

**A Study of Behaviour Problems and Psychiatric
Disorders among People with Intellectual Disability.**

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Abstract

The present thesis investigates behaviour problems and their relationship to psychiatric disorders in people with intellectual disability living in the northern part of Norway, as well as the concordances between four of the most commonly used assessment instruments for psychiatric disorders in people with intellectual disability. A total of one hundred and eighty-one individuals with intellectual disability living in the counties of Nordland, Troms and Finnmark participated in the studies.

Four checklists for psychiatric disorders in people with intellectual disability were used: the Reiss Screen, the Mini Psychiatric Assessment Schedule for Adults with Developmental Disability, Mini PAS-ADD, the Diagnostic Assessment for the Severely Handicapped-II, DASH-II, and the Assessment of Dual Diagnosis, ADD. The Aberrant Behavior Checklist was used to assess behaviour problems, Vineland Adaptive Behavior Scales was used to measure adaptive functioning and Leiter International Performance Scale, Wechsler Intelligence Scale for Children-Revised-III or Wechsler Adult Intelligence Scale-III were used to assess cognitive functioning. A checklist developed for the project was used to assess service needs.

Behaviours rated as problems by family and care staff was common in the individuals with administratively defined intellectual disability. Twenty percent of the participants were reported to have severe behaviour problems and this corresponded to a prevalence rate of 63.6 people per 100 000 people in the general population when calculated relative to the corresponding age group in the general population. On the average, people showing challenging behaviour had seven behaviours rated as severe problems. People with severe behaviour problems were less likely to have friends and were perceived to be significantly less satisfied with their life-situation than people without severe behaviour problems.

The participants with moderate and severe behaviour problems showed significantly more symptoms of psychiatric disorders than those without such problems, and the majority of the participants with behaviour problems had symptoms of the main psychiatric disorders. The participants with mild and moderate intellectual disability showed more symptoms of psychosis and depression than the participants with severe and profound intellectual disability. There were no direct associations between individual behaviour problems and psychiatric disorders, but the group with mild/moderate intellectual disability showed a somewhat different pattern of associations than the group with severe/profound intellectual disability. Depression was associated with screaming and aggression in the participants with severe and profound intellectual disability, and with self-injury in the participants with mild and moderate intellectual disability.

On the four checklists for psychiatric disorders used in the project, the correlations between the participants' sum scores were moderate to high, suggesting that the checklists give fairly similar indications of the psychiatric health status of the

participants. The concordances between individual corresponding scales, however, were lower, suggesting that these scales do not measure the same underlying problems.

The results indicate that psychiatric disorders are prevalent among people with behaviour problems. The evaluations of the assessment instruments suggest that the four assessment instruments used in the present project may be useful for identifying such disorders in people with intellectual disability, but the checklists seemed to be most useful as general indicators of psychiatric disorders and of less value for specifying the nature of the disorders.

List of papers

Paper I

Myrbakk, E and von Tetzchner, S. (Submitted) The prevalence of behaviour problems among people with intellectual disability living in community settings.

Paper II

Myrbakk, E. and von Tetzchner, S. (2007) Psychiatric disorders and behavior problems among people with intellectual disability. *Research in Developmental Disabilities*, doi:10.1016/j.ridd.2007.06.002

Paper III

Myrbakk, E. and von Tetzchner, S. (2008) Screening individuals with intellectual disability for psychiatric disorders: Comparison of four measures. *American Journal on Mental Retardation*, 113, 54-70.

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Introduction

In most western countries processes of deinstitutionalisation of care for people with intellectual disability are in progress. With the Act of June 10, 1988, the responsibility for services for all people with intellectual disability in Norway was decentralised from the counties to the municipalities and the large residential institutions were closed down. The municipalities now have the basic responsibility for care and services for all people with intellectual disability, including those with severe behaviour problems.

The main objective of the deinstitutionalization reform in Norway was to improve and normalize the living conditions for people with intellectual disability and to enhance their quality of life. However, the services for the group with severe behaviour problems and psychiatric disorders have not been well functioning in Norway. An evaluation of the services for this group (Statens helsetilsyn, 2000) revealed inadequate services both in the municipalities and in the specialist health care systems. Major shortcomings related to all aspects of the psychiatric health services were reported (Statens helsetilsyn, 2000, p. 32). Similar findings are reported in other countries. In Sweden, Gustafsson (1997) found that the psychiatric care utilization was not in proportion to the estimated need for psychiatric treatment and care. Related to the situation in the UK, Moss, Bouras and Holt (2000) concluded that "... At present, services have reached a crisis point which is characterized by unclear policies, inter-agency disagreements, and limited service responses with unpredictable consequences for the quality of life of users, their families and carers" (p. 105). Research comparing the situation before and after deinstitutionalization in Norway has found that behaviour problems increased after deinstitutionalization (Nøttestad, Strømngren & Linaker, 2000) and that psychiatric problems remained frequent (Nøttestad and Linaker, 1999).

