‘*Composite International Diagnostic Interview*’ (CIDI) (WHO, 1990)). For adults with ID, no ‘gold standard’ for diagnosing mental disorders currently exists (Holden & Gitlesen, 2004; Sturmey, 2007). One reason for this may be the shortcomings of the standard diagnostic manuals mentioned above. Difficulties with establishing reliable and valid diagnoses of mental disorders (Dagnan, 2007; Sturmey, 2007) may be due to the lack of a ‘gold standard’ for clinical assessment.

### **Symptom checklists for use with adults with ID**

Several symptom checklists designed for use with adults with ID are available. Unlike the clinical diagnostic interview, a screening instrument is often self-administered (or in the case of people with ID, administered by a third-party informant) and with less items covering fewer diagnostic categories. In general health services, symptom checklists may be valuable for the screening of mental health problems that require a referral to specialist services. It may also be valuable in the initial phase of the clinical assessment of mental disorders because it targets specific emotional, cognitive and behavioral reactions that will be evaluated by a multidisciplinary team in various settings. They are not adequate, however, as the only source of information when diagnosing mental disorders.

Table 1 presents the most widely used checklists for adults with ID. These instruments assess a wide range of mental health problems using third-party informants such as family members or community health care staff. Most of these checklists are designed to be completed by non-professionals. The Mini PAS-ADD interview should, however, be administered by a trained professional.

Table 1.  
Mental health screening tools for use with adults with ID

Name of instrument	No. of items	Item-grad scale	Sub-scales	Taxon
Mini Psychiatric Assessment Schedule for Adults with Developmental Disabilities (Mini PAS-ADD) Interview	49 <sup>a</sup>	4-point	6 <sup>a</sup>	ICD-10
Psychiatric Assessment Schedule for Adults with Developmental Disabilities (PAS-ADD) Checklist	29	4-point	5	ICD-10
Assessment of Dual Diagnosis (ADD)	79	Yes/No <sup>b</sup>	13	DSM-IV-TR
Diagnostic Assessment for the Severely Handicapped Scale-II (DASH-II)	84	Yes/No <sup>b</sup>	13	DSM-IV-TR
Developmental Behavior Checklist for Adults (DBC-A)	106	3-point	6	Empirical
Reiss Screen for Maladaptive Behavior (RSMB)	38	3-point	8	DSM-III-R/ empirical
Aberrant Behavior Checklist (ABC)	56	4-point		Empirical

Note: The ADD is the successor of the Psychopathology Instrument for Mentally Retarded Adults PIMRA (Matson, Kazdin, & Senatore, 1984); <sup>a</sup> Excluding autism; <sup>b</sup> Assesses severity, frequency and duration of symptoms of mental disorders

### Reliability and validity of screening tools for adults with ID

Reliability estimates for several of the checklists used to screen for mental disorders in adults with ID have been summarized by Mohr & Costello (2007) as inconsistent, with practical, theoretical and methodological limitations. Reliability, estimated as internal consistency, has shown mainly acceptable values in all of the instruments when based on the total scale with a larger number of items. More variability is found in the internal consistency of shorter subscales and in test-retest and inter-rater measures for both total scales and subscales (Table 2).

To our knowledge, no study has to date assessed the reliability of screening instruments with regard to different levels of ID. Typically, studies collapse levels of ID into one category or comprise a selected sample with regard to the ID-levels included. Reliability in the collapsed category milder and lower levels of ID is addressed in the present study.

Table 2.  
Internal consistency and reliability of assessment and monitoring tool (adopted from Mohr & Costello, 2007)

Instruments	Internal consistency		Reliability		
	Total scale	Subscale	Test-retest		Inter-rater
			Total scale	Subscale	Total scale/subscale
PIMRA (13*)	.64-.90	-.10-.77	.65-.91	-.15-1.0	.40-.77 ss
ABC (9)	.94	.78-.94		.84-.99	.58-.78 ts
RSMB (8)	.80-.92	.46-.87	.75	.50-.70	.60-.81 ts / .50-.80 ss
DASH (9)	.86	.20-.84	.84-.91		.85 ts
PAS-ADD Checklist(2)	.87	.51-.84			.79 ts / .55-.60 ss
DBC-A (3)	.95	.61-.89	.75-.85		.72 ts

Note: \*Number of studies; ts – total scale; ss – subscale

Efforts have been made to analyze aspects of both construct and concurrent validity of the existing tools. Although some of the checklists have shown stable factor structure across studies (e.g. the ABC), variations in factor structure (Mohr & Costello, 2007) and/or lack of convergent and divergent validity (Mohr & Costello, 2007; Myrbakk & von Tetzchner, 2008b) are common. The principal finding in a recent study of convergent and divergent validity of the four instruments RSMB, Mini PAS-ADD, DASH-II and ADD (Myrbakk & von Tetzchner, 2008b) was that they have high agreement in overall scores, but limited agreement on specific diagnosis. Further, the content of checklists differs in that some items are not comparable across checklists and some diagnostic categories are included in some checklists and not in others. Both Mohr and Costello (2007) and Myrbakk and von Tetzchner (2008b) concluded that the existing checklists may be used to identify adults at risk or with a possible mental disorder. Other instruments are needed to further specify the existence and content of the disorder.

## 1.5 DC-LD: Diagnostic criteria for mental disorders for use with adults with ID

DC-LD is a comprehensive axis system with three main axes and five sublevels in axis III (Table 3). Axis I and II (severity and causes of ID) use the relevant ICD-10 categories (e.g. F7x: Level of ID and Q90.0: Down's syndrome, respectively). Similar, pervasive developmental disorders in axis III, level A, uses ICD-10 categories except

that the name has been changed from childhood autism to autism (childhood onset).

Table 3.  
DC-LD hierarchical diagnostic system

Axis and level	Diagnostic category
Axis I	Severity of learning disability
Axis II	Cause of learning disability
Axis III	Psychiatric disorders
Level A	Developmental disorders
Level B	Psychiatric illness
Level C	Personality disorders
Level D	Problem behavior
Level E	Other disorders

The following mental disorders comprise Level B: dementia and delirium, non-affective psychotic disorders, affective disorders, neurotic and stress related disorders, eating disorders, hyperkinetic disorders and tic and movement disorders. Eating disorders were not included in the present study as a study of eating disorders using DC-LD diagnostic criteria was recently conducted in a majority of the sample used in the present study (Hove, 2004). Regarding tic disorder, which is included in the ‘disorders of childhood and adolescence’ section in ICD-10, the DC-LD only notes that this can occur in adults with ID. For this reason it was not included in the present study. Hyperkinetic disorders were not included as the major difference in the DC-LD compared to ICD-10 is that a new sub-category is added introducing the criteria “age of onset unknown”. The chapter on personality disorders comprises paranoid, dissocial, emotionally unstable (impulsive and borderline type), histrionic, anankastic and other personality disorders. Personality disorders were not included in the present study. Level D comprises the following problem behaviors: verbally aggressive, physical aggressive, destructive, self-injurious, sexually inappropriate, oppositional, demanding and wandering behavior. Level E (not included in the present study) concerns other disorders and comprises 15 disorders included in ICD-10 that are not categorized in the DC-LD level A-D (e.g. substance use disorder, sleep disorders, sexuality related disorders, etc).

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### **DC-LD discrepancies compared to the ICD-10 diagnostic criteria**

Although the different types of mental disorders seen in adults with ID are essentially the same as seen in adults in the general population, a number of changes are made to the diagnostic criteria of mental disorders in the DC-LD system compared with the ICD-10 system. In general, DC-LD acknowledges the use of third-party reports and observations in the diagnosing of mental disorders. In the chapter on non-affective psychotic disorders, the most apparent change is the reduction of the number of diagnostic subcategories (Melville, 2003) from eight ICD-10 subcategories to three categories in the DC-LD: schizophrenic/delusional disorder, schizoaffective disorders and other non-affective psychotic disorders. By doing this, the diagnostic criteria are broadened as in, for example, the ICD-10 categories schizophrenia, persistent delusional disorders and acute and transient psychotic disorders are collapsed into a single category of schizophrenia/delusional disorders. In addition, the duration criterion has been reduced from one month to two weeks for two of the symptom criteria, and a diagnosis can be made if a single mood incongruent psychotic symptom is present for one month.