The issues of quality of life for people with disabilities and the right to participation in community are addressed in the United Nation's Convention on the Rights of Persons with Disabilities (United Nations, 2007). The purpose of the Convention, as described in Article 1, is "...to promote, protect and ensure the full and equal enjoyment of all human rights and fundamental freedoms by all persons with disabilities, and to promote respect for their inherent dignity. Persons with disabilities include those who have long-term physical, mental, intellectual or sensory impairments which in interaction with various barriers may hinder their full and effective participation in society on an equal basis with others". The policies related to medical, psychological and social services for people with intellectual disabilities in the states ratifying the Convention on the Rights of Persons with Disabilities have to address the issue of full participation in the community on an equal basis with others. According to the principles of the Convention, societal integration constitutes the framework for all measures related to individuals with intellectual disability, including individuals with intellectual disability who have behaviour problems. Norway signed this Convention in April 2007.

Individuals with severe behaviour problems may be excessively controlled by others, and both the physical and the social environment may be restricted as a consequence of the behaviours (Emerson, 2001; von Tetzchner, 2003). Behaviour problems may thus be a major obstacle for participation in the community and for a normalized living. Studies have found that people with behaviour problems are likely to be placed out of home earlier than individuals without behaviour problems (Sherman, 1988), and readmission to residential institutions have been a consequence of behaviour problems (Sutter *et al.*, 1980).

In recent years there has been a growing interest in the relation between behaviour problems and psychiatric disorders (Rojahn *et al.* 2004; Moss, Emerson, Kiernan, Turner, Hatton & Alborz, 2000). However, there are few studies which have addressed this issue, and to provide a better life situation in the community for people with behaviour problems more knowledge on the relations between behaviour problems and psychiatric disorders is needed.

Disability

The World Health Organization (WHO) is part of the United Nations and works primarily with health related issues. On their website, the WHO refers to two major conceptual models for disability (World Health Organization, 2007). The first model, called the medical model, interprets disability as an illness or impairment in the individual's body or mind and the second model, called the social model, views disability as a social construct that primarily is analysed in terms of the socio-economic, cultural and political disadvantages resulting from the individual's exclusion by society. According to the World Health Organization, the medical model views disability as a feature of the person, directly caused by disease, trauma or other health conditions, which requires medical care provided in the form of individual treatment by professionals. Disability, on this model, calls for medical or other treatment or intervention to "correct" the problem with the individual. The social model of disability, on the other hand, sees disability as a socially-created problem and not as an attribute of an individual. On the social model, disability demands a political response, since the problem is created by the social environment. Both the medical and the social model are partially valid, according to World Health Organization, but neither model is adequate on their own. Disability is a complex phenomenon that is both a problem at the level of the person, and a complex and primarily social phenomena. Disability is always an interaction between conditions related to the person and conditions related to the environment in which the person lives. According to the World Health Organization, a model of disability should include both the medical and social conditions, without making the mistake each makes in reducing the whole, complex

notion of disability to one of its aspects. The comprehensive model for disability recommended by the World Health Organization is termed the biopsychosocial model

The World Health Organization has developed a classification system for description of health conditions based on the principles of the biopsychosocial model, and this system is called the International Classification of Functioning, Disability and Health, ICF (World Health Organization, 2007). Disability is used as an umbrella term for impairments, activity limitations and participation restrictions in this classification system. According to the model for disability commended by the World Health Organization, the health conditions are extremely poor for people with intellectual disability who in addition to their cognitive impairment have activity limitations and participations restrictions due to behaviour problems. Thus, the medical, psychological and social aspects of severe behaviour problems among people with intellectual disability constitute multifaceted challenges for families, health-services and society.

Intellectual disability

People with intellectual disability have historically been a group that has been looked down upon, and the terms used to refer to this group have varied considerably over the years (Turnbull *et al.*, 2002). To avoid devaluating language and stigmatizing connotations the terms for referral to this group have often been changed. The use of the term “intellectual disability” has lately been more common in the literature and is now often used to refer to people with significantly reduced cognitive functions. The term “intellectual disability” will be used in the present thesis and it is used synonymously to terms like “mental deficiency”, “mental handicap”, “learning disability” and “mental retardation”. What is considered as neutral and respectful language is cultural dependant. At the present, the terms intellectual disability or learning disability is preferred by many in the UK while mental retardation is frequently used in the USA. However, terms are rapidly changing and the American Association on Mental Retardation (AAMR) on January 1, 2007 officially changed their name to the American Association on Intellectual and Developmental Disabilities (AAIDD) to avoid the negative connotations of the term mental retardation.

Intellectual disability in the ICD and DSM diagnostic systems

The International Statistical Classification of Diseases and Related Health Problems, tenth revision, ICD-10 (World Health Organization, 1992), is the diagnostic system used in Norway. The ICD-10 is a classification system for diseases and complements the World Health Organisation’s ICF-system of classifying functioning, disability and health. In the ICD-10 diagnostic system the term “mental retardation” is currently used, and this term is also used in the American Psychiatric Associations Diagnostic and Statistical Manual of Mental Disorders, DSM IV-TR (American Psychiatric Association, 2000). In both the ICD-10 and in the DSM IV-TR intellectual disability is

psychometrically defined with IQ-scores two standard deviations below the average for the age-group. The major characteristic of intellectual disability is intellectual functioning considerably below the average for the age group and developmental delays of social competencies, abilities to communicate and abilities to manage the activities of daily life. In the diagnostic guidelines in the ICD-10 Guide for Mental Retardation (World Health Organization, 1996) intellectual disability is presented as a condition of arrested or incomplete development of the mind, which is especially characterized by impairment of skills manifested during the developmental period, which contribute to the overall level of intelligence, i.e. cognitive, language, motor, and social abilities. Significant limitation in adaptive functioning is an essential feature for the diagnosis of intellectual disability both in the ICD-10 and in DSM IV-TR diagnostic guidelines.

<i>Diagnostic system</i>	<i>Category</i>	<i>Intellectual disability</i>	<i>IQ range</i>	<i>Mental age (years)</i>
<i>ICD</i>	<i>F70</i>	<i>Mild</i>	<i>50 to 69</i>	<i>9 to under 12</i>
<i>DSM</i>	<i>F70.9</i>	<i>Mild</i>	<i>50-55 to 70</i>	
<i>ICD</i>	<i>F71</i>	<i>Moderate</i>	<i>35 to 49</i>	<i>6 to under 9</i>
<i>DSM</i>	<i>F71.9</i>	<i>Moderate</i>	<i>35-40 to 50-55</i>	
<i>ICD</i>	<i>F72</i>	<i>Severe</i>	<i>20 to 34</i>	<i>3 to under 6</i>
<i>DSM</i>	<i>F72.9</i>	<i>Severe</i>	<i>20-25 to 35-40</i>	
<i>ICD</i>	<i>F73</i>	<i>Profound</i>	<i>Below 20</i>	<i>Less than 3</i>
<i>DSM</i>	<i>F73.9</i>	<i>Profound</i>	<i>Below 20 or 25</i>	

Table 1 Degrees of intellectual disability

According to the ICD-10 Diagnostic Criteria for Research (World Health Organization, 1993) detailed diagnostic criteria that can be used internationally for research is difficult to specify for intellectual disability. This is because manifestations of the two main components for mental retardation, namely low cognitive ability and diminished social competence, are profoundly affected by social and cultural influences. The ICD-10 Guide for Mental Retardation underlines that IQ levels are arbitrary divisions of a complex continuum and should not be applied rigidly in view of the problems of cross-cultural validity. However, both the ICD-10 and the DSM IV-TR specifies four levels of intellectual disability according to intelligence quotient (IQ). Additionally, the ICD-10 Diagnostic Criteria for Research specifies mental age. The span of age equivalents of cognitive abilities in people with intellectual disabilities varies from a few months up

to under twelve years of age so the span of cognitive capacities in this population is huge and the differences in cognitive capacities within the population with intellectual disability should not be underestimated.

Assuming that intelligence is normally distributed in the population, the psychometric definition of intellectual disability in the ICD-10 and the DSM IV-TR implies that about two percent of the total population may have an intellectual disability. About 85 percent of people with intellectual disability have mild intellectual disability, ten percent have moderate intellectual disability, three to four percent have severe and one to two percent have profound intellectual disability (American Psychiatric Association, 1995).

Administratively defined intellectual disability

Because of their service needs, some of those who have an intellectual disability are known by the administration in the municipalities they live in. Those who are known by the administrations in the municipalities constitute the group with so called “administrative” intellectual disability. Generally people with an administratively recognized intellectual disability are people with more severe intellectual disability as they are most likely to need special services and support because of their condition. Studies have reported different prevalence figures for administratively defined intellectual disability (e.g., Emerson *et al.* 2001b; Holden & Gitlesen, 2006), and the number of people receiving services may be closely associated with political and cultural factors.

A prevalence rate of administratively defined intellectual disability between 0.23 and 0.47 percent was found by Emerson and associates (2001b) and a prevalence rate of 0.48 percent was found by Holden and Gitlesen (2006). Compared to the estimated prevalence of intellectual disability of about two percent in the general population (American Psychiatric Association, 1995), the prevalence of administratively defined intellectual disability is lower. According to the American Psychiatric Association (1995), about 85 percent of people with intellectual disability have a mild disability. The proportion of mild intellectual disability is much lower in sample with administrative disability (Emerson *et al.* 2001b, Holden & Gitlesen, 2006) and people mild intellectual disability generally seem to be underrepresented in samples with administratively disability.

Behaviour problems among people with intellectual disability

When referring to behaviour problems among people with intellectual disability authors have used different terms like “problematic behaviours” (Moss, Emerson, Bouras &

Holland, 1997), “challenging behaviour” (Emerson, 2001), “problem behaviours” (Hemmings, Gravestock, Pickard & Bouras, 2006), “maladaptive behaviour” (Dawson, Matson & Cherry, 1998) and “behaviour disorders” (Cooper 1998, Carvill & Marston, 2002). The term “challenging behaviour” is now often used to describe behaviour problems, especially in the United Kingdom. Emerson (2001) defines it as “culturally abnormal behaviour(s) of such intensity, frequency or duration that the physical safety of the person or others is likely to be placed in serious jeopardy, or behaviour which is likely to seriously limit use, or result in the person being denied access to, ordinary community facilities” (Emerson 2001, p. 3). Challenging behaviours, as defined by Emerson (2001), are severe behaviour problems.