Several changes of the ICD-10 diagnostic criteria for affective disorder are present in the DC-LD. As with the non-affective psychotic disorders, the number of subclasses in the affective disorder chapter is kept to a minimum. Symptoms assumed to be more common in adults with ID such as irritability and aggression, changes in social behavior and increase in somatic complain are included in the DC-LD. The ICD-10 criteria for depressive episode related to loss of confidence and reduced ability to concentrate have been modified, and the so-called 'core' mood symptoms of reduced energy or lethargy in the ICD-10 are intermixed with other symptoms in the DC-LD. Depressive mood and loss of interest or pleasure are retained as 'core' mood symptoms. A diagnosis of depressive episode can be made with only one 'core' mood symptom present. In contrast to the ICD-10 system, the DC-LD system does not allow differentiation of depression with respect to severity.

To diagnose anxiety disorders, the DC-LD system makes use of behavioral equivalents to ICD-10 by allowing that the observed expression or behavioral demonstration of

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anxiety or fear in a person can be used to make a diagnosis of anxiety. Also, irritability due to anxiety is included as an observable symptom of anxiety. The more conceptually difficult criteria of depersonalization are removed and increased irritability and restlessness are added to the symptom criteria list in DC-LD.

### **Problem behavior**

Problem behavior is highly prevalent in adults with ID (Cooper, et al., 2007; Holden & Gitlesen, 2006) and comprises a majority of the referrals for the specialist services, e.g. habilitation services (Holden & Gitlesen, 2003; Myrbakk & von Tetzchner, 2008a). Unlike the standard diagnostic manuals, problem behavior is an explicate part of the diagnostic scheme in the DC-LD. As a rule, DC-LD suggests that problem behavior is used only when it is not part of a mental or somatic condition. When problem behavior is diagnosed concurrent with other mental disorders, DC-LD suggests that it is likely that the problem behavior is not part of the mental disorder as, for instance, a situation where a person with long standing self-injurious behavior starts showing symptoms of depression.

### **Field trial of DC-LD**

The development of DC-LD included a field trial and a total of 709 cases (Cooper, et al., 2003). All DC-LD axis III disorders were piloted except dementia in Huntington's disease, acute stress reaction and anankastic personality disorder. A 96.3% agreement between the DC-LD diagnosis and clinical opinion were reported. Inter-raters' agreement on individual diagnosis was not reported. As pointed out by Sturmey (2007), "its empirical basis, including basic questions of reliability and validity, remains to be demonstrated." p. 15.

## **1.6 Diagnostic algorithm**

A diagnostic algorithm describes the defined sequence of operations to generate a mental disorder diagnosis. Several instruments use diagnostic algorithm, for example, the '*Composite International Diagnostic Interview*' (CIDI) (WHO, 1990) and the '*Schedules of Clinical Assessment in Neuropsychiatry*' (SCAN) interview (Wing, et

al., 1990). These and other structured interviews usually inquire about symptoms in a standard manner and then the data obtained from the interview are combined to form diagnoses according to a priori algorithm. Diagnostic algorithms have been used for differential diagnostic purposes such as for depression in people with schizophrenia (Hausmann & Fleischhacker, 2002), anxiety (Pingitore & Sansone, 1998), autism (Gotham, et al., 2008) and Alzheimer (Foy, et al., 2007). Diagnostic algorithms are used to diagnose adults with ID in the ICD-10 version of the PAS-ADD interview (Costello, Moss, Prosser, & Hatton, 1997). In an effort to meet the inclusion and exclusion criteria for the categorical classification system adopted in the DC-LD diagnostic system, two-step computer based algorithms were used to generate DC-LD diagnoses from the recently developed screening instrument '*Psychopathology checklists for Adults with Intellectual Disability*' P-AID.

## 1.7 Aims in the project

The present project encompasses two goals: the development of assessment methods for mental disorders in adults with ID and the estimates of the prevalence of mental disorders.

### 1.7.1 Paper I

The main aim in Paper I was to evaluate the reliability, factor structure and to perform a preliminary analysis of validity of the psychopathology checklists (P-AID), which was recently developed for use with adults with ID.

### 1.7.2 Paper II

In Paper II, the three-month prevalence rates and patterns of co-morbidity of mental disorders in a population sample of adults with ID were investigated. Aspects of validity for the P-AID were also discussed.

Two-step computer-based algorithms were used to generate DC-LD diagnoses. Details on the application of the symptom criteria are outlined in Paper I. Application of the inclusion and exclusion rules for diagnoses are outlined in Paper II.

### **1.7.3 Paper III**

In Paper III, level of ID and other relevant factors were studied in relationship to the occurrence of symptoms of dementia, psychosis, depression, mania, anxiety, OCD and a collapsed variable of problem behaviors. The non-reactive factors (age, gender, autism, genetic syndrome and the neurological conditions of cerebral palsy and epilepsy), the reactive factors (negative life event, coherence of social care) and ID-level were categorized separately. These factors' effects were investigated in order to see if and to what extent their presence was associated with more symptoms of mental disorders.

In addition, we wanted to investigate the reliability of the two recently developed instruments Life Event Checklist for Adults with Intellectual Disability (L-AID) and Coherence of Social Care for Adults with Intellectual Disability (C-AID).

## 2. METHODS

### 2.1 Study population

The targeted study population in the present study was adults (e.g. above 18 years) with administratively defined ID. As the services are organized in different ways in the municipalities, the heads of the offices for health/ community care services in 32 municipalities in Western Norway were contacted to determine the number of people eligible for the study and to assign contact people and personnel that could serve as informants/raters. A total of 901 individuals with ID were identified, comprising 0.27% of the total adult population in the area. Following this initial contact, 901 sets of checklists were distributed to the contact people in each municipality. A second set of checklists were added for every 5<sup>th</sup> set to test inter-rater reliability. This resulted in 180 double sets of checklists. A total of 676 checklists for 593 individuals (66%) were returned, comprising 83 double sets of checklists.

### 2.2 Informants

To ensure homogeneity of raters, one rater for every administrative unit (e.g. group home) was selected according to the following criteria: 1. Informants must have known the subject well and for a long time, i.e. interacting with the individual on a weekly basis for at least one year. 2. Informants must have training in a social or health profession at a 3 year level. For the purpose of paper I, a separate rater from the same administrative unit filled in a second checklist independent of the main rater in a random sub-sample of participants, every 5<sup>th</sup> set giving at total of 83 double checklists.

### 2.3 Instruments

The questionnaire used in the study comprised demographic information; medical information including presence of genetic syndromes, pervasive developmental disorder and psychiatric history; an adaptive behavior scale in addition to checklists for level of ID; exposure to life-events during the last 12 month; a scale for the study

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of coherence of the social care provided by the municipalities; and checklists screening for symptoms of mental disorders and problem behavior.

### **2.3.1 Level of ID**

In the present study, an administrative definition of ID was used. No information regarding the methods used in the assessment of the diagnosis of ID is thus available. The ICD-10-MR (WHO, 1996) descriptions of typical functioning in the four levels of ID were used to define level of ID. These descriptions include information about scholastic skills, language and social behavior, independence skills and indication of known or unknown cause of the ID. The informants were instructed to read the clinical descriptions for each level of ID and mark the descriptions that best described the rated person. In Paper I, rating of ID level according to the clinical descriptions was found to have good inter-rater reliability, with a kappa agreement at 0.82 ( $p < 0.0001$ ). In the same paper, the ratings were validated against a measure of adaptive behavior addressing the following domains: communication, daily living, socialization and motor behavior. Each domain has two and three sub-areas that were evaluated by the informant on a scale from 1 to 6 based on the overt behavior of the individual that she/he was rating. It was found that when level of ID moved from mild ID to profound ID, a corresponding decrease was found in level of adaptive functioning ( $r = -0.77$ ;  $p < 0.0001$ ). In Paper I, the four categories of ID were collapsed into the two categories mild/moderate ID and severe/profound ID to increase the sample size in each category. In paper III, all four levels of ID were analyzed.