Studies have found that behaviour problems may be very persistent in people with intellectual disability. Reid and Ballinger (1995) studied the natural history and persistence of behaviour problems among 100 adults with severe and profound intellectual disability over a period of 17 years. They found that certain problems, such as stereotypies, eye avoidance and emotional withdrawal, were particularly persistent. A seven-year follow up of people showing severe self-injurious behaviour found similar persistence of behaviour problems (Emerson *et al.*, 2001a). Seventy-one percent of the participants still had severe self-injurious behaviour and the specific topographies of self-injury were extremely stable. At follow up, self-injury status was predicted with 76 percent accuracy by site of the injury (higher persistence for participants with head-directed self-injury), by the initial stability of the self-injurious behaviour, and by younger age. Thus, challenging behaviour seems to have long-lasting negative effects the life-situation for people with intellectual disability.

Prevalence of behaviour problems

Many studies have found a high prevalence of behaviour problems in people with intellectual disability (Emerson, 2001; von Tetzchner, 2003). Emerson and Bromley (1995) found that 33 people per 100 000 of the general population in a metropolitan borough in the north-west of England showed challenging behaviour. A somewhat higher prevalence rate was found in a study published by Emerson and associates in 2001 (2001b). In this study data collected in seven areas in 1988 and in two areas in 1995 were analysed. In the seven areas studied in 1988 they found a prevalence of challenging behaviour of 45.3 of per 100 000 base population and in the two areas studied in 1995 they found a prevalence of 58.5 per 100 000.

Joyce, Ditchfield and Harris (2001) examined the prevalence of severe behaviour problems among adults with intellectual disability residing in three boroughs in London, UK. They found that 448 people of a total population of 670 000 had severe behaviour problems, giving a total population prevalence of between 60 and 70 individuals per 100 000 base population. In Norway the services for people with severe behaviour problems were evaluated by the Board of Health (Statens helsetilsyn, 2000) in 1998 as part of the “Escalation Plan for Psychiatric Health 1999-2006” (Sosial- og helsedepartementet, 1998). A mean of 60 people per 100 000 population were reported

to have severe behaviour problems (Statens helsetilsyn, 2000). In their study of challenging behaviour in the county of Hedmark, Norway, Holden and Gitlesen (2006) found that 11.1 percent of people with intellectual disability showed challenging behaviour, corresponding to 48.4 people per 100 000 base population. In a study including children, young people and adults with intellectual disabilities in Wales, Lowe and associates (2007) found a prevalence of challenging behaviour of 45 per 100 000 total population.

Study	Prevalence of administratively defined intellectual disability	Prevalence of severe behavior problems per 100 000 base population
Emerson and Bromley, 1995	-	33
Emerson et al., 2001b*	0.27%	45.3
Emerson et al., 2001b#	0.47%	58.5
Joyce et al., 2001	-	60-70
Statens helsetilsyn, 2000.	-	60
Holden and Gitlesen, 2006	0.48%	48.4
Lowe et al., 2007	-	45

* average of seven areas in 1988, # average of two areas in 1995

Table 2 The prevalence of administratively defined intellectual disability and the prevalence of severe behavior problems found in different studies

The prevalence of severe behaviour problems found in different studies varies (table 2). The age distribution in the samples studied may explain some of the differences between the studies. For example, in the 1995 sample studied by Emerson and associates (2001b), sixty percent of the participants were between 12 and 35 years of age, while 24.7 percent of the sample studied by Holden and Gitlesen (2006) were aged between ten and 30 years. Nearly 36 percent were above 50 years. As severe behaviour problems seem to decrease with age (Emerson *et al.* 2001b; Holden & Gitlesen, 2006), the differences in age distribution in the samples may explain some of the differences.

In addition, very few studies have included individual assessment of intellectual disability. Variation in degree of cognitive impairment in samples may also explain variations in the prevalence of behaviour problems. Self-injurious behaviour, for example, is associated with more severe levels of intellectual disability (Emerson & Bromley, 1995) and is less prevalent in samples with mild intellectual disability.

Another source of variation is the methods used for calculating prevalence rates. The participants in the study by Joyce and associates (2001), for example, were

19 years or more whereas Emerson and associates (2001b) included children of five years or older. However, both studies reported prevalence rates relative to the total population living in the areas and not relative to the corresponding age group in the base population. Such differences in the methods of calculating and reporting prevalence rates may explain some of the variations in the reported prevalence rates. Calculation of prevalence rates relative to the corresponding age group in the general population will give more accurate estimates than prevalence rates relative to the total base population.