### **2.3.2 Psychopathology Checklists for Adults with Intellectual Disability (P-AID)**

Screening for symptoms of mental health problems was conducted using the P-AID (Appendix I). The instrument screens for dementia; psychotic disorder; the affective disorders of depression, mania, and bipolar disorder; the anxiety disorders agoraphobia, social phobia, specific phobia, panic disorder and generalized anxiety; as well as eight different types of problem behavior. Alpha values for the checklists assessing mental disorders are presented in table 4. Alpha values for the problem

behavior checklists ranged from 0.89-0.96.

Table 4.

Total number of items in each checklist, number of clusters within each checklist, sub-scale and sub-scale cluster alpha value, the minimum number of items needed for a symptom diagnosis.

P-AID sub-scales	No of Items	Total alpha	No of clusters	Cluster alpha	Min. items for diagnosis
Dementia	25	.93	3	.92/.85/.79	4
Psychosis spectrum	40	.89	2	.89/.82	5
Depression	37	.92	2	.90/.86	4
Mania	24	.88	2	.75/.86	4
Agoraphobia	15	.87	2	.68/.82	2
Social phobia	20	.85	3 <sup>a</sup>	.63/.83	3
Specific phobia	19	.83	2	.72/.71	2
Generalized anxiety <sup>b</sup>	18	.89	3 <sup>a</sup>	.85	3
Panic attack	14	.89	2	.89/.79	2
OCD	5	.90	1	-	4

Note: OCD - obsessive-compulsive disorder; <sup>a</sup> Cluster 2 and 3 are collapsed; <sup>b</sup> No alpha value calculated for Cluster 1

Each checklist has a unique introduction that specifies criteria of symptom duration if relevant. Items comprising the checklists were derived from the diagnostic criteria for the actual diagnoses in DC-LD. Behavioral examples of symptoms from the DC-LD manual were used as single items to operationally define more complex constructs, which reduces the possibility for idiosyncratic and inconsistent interpretations by the informants. The diagnostic criteria were first translated from the English version of the DC-LD by OH and retranslated by OEH.

### 2.3.3 Life event checklist for adults with ID

Number of negative life events during the last year was assessed using the Life event Checklist for Adults with Intellectual Disability (L-AID) (Appendix II). The checklist was developed for assessing life event exposures thought to be of particular relevance for people with ID. L-AID items are about changes in chronic disease, epileptic seizures, possibility for privacy, etc in addition to life-events typically assessed in the general population such as change in place of residence. Some items relevant for the general population, such as being divorced or having a child are very uncommon in people with administrative ID, and were thus excluded from the checklist. The original checklist has 23 items rated on a 6-stepped scale. For the analysis in Paper III, life

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events rated as having a negative impact on the person (step 1 to 3 on the scale) was coded 1 and absence of negative life events and positive life events exposures were coded 0. Inter-rater reliability for each of the negative life event items was calculated using the set of 83 checklists independently filled in by two informants. Following the reliability analysis, 14 items with significant inter-rater reliability were retained for further analysis.

#### **2.3.4 Coherence of social care**

Coherence of social care provided for each participant were assessed using items covering relative's collaboration and satisfaction and coherence and consistency of care (Appendix III). The checklists were termed Coherence of social care as the items are intended to capture the extent to which the everyday environment for the person with ID is structured, predictable, and explicable (Antonovsky, 1987). The mean sum score for the five items was used in Paper III to explore its relationship to mental disorders and problem behavior.

## **2.4 Diagnostic algorithm**

Two-step computer-based algorithms were developed to generate DC-LD diagnoses. In the first step, type and number of symptoms of specific mental disorders were clustered to include people that qualified for a diagnosis with respect to symptom criteria. In depression, for instance, a symptom diagnosis is probable when four or more symptoms of depression are present and if one or more of these belong to the 'core' symptoms. Some exceptions from the decision rules described in the DC-LD manual were made. Two rather than three clusters were needed on the dementia checklist to make a preliminary diagnosis of dementia. The decision rules for dementia in DC-LD were altered for two reasons: firstly, recent findings suggest that memory impairment is less prominent in the early stage of dementia in people with Down's syndrome (Ball, et al., 2006) and secondly, in lack of long-term information about cognitive functioning, non-cognitive features are suggested to improve diagnostic accuracy (Moss & Patel, 1995). In an effort to add contextual information to the

psychosis symptoms reported, thus reducing the possibility for false positive diagnoses of psychosis, four positive items on the checklists screening for odd or suspicious behavior were needed in addition to the criteria listed in the manual. This may be particularly important when considering psychosis, as only one positive symptom is needed to make a diagnosis, and the possibility for misinterpretation of psychotic symptoms in people with intellectual disability is larger than in the intellectually average population (Hatton, et al., 2005; Hurley, 1996). In the anxiety checklists, agoraphobia required three positive items rather than four, generalized anxiety required two rather than four, and panic anxiety required two rather than three autonomic responses to make a preliminary diagnosis. This was done because we expected that the informant under reported autonomic reactions. In OCD, three of the five features described in the DC-LD manual were included. All individuals with one or more positive preliminary disorders entered to the second step of the diagnostic algorithm. In the second step of the diagnostic algorithm, a hierarchical diagnostic approach was used to exclude diagnosis that over-ruled other diagnoses. For instance, a diagnosis of depression was overruled by a psychosis disorders and bipolar disorder (see Paper II for further information).

## 2.5 Missing data

In some cases, not all checklists were filled in by the informant, thus the number of cases in the statistical analyses varies. In addition, some of the checklists were excluded from analyses as the number of items filled in was lower than required for making a diagnosis in Paper I and II. In paper III, missing data on single items were replaced by the individual's mean value on the relevant checklist. If more than 50% of the items were missing for an individual, the checklist for that particular individual was not included.

## 2.6 Statistics

Data analyses in Paper I and II were conducted using the Statistical Package for the Social Sciences (SPSS) version 14.0. Version 15.0 was used in Paper III.

### **Paper I**

To estimate internal consistency, Cronbach's alpha was calculated. Analysis of inter-rater reliability was conducted using ICC and Cohen's kappa. A two-way random ICC model was used to estimate consistency of the two independent raters of the checklists. The kappa analysis was conducted to indicate agreement of the presence or absence of specific diagnoses among raters after checklists scores were transformed into categorical diagnoses and the diagnostic algorithms were employed. Due to expected prevalence differences in the presence of a given mental disorder, prevalence indexes (PI) and prevalence-adjusted kappa (PAK) were also calculated (Sim & Wright, 2005). To explore the factor structure of the P-AID, principal component analysis (PCA) was conducted on the sum score on each of the 18 checklists. A preliminary analysis of sensitivity and specificity was conducted using information about the individuals' psychiatric diagnostic history.

It is generally recommended that the alpha value for research tools should be about .80, and about .70 in the early stages of research. For clinical purposes, the alpha value should be about .90 (Streiner, 2003) if the scale is assumed to measure a homogeneous dimension. The following intervals are suggested to describe both ICC and kappa: .01-.20 = slight, .21-.40 = fair, .41-.60 = moderate, .61-.80 = substantial and .81-1.00 = almost perfect (Landis & Koch, 1977).

### **Paper II**

The relationships between prevalence figures for mental disorders in three different studies were determined using chi-square analysis. Odds ratios for the relationships between predictors and mental disorders were estimated using binary logistic regression analysis.

### **Paper III**

The associations between the predictors and symptoms of mental and behavioral disorders were studied using a hierarchical linear regression model with forced entry. The predictors were entered in four separate blocks. To identify where the quadratic term peaked in the different mental and behavioral disorders, the ratio of the linear

term (b) to the quadratic term (a) were calculated using unstandardized Beta-values in the formula  $-b/2a$  (Simon, 2006). A two-way random ICC model was used to estimate consistency among the two independent raters of the L-AID and the C-AID.