Types of behaviour problems

Various forms of behaviours have been reported to be serious behaviour problems for people with intellectual disability. Qureshi and Alborz (1992) found that physical attacks was the most serious problem for 23 percent of adults with behaviour problems, self-injury for 17 percent, destructiveness for 16 percent and other socially or sexually unacceptable behaviour was the most serious problem for 52 percent. In a study by Emerson and associates (2001b), aggression was reported for seven percent of people with administratively defined intellectual disability, destructive behaviour for four to five percent, self injury was reported for four percent and “other behaviour” was reported for nine to twelve percent. Among the behaviours included in the category “other behaviour” were non-compliance, temper tantrums, screaming, running away, over activity, stealing and inappropriate sexual behaviour. Lowe and associates (2007) found that aggression was reported for just over half of children and adults showing challenging behaviour and that severe self-injurious and destructive behaviour were reported for around one third. Lowe and associates also identified a substantial number of people who showed challenging behaviour at lower degrees of severity. Deb, Thomas and Bright (2001b) found that about one in four individuals with administrative intellectual disability showed aggression, self-injurious behaviour, over activity and screaming, about one in three showed temper tantrums and attention seeking behaviour, and twelve percent showed destructive behaviour. Collacot, Cooper, Branford and McCrother (1998) found that 1.7 percent of people with intellectual disability had severe and frequently occurring self-injury.

The behaviours which are seen as the most challenging are those which disrupt the environment in one way or another (Lowe *et al.*, 1995), and aggressiveness is often reported to be a severe problem (Crocker *et al.*, 2006; Holden & Gitlesen, 2006; Tyrer *et al.*, 2006). Holden and Gitlesen (2006) found that attacking others was a common problem among people with more demanding challenging behaviour and in Crocker and associates (2006) over 50 percent of adults with intellectual disability had displayed one form or another of aggressive behaviour in the past 12 months. One quarter of the participants displayed physical aggression and 4.9 percent displayed aggressive behaviour leading to injury in the victim. Tyrer and associates (2006) found that 14 percent were physically aggressive towards others. Behaviours that may lead to

injury of the person or others are extremely problematic to relate to for family and care-staff (Emerson, 2001).

Factors associated with behaviour problems

Studies have found that behaviour problems may be associated with level of intellectual disability (Emerson & Bromley, 1995), gender (Tyrer *et al.*, 2006), syndromes (Anderson & Ernst, 1994), life events (Owen *et al.* 2004) and psychiatric disorders (Hemmings, 2006).

According to Tyrer and associates (2006), physical aggression is most common among people with more severe intellectual disability and the more severe challenging behaviour is shown by people with more severe disabilities (Emerson & Bromley, 1995). Individuals with severe/profound degree of intellectual disability are more likely to show self-injury and stereotyping than individuals with mild/moderate intellectual disability (Mc Clintock, Hall & Oliver, 2003; Collacot, Cooper, Branford & McCrother, 1998). Some studies have found associations between behaviour problems and gender. Tyrer and associates (2006), for example, found that physical aggression was most common among men, Collacot and associates (1998), however, found no gender differences related to self-injurious behaviour.

Specific syndromes are associated with behaviour problems. Lesh-Nyhan syndrome is always associated with self-injurious behaviour (Anderson and Ernst, 1994) and people with Cornelia de Lange and Fragile-X syndrome have been found to show more self-injurious behaviour than others (Harris, 1992). Clarke and Boer (1998) studied behaviour problems among people with Prader-Willi, Smith-Magenis, and cri du chat syndromes, and found that the groups with these three disorders had more behaviour problems than comparison groups. They argued that the results lend support to a partial specificity model of behaviours associated with genetically determined syndromes. According to Clarke and Boer each syndrome seemed to be associated with a relative characteristic constellation of behaviour problems.

In a review on the association between self-injury and genetic syndromes Deb (1998) concludes that self-injurious behaviours are associated with some genetic syndromes but that the causal relationships remains unclear. Read (1998) has suggested that self-injurious behaviour is part of a clinical syndrome of violence and self-injury, an organic behaviour disorder, in people with more severe intellectual disability. According to Chadwick and associates (2000), factors affecting the risk of behaviour problems such as degree of neurological damage and the severity of basic skills deficits in people with intellectual disability seem to override the effects of risk factors which are operative in populations without intellectual disability.

Behaviour problems may also be related to situations or events that may be perceived as traumatic for the person involved. Owen and associates (2004) studied the relation between problem behaviours and traumatic events, and the participants in their study had typically been exposed to between three and four negative life events mainly relating to staffing and residence changes, conflict, family bereavements, illness or

injury. Those exposed to more recent life events were also rated as displaying more frequent aggressive/destructive behaviour. According to Owen and associates the results indicated that life events had a specific effect on aggressive/destructive behaviour, but underlines that the causal relations are unclear.

Psychiatric disorders in people with intellectual disability

There has been a growing interest in the relation between behaviour problems and psychiatric disorders in recent years (Moss, Emerson, Kiernan, Turner, Hatton & Alborz, 2000; Rojahn *et al.* 2004; Hemmings *et al.*, 2006). According to Reiss and Valenti-Hein (1994), people with behaviour problems do not necessarily show conventional signs of psychiatric disorders and not all people with intellectual disability and psychiatric disorders have behaviour problems. Behaviour problems should therefore generally be detached from psychiatric disorders but may be regarded as symptoms of psychiatric disorders when the problems fits in the pattern of symptoms that adds up to the diagnosis (Reiss & Valenti-Hein, 1994).

Up to the 1980s research on psychiatric disorders among people with intellectual disability was scarce. In a review of the literature on psychiatric disorders among people with intellectual disability published in the early 1980s, Reid (1983) concluded that the progress in this field had been slow and that improvements had tended to be partial and palliative and that exaggerated claims and assertions lacked credibility. However, the 1980s and 1990s have brought about substantial more research in this area (Eaton & Menolascino, 1982; Göstason, 1985; Lund, 1985; Gillberg, Persson, Grufman & Themner, 1986, Linaker & Nitter, 1990; Borthwick-Duffy, 1994; Gustafsson, 1997; Nøttestad & Linaker, 1999; Moss, 2001) and in 1996 the World Health Organization (1996) expressed the view that people with intellectual disability might experience the full range of psychiatric disorders. In his review of research on psychiatric disorders in adults with intellectual disability, Moss' (2001) evaluation was that the mental health issues seemed to have come to greater prominence in the 1980s and 1990s. According to Moss, the growing body of research in mental health problems seemed to have developed within the context of a major shift to focus more on the subjective quality of life for people with intellectual disability. The state of the field thus looked somewhat more promising by the turn of the millennium.

Psychiatric assessment of people with intellectual disability

Several authors have addressed the diagnostic challenges posed by psychiatric evaluation of people with intellectual disability. Szymanski (1977) underlines that psychiatric symptoms should always be interpreted in the context of a child's

biological, cognitive, and psychosocial impairment. Reiss and colleagues (1982) have demonstrated that clinicians tend to overlook psychiatric disorders in patients with intellectual disability. In these patients psychiatric symptoms may be perceived as part of the intellectual disability and may therefore be overlooked and not properly diagnosed. Reiss and colleagues have termed this phenomenon “diagnostic overshadowing” (Reiss, Levitan, & Szyszko, 1982) as the intellectual disability seems to put the other diagnoses in the shadow.

Sovner (1986) points to four factors that may influence the actual appearance of psychiatric disorders among people with intellectual disability. The first factor is “intellectual distortion”, implying that the concrete thinking and impaired communication skills make it difficult for the person to observe and describe their own behaviour and feelings. The second factor is termed “psychosocial masking”, and Sovner here called to attention the effect that the intellectual disability might have on the expression of psychiatric symptoms. Self-reports may for example be devoid of the richness and detail that is associated with the symptoms of the major psychiatric disorders. The third factor is “cognitive disintegration”, and refers to a tendency to become disorganized when under stress. Bizarre expressions and psychotic-like states may therefore, according to Sovner, be misdiagnosed as schizophrenia. The fourth factor pointed to by Sovner is “baseline exaggeration”. This implies that pre-existing deficits and behaviour problems may be exaggerated in a period of emotional stress and make it more difficult to differentiate between the person’s ordinary behaviour repertoire and problems associated with a psychiatric condition. Thus, various factors related to cognitive impairment are believed to have an impact on the appearance of psychiatric disorders, and the identification of psychiatric disorders in this population may be more difficult than in people without intellectual disability.

Prevalence of psychiatric disorders among people with intellectual disability

After 1980, several studies have addressed the prevalence of psychiatric disorders among people with intellectual disability. In their study of 798 people with intellectual disability in a community based program in Nebraska, Eaton and Menolascino (1982) found that 14.3 percent had a psychiatric disorder. Organic brain syndromes occurring with transient behavioural or psychotic reactions were the most common diagnostic group (29.8%), followed by personality disorder (27.1%), adjustment reactions (21.0%) and schizophrenia (21.0%). In a study from Oregon, US, Clay and Thomas (2005) found that 31 percent had psychiatric disorders. Compared to the general population, they found an increased prevalence of mood disorders among people with intellectual disability.

There have been several studies on prevalence rates in the United Kingdom. Day (1985) studied psychiatric disorders among 357 long-stay hospital residents aged 40 and over and found that 30 percent had psychiatric disorders. Moss and Patel (1993) studied the prevalence of psychiatric disorders among people with intellectual disability over 50 years of age living in Oldham and found a prevalence of psychiatric disorders

of 11.4 percent. Deb, Thomas and Bright (2001a) found that the overall rate of psychiatric disorders was 16 percent among people with intellectual disability living in Wales. Cooper and Bailey (2001) studied the prevalence of psychiatric disorders among 207 adults with intellectual disability in Leicestershire. They found that 49.2 percent had psychiatric disorders. Cooper, Smiley, Morrison, Williamson and Allan (2007) found a point prevalence of diagnoses between 15.7 and 40.9 percent relative to the assessment method used and the rates were higher than those observed in the general population in the United Kingdom. In an Australian study, Einfeld and Tonge (1996) found that 40.7 percent of children and adolescents with intellectual disability could be classified as having severe emotional and behavioural disorder or as having a psychiatric disorder.