## 2.7 Ethical considerations

The study has been approved by the Regional Committee for Medical Research Ethics, Western Norway with no demand for informed consent, as no personal identification information was needed in this cross-sectional study. Some considerations regarding informed consent: Most people with mild and moderate ID would most likely be able to provide informed consent to this particular project. It is, however, unlikely that people with severe and profound ID would be able to provide the consent needed. Unlike in some other countries, Legal Representative does not exist in Norway. Thus, exemption from the requirement of informed consent must be provided by the Norwegian Health Authorities.

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### 3. MAIN FINDINGS

#### 3.1 Paper I

In this paper, the reliability and validity of the P-AID were examined. In the analyses of internal consistency, alpha values between .83 and .93 (mean=.89, SD=.03) were found for the mental disorder checklists and between .89 and .96 (mean=.93, SD=.03) were found for the problem behavior checklists. Alpha values for the group mild/moderate intellectual disability ranged from .82 to .93 (mean=.87, SD=.04) on the total scale for the 10 psychopathology checklists and from .86 to .95 (mean=.92, SD=.03) for the problem behavior checklists. Alpha values for the group severe/profound intellectual disability were very similar, ranging from .84 to .95 (mean=.89, SD=.03) for the total scale for the psychopathology checklists and from .91 to .97 (mean=.94, SD=.02) for the problem behavior checklists. ICC values for the P-AID sub scales were between .49 and .88 in the mental disorders and between .47 and .89 in problem behavior. The ICC for dementia, psychosis, depression and mania items added together were .77 (95% CI: .64 - .85) and .66 (95% CI: .47 - .78) for the anxiety items. ICC values ranged from .51 to .90 (mean=.70, SD=.11) for the mental disorder checklists in the mild/moderate intellectual disability group and -.13 to .83 (mean=.49, SD=.30) in the severe/profound group. The prevalence-adjusted kappa, however, was acceptable for all diagnoses. The PCA gave a solution with four components with eigenvalues exceeding 1.00, explaining 54.9% of the total variance. The rotated solution revealed a structure where 15 of the 18 checklists had high loadings on only one component.

#### 3.2 Paper II

In our sample, 43% showed indices of either a mental disorder or problem behavior (CI=39% - 47%), whereas 35% of the sample showed indices of mental disorders (CI=31% - 39%). Problem behavior was present in 20% of the participants. Among the mental disorders, anxiety disorder (16%) and depression (12%) were the most

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common. The overall rate of mental disorders was comparable to a Norwegian urban population and about twice the rate of a rural population. The use of the exclusion rules, the second step in the diagnostic algorithms, decreased the prevalence of several diagnostic categories. Yet, the overall rates of mental disorder were not affected. Analysis of co-morbid disorders showed that 22% of the sample had one mental disorder or problem behavior diagnosis, 10% had two diagnoses and 12% had three or more diagnoses. This is similar to co-morbidity figures found in people with schizophrenia. When considering only mental disorders, 28% had 1 diagnosis, 6% had two diagnoses and 1% had three diagnoses. Among the problem behavior diagnosis group, 7% had one diagnosis, 7% had two diagnoses and 6% three diagnoses. Thus, it appears that the prevalence of mental disorder is higher in adults with ID compared with the general population. The pattern of co-morbidity of mental disorders in adults with ID is similar to what is found in other groups of people with lifelong conditions of mental disorder.

### 3.3 Paper III

Symptoms of problem behaviors decreased with increasing level of intellectual ability, whereas the opposite linear trend was observed for symptoms of psychosis - symptom levels increased with increasing intellectual ability. For five domains, a curvilinear relation with symptom intensity was observed. In all domains, symptom intensity peaked at the severe or the severe/moderate level of ID. Higher age was related to more symptoms of dementia and lower age was associated with more anxiety symptoms. Down's syndrome was related to higher levels of dementia symptoms. Autism was related to psychosis, anxiety, OCD and problem behavior as well as overall mental ill-health. Gender was not related to any of the disorders studied. Negative life event was related to dementia, depression and mania. Coherence of social care was associated with fewer symptoms of all disorders except anxiety, OCD and problem behavior.

#### **Reliability of the L-AID**

Intra-class correlation of the 23 items initially included in the L-AID showed

significant inter-rater reliability in 14 of the items. The 14 items were used in further analysis. The two-way random ICC analyses of the sum score of the 14 items showed adequate inter-rater reliability (ICC=0.68,  $p<.0001$ ). Inter-rater reliability of five of the 14 items was found to be moderate, six items showed substantial inter-rater reliability and three items were found to have an almost perfect inter-rater reliability (range of all items=0.41 - 1.00).

### **Reliability of the C-AID**

Analysis of the internal consistency of the five items included in the C-AID showed a Cronbach's alpha=.73. The ICC analyses of the sum score of the five items showed poor but significant inter-rater reliability (ICC=.32,  $p<.05$ ). The ICC analysis showed significant, but poor and moderate inter-rater reliability of the individual items, ranging from .31 to .51.

## 4. GENERAL DISCUSSION

### 4.1 Synopsis of the results

The first of the two main objectives in this project concerns the methods of assessing mental disorders. The findings in Paper I indicate that the estimates of internal consistency of the checklists assessed are within the recommended level and, with few exceptions, have substantial inter-rater reliability. It was also shown that the instruments have strong construct validity. Problem behavior was found to be an independent construct, a finding that supports the separate classification of problem behavior in the DC-LD hierarchy. The findings in Paper II contribute to the concurrent validity of the P-AID in that the prevalence estimates, to a large extent, correspond to the most recent findings in the area. Building on the diagnostic criteria from the DC-LD, the P-AID shows equal or better psychometric properties compared to other available screening instruments at a more detailed diagnostic or symptomatic level.

The second main objective in this project concerns the prevalence of mental disorders and the factors associated with the increase and decrease of symptoms of mental disorders in adults with ID. Findings in the present project indicate that the mental health needs of adults with ID are greater than in the general population, even when problem behaviors are not included. It is important to note that mental disorders are more common than problem behavior. Looking at mental disorders in more detail, the present data suggest that some disorders are more prevalent in adults with ID compared with the general adult population (e.g. depression) and others are less prevalent (e.g. social phobia and panic anxiety). The findings also indicate a high comorbidity of mental disorders, although not necessarily higher than people with other lifelong conditions of mental disorders such as schizophrenia (Braga, Mendlowicz, Marrocos, & Figueira, 2005; Mendlowicz, Braga, Marrocos, & Figueira, 2005).

Level of intellectual disability contributed the explained variance of symptoms within six out the seven domains of mental disorder and problem behavior after controlling for other relevant factors. The relationship was either linear or curvilinear. The present

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findings extend previous findings regarding the relationship between symptoms of mental disorder and problem behavior and level of ID. Although the proportion explained variance related to ID-level was low, the finding suggests that the assessment of level of ID should be integrated into a comprehensive assessment of mental disorders and problem behavior in adults with ID. The finding questions the practice of collapsing the four ID-levels into the two groups mild/moderate ID and severe/profound ID. Previous findings showing that negative life events are associated with mental disorders and problem behavior have been replicated in the present study. The finding that the coherence of social care in the community system is related to several mental disorders expands previous knowledge regarding factors associated with mental disorders in adults with ID.

We also wanted to investigate the reliability of the recently developed checklists for sampling life events (L-AID) and coherence of the social care provided in group homes (C-AID). The inter-rater reliability of the L-AID was substantial. The C-AID, however, showed poor inter-rater reliability. Nevertheless, the internal consistency of the checklists showed acceptable values, which is an indication that the items used measure a homogenous dimension.

## 4.2 Results in view of earlier research

### 4.2.1 Reliability and validity of mental health measures

As shown by table 4, the internal consistency of instruments for adults with ID were almost perfect for the sub-scales (i.e. depression checklists), and substantial and almost perfect for the within sub-scale clusters. Clearly, the internal consistency of the P-AID checklists is sounder than what has been found in other instruments. Compared with the existing screening instrument that typically has 30-60 items, the P-AID has a total of 280 items. The high alpha values found in the present study may in part be explained by the high number of items in the P-AID checklists. This explanation is not likely because the analyses of within sub-scale clusters show substantial and almost perfect values even in clusters with few items (e.g. 3-4 items). Most likely the

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explanation is that the items comprising the cluster and sub-scales of the P-AID are homogenous. As shown in Table 3, inter-rater reliability of the established screening instruments has been found to be moderate (0.41-0.60) to substantial (0.61-0.80). The inter-rater values tend to be more variable in sub-scales than total scales in the existing instruments. In the P-AID, both the sum score of all anxiety checklists and the sum score of dementia, psychosis, depression and mania checklists showed substantial interclass correlations. Regarding the sub-scales of P-AID, inter-rater correlation was substantial to almost perfect (0.81-1.00) with the exception of the two less frequent anxiety disorders, generalized anxiety and panic anxiety. According to this, the P-AID seems to show at least equally strong inter-rater reliability as do the existing screening instruments design for adults with ID, and at a more detailed diagnostic level.

#### 4.2.2 Application of diagnostic algorithm

Validation of the diagnostic algorithm employed is difficult as no independent diagnostic evaluation was available. It is nevertheless relevant to consider how the final step in the diagnostic algorithm affects the prevalence of diagnoses in the first step. The overall mental health prevalence was not affected by the exclusion rules in the final step as all people continuing to step two would end up with a diagnosis.

**Dementia:** Dementia was overruled by a preliminary diagnosis of depression as symptoms of dementia and depression overlap to some extent. As the preliminary diagnosis of depression was significantly affected by the applied exclusion rules, the final diagnosis of dementia may have been less affected if only excluded by a final diagnosis of depression. In a future validation of the algorithm, the effect of using a final rather than a preliminary diagnosis of depression should be investigated to obtain the most accurate differential diagnosis of dementia. This can also be viewed differently. The prevalence of dementia was significantly reduced when people with co-existing depression were excluded. This may indicate that a high co-morbidity of symptoms in these disorders are present. This difference is masked by the application of the exclusion rules. It may be necessary to accept that these two disorders have a high co-morbidity.

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**Affective disorders:** Both the rate of depression and mania was significantly reduced by the exclusion rules in step two of the diagnostic algorithm. The rate of affective psychosis was higher than for mixed affective episodes, and it is, therefore, likely that the main part of the reduction is explained by the presence of co-occurring symptoms of psychosis and depression or mania rather than by the presence of mixed affective episodes. In the present study, the term affective psychosis, rather than schizoaffective disorder, was used to label people with symptoms of psychosis and affective disorder. The reason for this is that the diagnostic criteria C in the DC-LD manual, in our view, were difficult to employ as it states that the symptoms of schizophrenia in the schizoaffective disorder diagnosis in DC-LD must be prominent in the clinical picture and there should be a balance of number, severity and duration of psychotic and affective symptoms. As a diagnosis of schizophrenia may be present with only one positive symptom, but at least four symptoms are needed for a depressive or mania episode, a balanced number is hard to obtain. The category affective psychoses may include both people with schizoaffective disorder and schizophrenia with co-morbid depressive disorder or mania. In the case of the latter, the true rate of depression and mania is higher than what was found in the present study. The finding that the rate of depression was significantly reduced by psychosis disorders indicates that a high co-morbidity of these disorders exists.

**Anxiety:** Generalized anxiety and panic anxiety was significantly reduced by the exclusion criteria in step two of the algorithm. This may be explained by the co-occurrence of specific phobia as both generalized anxiety and panic anxiety was excluded by specific phobia, and the latter was the single most prevalent disorder in the study. Also, the two anxiety disorders agoraphobia and social phobia that were not excluded by specific phobia were not significantly reduced by the exclusion rules.

As evident in several disorders mentioned above, the application of the final step in the diagnostic algorithm affects the possibility of co-morbidity of disorders. This is apparent when comparing co-morbidity of mental disorders and co-morbidity of problem behavior – the latter of which no exclusion rules within diagnoses were employed. Concerning problem behavior, it is equally likely that a person has two or

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three diagnoses as opposed to one diagnosis; the majority had only one diagnosis of mental disorder.

### **4.2.3 Prevalence of mental disorders and problem behavior**

One of the main aims in Paper II was to see if P-AID replicated the prevalence rates found in Cooper et al. (2007). The overall prevalence in the present paper was 43%. This is somewhat higher than the 37% (CI=34% - 40%) found in Cooper et al. (2007). Considering the specific diagnoses, six of ten diagnoses of mental disorders were in the same range, three diagnoses showed higher rates and one showed a lower rate in the present study compared to the Cooper et al. study. There are several possible reasons for the discrepancy found. The P-AID is a screening instrument, and as such one might expect a somewhat higher degree of false positive diagnosis because screening instruments have high sensitivity. Compared with Cooper et al., it may be that the P-AID has high sensitivity for depression and agoraphobia. The rate of depression and agoraphobia in Cooper et al. is lower than what is found in the general population, whereas the findings in the present study are equal to that of the general population. This may indicate underestimation in some of the disorders in Cooper et al. Another possible explanation for the discrepancy between the present study and Cooper et al. is that fewer people with mild ID were included in the present study. Most likely, the people not included in the present study have fewer mental disorders, which may lead to an overestimation in the present study.

Taken together, the prevalence rates found in the present study and the Cooper et al., we suggest that the overall prevalence of mental ill-health in adults with administratively defined ID is between 35% and 45% when DC-LD diagnostic criteria is employed. Excluding problem behavior from these figures, we suggest the rate of mental disorders to be between 30% and 40%.

**Problem behavior:** The overall rate of problem behavior in the present study was 20%. This finding is in accordance with Jones et al. (2008) and Cooper et al. (2007), both studies employing DC-LD diagnosis of problem behavior. Several studies has found rates between 10% and 15% in studies of challenging behavior (Emerson, et al.,

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2001; Holden & Gitlesen, 2006) that use the Challenging Behavior Survey (Alborz, Emerson, Kiernan, & Quershi, 1994). Further studies are needed to clarify the relationship between DC-LD defined ‘problem behaviors’ and the commonly used ‘challenging behaviors’.

#### **4.2.4 Factors associated with mental disorders and problem behavior**

The factors age and negative life events which are typically associated with mental disorders in the general population, were also associated with symptoms of mental disorders in the present study of adults with ID. No relationship with gender was found in the present sample. This was somewhat unexpected as gender differences have been noted in the general population (APA, 2000) and that an association, albeit weak, has been found between gender and mental ill-health in adults with intellectual disability (Cooper, et al., 2007). In line with findings in epidemiological studies of the general population, higher age was related to more symptoms of dementia (Roth, Tomlinson, & Blessed, 1966). Also, in accordance with previous findings, lower age was associated with more problem behavior (Emerson & Bromley, 1995; Holden & Gitlesen, 2006). Autism was related to psychosis, anxiety, OCD and problem behavior. An association between autism and problem behavior has been reported (McClintock, Hall, & Oliver, 2003). A relationship can be expected as autism shares some features with OCD, e.g. ritualistic and repetitive behavior (Cullen, et al., 2008), and psychosis, e.g. lack of social interaction.

The finding that Down’s syndrome was related to higher levels of dementia symptoms is consistent with other findings (Lott & Head, 2001; Temple, et al., 2001). In accordance with findings from the general population, we also found that more exposure to negative life events was associated with symptoms of mental disorders. Studies based on general population samples have found that negative life events are associated with later dementia (Charles, Bouby-Serieys, Thomas, & Clement, 2006), increase the risk for relapse of bipolar disorder (Aronson & Shukla, 1987) and are a risk factor for developing depression. It has also been found that negative life events may trigger acute and transient psychosis (Chakraborty, Chatterjee, Choudhary, Singh,

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& Chakraborty, 2007). Although the relationship between negative life events and specific mental disorders has been found in several studies with different research designs, it is still not possible to draw conclusions about causality as mental disorders may increase the possibility of encountering negative life events.