<i>Study</i>	<i>Country</i>	<i>Prevalence of psychiatric disorders (%)</i>
Eaton and Menolacino (1982)	United States	14.3
Day (1985)	United Kingdom	30.0
Lund (1985)	Denmark	27.1
Iverson and Fox (1989)	United States	35.9
Moss and Patel (1993)	United Kingdom	11.4
Einfeld and Tonge (1996)	Australia	40.7
Deb <i>et al.</i> (2001a)	United Kingdom	16.0
Cooper and Bailey (2001)	United Kingdom	49.2
Clay and Thomas (2005)	United States	31.0
Gustafsson and Sonnander (2004)	Sweden	34 to 64
Cooper <i>et al.</i> (2007)	United Kingdom	15.7 to 40.9
Göstason (1985)	Sweden	33* and 71#
Gillberg <i>et al.</i> (1986)	Sweden	57* and 64#
Strømme and Diseth (2000)	Norway	33* and 42#

* people with mild intellectual disability

people with severe degrees of intellectual disability

Table 3 Prevalence rates of psychiatric disorders in different studies

There have also been some major studies in the Scandinavian countries (Göstason, 1985; Lund, 1985; Gillberg *et al.*, 1986; Strømme & Diseth, 2000; Holden & Gitlesen, 2003; Gustafsson & Sonnander, 2004). In a study of the prevalence of psychiatric disorders among 302 adults with administratively defined intellectual disability in

Denmark, Lund (1985) found psychiatric disorders in 27.1 percent of the sample and a prevalence rate of 1.3 percent for schizophrenia and 1.7 percent for affective disorder. Strømme and Diseth (2000), in their study of the prevalence of psychiatric diagnoses in children with intellectual disability, found that 37 percent of had a psychiatric diagnosis. In a study of mental health problems in samples from two Swedish counties, Gustafsson and Sonnander (2004) found that the overall occurrence of mental health problems in adults with intellectual disability ranged from 34 to 64 percent.

The reported prevalence rates vary from 11.4 percent to 71.0 percent (table 3). The varied methods for identifying psychiatric disorders may explain some of the differences. Gustafsson and Sonnander (2004), for example, used checklists while Cooper and Bailey (2001) used ICD diagnostic criteria. In a review of empirical studies on the use of DSM and ICD diagnostic criteria in people with intellectual disability, Sturmey (1993) concluded that the application of ICD and DSM criteria had expanded over the last ten years, but noted that most studies in the review had modified the diagnostic criteria in some way. Sturmey points to the need for developing new criteria for some disorders for use with people with severe and profound intellectual disability where current diagnostic criteria are inappropriate. Singh, Sood, Sonenklar and Ellis (1991) has presented a model for assessment and diagnosis of psychiatric disorders emphasising comprehensive assessment of the person's behaviour, based on family history, self- and informant clinical interviews, rating scales, direct observations, and analysis of the behaviour. Singh and associates (1991) conclude that the present state of diagnosis was more art than science, and the need for development in this area was underlined. Barnhill (2003) has suggested an alternative to the DSM-IV for individuals with severe intellectual disabilities by integrating aetiology, temperament, and genetic risk in the assessment.

In a paper on taxonomy of psychopathology in mental retardation, Einfeld and Aman (1995) argues that several factors impede the development of a valid taxonomy, including a) the lack of a widely accepted definition of psychopathology in people with intellectual disability, b) disagreement on the nature of the relationship between intellectual disability and psychopathology, and c) insufficient evidence for the reliability and validity of current DSM or ICD systems in this population. Recently diagnostic manuals with criteria developed specially for people with intellectual disability based on the ICD and DSM systems have become available. In the UK, the Royal College of Psychiatrists (2001) has published diagnostic criteria for psychiatric disorders for use with adults with learning disabilities/mental retardation (DC-LD) based on the ICD-10 classification system and the National Association for the Dually Diagnosed (NADD) in the US has published a textbook and a clinical guide for diagnosis of mental disorders in persons with intellectual disability based on the DSM classification system (Fletcher, Loschen, Stavrakaki, and First, 2007, a,b).

In addition to the diagnostic difficulties, the samples in the different studies may not represent the same populations. Few studies have included individual assessment of intellectual disability, and the reported degrees of intellectual disability may thus not be comparable across studies. Göstason (1985), for example, found significant differences in prevalence rates between people with mild and people with

more severe intellectual disability, and variations in degree of intellectual disability in samples may explain some variations in findings related to the prevalence of psychiatric disorders.

Factors associated with psychiatric disorders

Studies of the association between psychiatric disorders and factors such as gender, age and degree of disability tend to disagree. Göstason (1985), for example, found that men had the highest prevalence of psychiatric disorders whereas Einfeld and Tonge (1996) found no associations between gender and psychiatric disorders. Deb, Thomas and Bright (2001a) found that increasing age was associated with psychiatric disorders whereas Cherry and associates (1997) did not find such associations.