Lower score on The Coherence of the Social Care Scale was associated with more symptoms in four disorders: dementia, psychosis, depression and mania. Contrary to the more unpredictable nature of negative life event exposure, the items covered in the Coherence Scale may easily be approached prior to onset of a mental disorder. Thus, the aspects covered by the scale may be targeted in prevention programs for adults with ID living in community settings.

#### **4.2.5 Relationship between level of ID and mental disorders and problem behavior**

In the present study, associations between level of ID and symptoms of several mental disorders were found after controlling for relevant factors associated with ID.

Relationship with level of ID was found in the following six mental disorders in addition to the composite mental disorder index: dementia, psychosis, depression, anxiety, OCD and problem behavior. The structure of the association was linear only in psychosis, whereas it had both a linear and a curvilinear term in the analysis of problem behavior. In the other disorders, a linear association was found only after the relationship was controlled for curve-linearity. This indicates the presence of a suppression effect, in which the curve-linear term of ID increases the predictive validity of the linear term of ID (MacKinnon, Krull, & Lockwood, 2000). In adults with profound ID there was a clear tendency towards lower number of symptoms in all disorders except problem behavior. The symptom level peaked between severe ID and moderate ID in all disorders except for psychosis.

**Dementia:** In a recent study of dementia in older people (60+ years) with ID, Strydom et al. (2009) found that although people with ID showed higher rates of dementia than people without ID, no differences in prevalence of dementia were found with regard to level of ID within the ID-group although there was a clear tendency for lower rates in

people with severe ID. As the sample in Strydom et al. (2009) is older people, comparing the present study with that study is not without problems. There is higher mortality in people with lower levels of ID, and that the people with severe ID in Strydom et al. have survived into older ages, we can assume that they perhaps have particular advantages. Further, it is not completely clear what defines the three levels of ID in the study, that is, if people with profound ID are excluded from the sample or collapsed with severe ID.

**Psychosis:** The findings in Paper III showing that symptoms of psychosis decrease linearly with decreasing intellectual ability is in accordance with recent findings in two other Norwegian studies (Holden & Gitlesen, 2004; Myrbakk & von Tetzchner, 2008a). However, no differences between ID-levels were found in Cooper et al. (Cooper, et al., 2007), although the findings tended towards an inverse relationship between ID and rate of psychosis. In a review of findings on the relationship between IQ and schizophrenia in non-ID populations, Woodberry et al. (2008) found that schizophrenia was associated with lower premorbid IQ. To our knowledge, no studies of IQ and psychosis have sampled the whole range of IQ; it is not clear if these findings contrast each other or reflect a curvilinear relationship with a peak of symptoms at a higher level of intellectual functioning (e.g. borderline ID).

**Affective disorders:** Previous findings on the relationship between level of ID and depression are conflicting, and inclusion biases induced by small and restricted samples and different assessment methods (e.g. Mini PAS-ADD versus RSMB) may explain some of the divergent findings. The findings in the present study that the relationship between level of ID and depression may be curvilinear add to the explanation as to why previous findings are conflicting. In this regard, we note that Cooper et al. (2007) reported higher odds ratio values in adults with moderate ID and severe ID compared to mild ID. A curvilinear relationship was, however, not analyzed in that study. Regarding mania or bipolar disorder, similar findings as in the present study have been reported (Cooper & Bailey, 2001; Holden & Gitlesen, 2004; Myrbakk & von Tetzchner, 2008a).

**Anxiety and OCD:** A significantly higher rate of anxiety symptoms was found in adults with moderate ID compared to those with severe ID and profound ID in Holden and Gitlesen (2004). Myrbakk and von Tetzchner (2008a), using the same diagnostic instrument, did not find any difference between the collapsed groups mild/moderate ID and severe/profound ID with regard to anxiety. The use of collapsed ID categories may explain the result in the latter study. Collapsing categories tends to increase the within group variance and reduces the possibility of identifying between group differences. This is in line with the findings in the present study that symptoms of anxiety peaked at severe ID and that adults with profound ID showed markedly lower frequency of symptoms than did people with severe ID and moderate ID. In accordance with the present study, none of the two previous studies found any relationship between level of ID and OCD.

**Problem behavior:** In the present study, both a linear and a curvilinear relationship between level of ID and problem behavior was found, with a peak of symptoms in people with severe ID. The linear relationship of problem behavior increase when there is a level of functioning decrease has been reported in several other studies (Cooper & Bailey, 2001; Deb, Thomas, & Bright, 2001b; Holden & Gitlesen, 2006; Jones, et al., 2008). Regarding the curvilinear relationship found in the present study, none of the studies above analyzed the curvilinearity of level of ID and problem behavior. Further, both Cooper and Bailey (2001) and Deb et al. (2001b) used collapsed ID categories, making it impossible to consider possible curvilinearity. There are, however, some indications of curvilinearity both in Holden and Gitlesen (2006) and Jones et al. (2008). There is need for more studies on the relationship between level of ID and problem behavior. Future studies should focus on specific types of problem behavior in all levels of ID and use statistical models that allow for the assessment of effects caused by the presence of confounding factors such as neurological conditions and co-morbid autism.

## 5. METHODOLOGICAL CONSIDERATIONS

### 5.1 Representativity of sample

The sample comprised adults with administratively defined intellectual disability, which means people reported to the Norwegian Health authorities (Helsedirektoratet) with a diagnosis of ID and who receive a certain amount of social services from the community care system. The registry has been criticized for the lack of comprehensible criteria for the ID diagnosis and at what professional level the person is who makes the diagnosis (e.g. specialist in psychology or psychiatry). From 2004, the ICD-10 diagnostic criteria for ID are to be employed as the basis for the diagnosis. According to figures from Norwegian Health authorities (Helsedirektoratet), the number of individuals registered with ID represent about 0.45% of the Norwegian population in all age groups. People 16 years or older comprise about 75% of the total number. As the number of people reported to health authorities is the base for the government's financial support to the municipality, it may be that some of the people reported to the registry do not fulfill the diagnostic criteria for ID. It cannot be completely ruled out that some of these people are enrolled to this project. This is unlikely, however, as it was explicitly stated to the contact people in each municipality that the person should have a diagnosis of ID. In our sample, adults with mild ID are not expected to be fully represented because the condition is assumed to be under-diagnosed and most people in this group often do not receive a sufficient amount of community services to be included in the present sample. As use of direct staff services were required to be included in the present study, some people with mild ID may not have been included in the study even though they qualify for the label 'administratively defined ID'. These people are most likely to have less symptoms of mental ill-health than people with mild ID included in the present study. This may have resulted in an overestimation of prevalence in Paper II. Including these people could have strengthened the curve-linear relationship between level of ID and symptoms of mental disorders found in Paper III. The sample is regarded as representative for these intellectual levels because most people with moderate to

profound ID receive a minimum of health and/or social services.

## 5.2 Quality of measures

### 5.2.1 The use of informants

The use of informant measure of symptoms of mental health may reduce the validity of the measure. In many cases, however, the use of third-party informants (e.g. staff members or parents) are inevitable in the screening or assessment of symptoms of mental disorders in people with ID and other groups in which the ability of the person to communicate her/his own symptoms is limited (e.g. dementia). Thus, we argue that the ratings of operationalized diagnostic criteria by informants with first-hand knowledge of the people with ID in the present study are acceptable.

### 5.2.2 Measure of ID-level

The measure used to assess level of ID was found to have substantial inter-rater reliability. Indication of its validity was also provided. The validity of the scale, should, however, be regarded as preliminary; it has not been tested against the gold standard diagnosis of a trained professional employing standard intelligence test, test of adaptive behavior and clinical judgment (AAMR, 2002). No biases in the rating of ID-level are apparent, with the possible exception that ratings tend to cluster around the center of a scale.

### 5.2.3 Psychopathology checklists (P-AID)

The 18 checklists of the P-AID have a total of 280 items. This makes the instrument lengthy for a screening instrument. The high alpha values in several checklists in P-AID may indicate unnecessary duplications of content across items. At present, however, the knowledge of how mental disorders present in people with intellectual disability is still limited, and it is not clear whether the presentation of such disorders is identical across different severities of intellectual disability. This is particularly important for checklists screening for symptoms and generating DC-LD diagnoses, as DC-LD is developed for use with all severities of intellectual disability.

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Investigation of convergent and divergent validity of the P-AID is difficult for several reasons. As the convergent and divergent validity of the most used screening instruments available are limited for specific disorders and that the P-AID was designed for screening mental disorders in more detail, comparison with other instrument may give little information. In the lack of a ‘gold standard’ measure, analysis of criterion validity is difficult. Typically, screening instruments are developed from more complex measures that are longer or more expensive to administer. It may be that adequate measures of criterion validity are possible only when a comprehensive standardized clinical interview that incorporates adaptations to the standard manual are available as, for instance, in the DC-LD.

#### **5.2.4 Life event checklist (L-AID)**

Although some of the items showed only moderate inter-rater reliability, the overall inter-rater reliability was sound. In the present study only negative life events ratings have been employed in the analysis. The interpretation of the exposure in terms of being negative or positive for the person with ID was carried out by a third person. Obviously, the personal experience of the life event as negative or positive is not known to a third person unless the exposed person communicates this to others. In cases with poor communication as in the person with lower levels of ID, staff must interpret changes to overt behavior of the person and then relate this to the exposure. This may in part explain why some inter-rater reliability estimates at the item level were only moderate. We expect that information about major happenings regarding a people with ID in a community service program is somehow available to the most central staff members and, thus, also the informants in this study. There is a chance, however, that some episodes are not reported by other staff members and as such unknown to our informants. Staff meetings in group homes may be used to discuss past exposure that can explain abnormal behavior of people with ID. This type of recall bias may overestimate the report of prior exposures. In contrast to the Life Event Checklist in the Mini PAS-ADD, the L-AID distinguishes between possible negative and positive life events.

To our knowledge, this is the first report of inter-rater reliability of a negative life event checklist adapted for adults with ID. Although most of the items showed substantial inter-rater reliability, more work is needed to increase the inter-rater reliability of items with lower reliability and to include alternatives to the items that did not show significant reliability in the present study. Still, the replication of previous findings that life events are associated with mental ill-health is strengthened with the use of more rigorous method in the present study.

### **5.2.5 Coherence of social care (C-AID)**

The internal consistency of the items was acceptable. Inter-rater reliability of individual items showed three items with moderate reliability and two with poor reliability. Inter-rater reliability of the total scale was poor. The poor inter-rater reliability of the scale implies that the findings regarding associations between the predictor and mental disorders in this study should be interpreted with caution.

## **5.3 Categorical versus dimensional classification of mental disorders**

Typically, psychopathology is classified categorically, e.g. ICD-10 and DSM-IV; based on a set of criteria defining the presence or absence of a diagnosis (Franklin, Strong, & Greene, 2002). Using this approach, a disorder is either present or absent. The main disadvantages with categorical classification systems are that they propose that a diagnosis represents a distinct clinical entity, whereas diagnostic co-morbidity (co-occurrence of distinct disorders) seems to be the norm rather than the exception (Brown, Campbell, Lehman, Grisham, & Mancill, 2001). This has instigated discussions about the boundary between categories (Widiger & Samuel, 2005). Both issues indicating the existents of shared dimensions rather than distinct entities between disorders (Widiger & Samuel, 2005). A dimensional classification model addresses co-morbidity and boundaries generated by the existing diagnostic categories. For this reason, and because it takes into account more of the variation in human behavior than what is possible with classifications based on categorical systems, a

dimensional model of classification has been suggested as a more valid description of psychopathology. Considering the difficulties associated with diagnosing mental disorders in adults with ID, study designs relying on a dimensional classification may obtain more valid results than designs relying on categorical diagnosis.

In the present study, both categorical and dimensional classification of mental disorders were employed. In paper I, the inter-rater reliability was calculated using the sum score of items in each checklist. However, kappa analysis with and without prevalence adjustments were also conducted. Inter-rater reliability was only slightly affected by the classification model employed in the present study, with a small advantage for the categorical approach when comparing the prevalence adjusted kappa (PAK) with the ICC values. In Paper II, categorical classification of mental disorders was employed. As discussed above, the final step in the algorithms resulted in a significant reduction of the prevalence and co-morbidity in several disorders. It is, however, not possible to say whether the algorithms resulted in any under or overestimation of the prevalence figures as the algorithms are not yet validated against 'gold standard' diagnosis. For this reason, checklist composite scores were used for the analysis of associations between study variables and specific mental disorders in Paper III.

## 5.4 Response bias

A response rate lower than 80% tends to reduce the validity of survey findings (Prince, Stewart, Ford, & Hotopf, 2003) as non-responders are likely to differ from responders in many ways (Fischer, Dornelas, & Goethe, 2001). In our data, no information about those who refused to participate is available. Thus, we cannot rule out the possibility that the generalizability of the findings is somewhat limited. It may, for instance, be that informants working with people with more mental and behavioral problems were more prone to participate than others. In that case, the findings in the present study would be an overestimation of the population prevalence. However, there are several other possible reasons for not participating in the study that do not reflect a response bias such as administrative decisions to not participate at the group home level, no

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staff at the group home level filled the informant inclusion criteria, or the informants did not have time to fill the questionnaire.

## 5.5 Using collapsed categories

In order to study the characteristics of rare disorders with a reasonable degree of precision in cross-sectional survey design, a large sample is needed. In the present study, some disorders (e.g. profound ID, panic anxiety and mania) were found to have very low prevalence rates. One way of dealing with the low prevalence of single disorders is to collapse two or more disorders into one larger category. Collapsing categories, however, may reduce the validity of the category. Thus it is important that the variables collapsed share important features. Anxiety disorders may, for instance, successfully be collapsed as they share the central feature of presence of distinct autonomic reactions in specific situations. In Paper I, profound ID and severe ID were collapsed into the category lower ID-levels and moderate and mild ID were collapsed into the category milder ID-levels to obtain a larger number of cases (N). This increases the probability of identifying differences between ID-levels when using Cohen's kappa. In Paper II, depression, mania and bipolar disorder were collapsed into a single category of any affective disorder and the five anxiety disorders agoraphobia; social phobia; specific phobia; generalized anxiety and panic anxiety were collapsed into a single category of any anxiety disorders. This increases the probability of identifying differences between study variables and symptoms of mental disorders, e.g. genetic syndrome and anxiety disorders using, e.g. binary logistic regression (Paper II). Findings in Paper III question the practice of collapsing profound ID and severe ID into a lower ID category as differences in symptom levels were found between severe ID and profound ID in most disorders in Paper III. The differences found between profound ID and severe ID in Paper III would have been masked if the two categories were collapsed. To be able to describe the less frequent disorders in more detail one might have to use clinical samples.

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## 6. CONCLUSION AND DIRECTON FOR RESEARCH

### 6.1 Conclusion

Compared to other available instruments the screen for symptoms of mental disorders in adults with ID, the P-AID was shown to have equal or stronger reliability. The reliability of the P-AID checklists was acceptable on a more detailed diagnostic and symptomatic level. The reliability was lower in people in the lower ID-range compared with those with milder levels of ID. Problem behavior was found to be an independent construct, supporting the use of separate classification of problem behavior in the DC-LD hierarchy. The construct validity of the P-AID is strong. The finding in Paper III that several predictive factors for mental disorders in the general population were found to be associated with mental disorder in adults with ID indicates an acceptable concurrent validity of the instrument.

In our sample, 43% showed indices of either a mental disorder or problem behavior, whereas 35% of the sample showed indices of mental disorders. Taken together with the prevalence estimate of another recent study using DC-LD diagnostic criteria this suggests that a reasonable estimate of the true prevalence of mental disorders is between 35% and 45% when problem behavior is included. As in the general population, anxiety (16%) and depression (12%) were the most common disorders in adults with ID. This suggests that mental disorders are more common in adults with ID compared with adults in the general population, but that the pattern of the most common mental disorders is similar for the two groups. Analysis of co-morbid disorders showed that 22% of the sample had one mental disorder or a problem behavior diagnosis, 10% had two diagnoses and 12% had three or more diagnoses. It is concluded that people with ID have similar burden of co-morbidity as other people with lifelong conditions of mental disorders, for example, schizophrenia.

Level of ID was found to have an independent contribution to the explained variance in symptoms of metal disorders and should consequently be included in future studies of psychopathology models in adults with ID. Level of ID was both linearly and curve-

linearly related to symptoms of mental disorders investigated. Symptom levels of mental disorders tended to peak in severe and moderate ID in most disorders. Although some indication of curve-linear relationship between mental disorders or problem behavior has been found in the reviewed literature, this is the first report where these relationships are directly investigated. The result of this investigation therefore presents new knowledge. In addition, that lower coherence of social care was related to increasing symptoms of dementia, psychosis, depression and mania is also a new finding.

## 6.2 Implication

The psychometric properties of the P-AID support the use of P-AID as a screening instrument in psychiatric epidemiological research in adults with ID. Mental disorders have often been mistakenly interpreted as learned problem behavior. Thus, assessment strategies and diagnostic tools that help to sort between symptoms of mental disorders and problem behavior are needed. In the present study, problem behavior was shown to be an independent entity, which may imply that the P-AID can be particularly helpful in the initial clinical assessment of mental health disorders in adults with ID and can be used as a screening tool in other health services such as habilitation services for referral to specialist mental health services.

The high prevalence figures and co-morbidity of mental disorders found in the present study indicates that adults with ID are in more need of specialist mental health services than people in the general population. As specialist mental health services lack quality, availability and competence when it comes to people with ID, more focus on mental health services for adults with ID is clearly needed. The high symptom level identified in adults with severe and moderate ID suggests that assessment and treatment of mental disorders should be targeted for these ID-levels. Assessment of level of ID should be part of comprehensive clinical assessment of mental disorders and problem behavior in adults with ID.

The items that comprise the Coherence of Care Scale may easily be worked on prior to onset of a mental disorder. Thus the aspects covered by the scale may be used to target this in prevention programs for adults with ID living in community settings. Two cautionary notes should be mentioned though: firstly, more work on the scale is needed to improve its inter-rater reliability. Secondly, the observed relationships indicating that better coherence is related to fewer symptoms may indicate that it is difficult to establish and maintain service quality for patients with more pervasive and severe symptoms.

Although the present study has participants who are relatively young (as young as 18 years of age), it is not clear if the findings can be generalized to younger people. There are two main reasons for this: Firstly, the diagnostic criteria employed in the present study are developed for use with adults and not children or adolescents with ID. Secondly, level of ID is assumed to be less fixed in children with ID compared with adults. Level of ID may thus be differentially related to symptoms of mental disorders, or less apparent in children than in adults.

### 6.3 Direction for research

More work is needed on the sampling of symptoms of mental disorders in people with lower levels of ID to improve the reliability of the measures. This is important as low reliability increases the probability of unsubstantial differences between studies and limits the validity of the measure. There is also a current need for a ‘gold standard’ diagnostic assessment procedure for mental disorders in this group.

There is a possibility that disorders currently undetected in people with profound ID exist. Perhaps there is a need for selective validation of symptoms of mental disorders in this group, for instance, by weighting particular symptoms or improving the specificity of the behavior to be observed. It may, however, be that the possibility of reliable and valid detection of mental disorders in adults with profound ID is dependent on the detection of biological markers for specific disorders. For this

reason, research on biological markers of mental disorders should also include people with ID, and lower levels of ID in particular.

Clearly, longitudinal prospective studies on the relationship between factors associated with mental disorders are needed. We suggest an exploratory approach to this, as several factors that predict mental disorders may not have been discovered yet in adults with ID. More research on the possible triggering effect of psychosocial phenomena, such as experiencing negative life events or living in social conditions with low sense of coherence, may be particularly relevant for interventions for the prevention of mental disorders. More research is also needed to gain insight into the nature of the relationship between intellectual ability and mental disorders in general. Assessing people with borderline intellectual disabilities may be of particular relevance in future studies on this issue. One may, for instance, speculate that a curve-linear relationship may be found in psychosis disorder if the whole range of intellectual ability is sampled.

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## 7. Appendix I

### Psykopatologisjekklister for voksne med utviklingshemning

# :P-AID

Psychopathology Checklists for Adults with Intellectual Disability

Kjønn	_____
	Kvinne <input type="checkbox"/> Mann <input type="checkbox"/>
Alder	_____ år
Navn på informant	_____
Informantens utdanning	_____
Hvor lenge har informant kjent bruker	_____
Dato for utfylling	_____



## 9. Appendix III

### Sammenheng i sosiale tjenester for voksne med utviklingshemning

#### INSTRUKSJON

Nedenfor er det listet opp ulike utsagn om tjenestetilbud til utviklingshemmede. Jeg vil at du skal vurdere om utsagnene stemmer eller ikke på en skala fra 1 til 4. Du skal vurdere hvordan utsagnene stemmer for de siste 6 måneder for ditt arbeidssted.

	1	2	3	4
	Passer dårlig	Passer delvis	Passer Ganske godt	Passer godt
<b>I hvilken grad mener du følgende utsagn er beskrivende for tjenestetilbudet som har vært gitt de siste 6 måneder?</b>	<b>1</b>	<b>2</b>	<b>3</b>	<b>4</b>
1. Tjenestetilbudet er utformet i samarbeid med bruker/pårørende og personalet. Dette gjelder hvilke aktiviteter tjenesten skal inneholde, hvordan personalet skal gi hjelp, hvordan personalet skal motivere, korrigere m.m	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
2. Pårørende er tilfreds med det tjenestetilbudet som gis	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
3. Det er samsvar mellom klientens behov og personalets praksis	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
4. Personalgruppen er enig om hvilke praktiske regler/gjennomføring som skal gjelde for den daglige samhandling med bruker	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
5. Personalet arbeider på samme måte med klienten	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

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## Errata

### Paper I

- Table 2, last row: replace 6 with 5 in column 'Items'
- Page 472, line 1: Replace the sentence "In line with DC-LD, at least one positive item from each of the clusters was required to make a diagnosis of anxiety" with the following: "One or more positive items from each of the two cluster were required to make a diagnosis of social phobia and generalized anxiety. One positive item from cluster one and two from cluster two were required to make a diagnosis of agora phobia and specific phobia. All three items from cluster one, and two items from cluster two were required to make a diagnosis of panic anxiety "

### Paper II

- Page 228, last sentence: Replace "Higher prevalence of overall mental ill-health was found in the present study compared with Cooper et al., even when problem behavior and specific phobia." with "Higher prevalence of overall mental ill-health was found in the present study compared with Cooper et al., even when problem behavior and specific phobia were excluded."
- Table 4. Remove asterisk in row 4, column 2, 4, 6, 8, 10 and 12; Row 5, column 2, 4, 6 and 12; row, 7, column 2, 4, 6, and 12; row 8, column 4, 6 and 12; row 9, column 12. Row 5, column 8: Replace "6.51\*\*" with "6.51\*"; Row 5, column 10: Replace "1.65\*\*" with "1.65\*"; Row 7, column 10: Replace ".40\*\*" with ".40\*"; Row 8, column 2: Replace "1.82\*\*" with "1.82\*"; Row 8, column 8: Replace "3.03\*\*" with "3.03\*"; Row 8, column 10: Replace "1.58\*\*" with "1.58\*"; Row 9, column 4: Replace "2.21\*" with "2.21\*"
- Table 5, Row 11, column 4: Replace "2.5" with "2.5\*"