Studies of the association between degree of intellectual disability and psychiatric disorders have similar divergences in results. Some studies have found that people with more severe intellectual disability have a higher prevalence of psychiatric disorders than people with milder degrees of intellectual disability (Göstason, 1985; Gillberg, Persson, Grufman & Themner, 1986; Cooper and Bailey, 2001) whereas others have found that people with milder degrees of intellectual disability have a higher prevalence of psychiatric disorders than people with more severe degrees of intellectual disability (Iverson & Fox, 1989; Holden & Gitlesen, 2004a).

One explanation of such differences in results may be sample differences. Holden and Gitlesen (2004a), for example, had no participants with mild intellectual disability in their sample whereas 14.2 percent of the participants in Cooper and Bailey's (2001) sample had a mild degree of intellectual disability. Another source of variation may be different definitions of psychiatric disorders. Cooper and Bailey (2001), for example, included autism and behaviour disorders among psychiatric disorders, whereas Holden and Gitlesen (2004a) did not include these conditions among psychiatric disorders. Thus, the results of the studies are not readily comparable.

Behaviour problems and psychiatric disorders

Emerson (2001) mentions three possible ways in which psychiatric disorders may be associated with challenging behaviour. Firstly, challenging behaviour may represent an atypical presentation of the core symptoms of a psychiatric disorder in people with severe intellectual disabilities. The cognitive impairment is thus believed to have an impact on the appearance of the psychiatric disorders. Secondly, challenging behaviours may occur as secondary features of psychiatric disorders among people with severe intellectual disabilities. For example, aggression and self-injurious behaviour may occur as secondary features of affective disorders (Matson *et al.*, 1999; Tsiouris, 2001). And thirdly, psychiatric disorders may provide a motivational basis for operant-

maintained challenging behaviour. Emerson (2001) gives an example of depression that may be associated with an unwillingness to participate in educational or social activities. An episode of depression may be associated with increase in challenging behaviour if the person previously has learned that challenging behaviour terminates activities.

Even though there has been some focus on the association between psychiatric disorders and behaviour problems this is still an under-researched area (Hemmings, Gravesstock, Pickard and Bouras, 2006). One of the first studies in this area was Phillips (1967). Phillips studied disturbed behaviour and emotional problems in a group of 227 children and found that intellectual disability often was accompanied by emotional maladjustment. Phillips found that the disturbed behaviour among people with intellectual disability was not primarily due to limited intellectual capacities but to delayed, disordered personality functions and disturbed interpersonal relationships with meaningful people in the environment (Phillips, 1967).

Rojahn, Borthwick-Duffy and Jacobson (1993) studied the association between psychiatric disorders and behaviour problems using client databases in California and New-York containing information of about 135 000 individuals with intellectual disability. They focused on nine major psychiatric disorders recorded in case files, and severe forms of aggressive behaviour, property destruction, self-injurious behaviour and stereotyped behaviour. Rojahn and associates found no association between the recorded psychiatric diagnoses and behaviour problems, and points to several reasons for this in their discussion, among others that clinicians tend to be reluctant to attribute disturbed behaviour to a mental illness. The client databases may therefore lack the relevant information on psychiatric disorders. Rojahn, Matson, Naglieri and Mayville (2004) have maintained that a correct diagnosis may actually be withheld from the case-files when there is a concern that service providers might not accept a person who has a psychiatric diagnosis.

However, other studies using data-base information have revealed some associations between behaviour problems and psychiatric disorders (Borthwick-Duffy & Eyman, 1990). In a study including 78.603 individuals with intellectual disability, Borthwick-Duffy and Eyman (1990) found that out-acting behaviour problems were associated with diagnoses of psychiatric disorders. They underline that they do not know whether the association is found because of the nature of the service delivery systems or because of the actual prevalence among people with intellectual disability.

A number of studies have used checklists for psychiatric disorders specially developed for people with intellectual disability, and these studies have generally found that behaviour problems are associated with psychiatric disorders (Moss, Emerson, Kiernan, Turner, Hatton & Alborz, 2000; Holden & Gitlesen, 2003; Rojahn *et al.*, 2004). Moss and associates (2000) studied challenging behaviour and psychiatric disorders among 320 people with administratively defined intellectual disability and found that increasing severity of challenging behaviour was associated with increased prevalence of psychiatric symptoms. Rojahn and associates (2004) found that individuals with self-injurious, stereotyped, or aggressive/destructive behaviour had generally higher psychopathology scores than individuals without, and the presence of

behaviour problems increased the likelihood of almost all psychiatric conditions up to three-times. In a study of 165 adults with intellectual disability, Holden and Gitlesen (2003) found that challenging behaviour was associated with increased prevalence of anxiety and psychosis.

Thus, most studies of the association between behaviour problems and psychiatric disorders seem to conclude that there is a higher prevalence of psychiatric disorders among people with behaviour problems than it is among others.

Associations between specific behaviours and specific psychiatric disorders

Studies of the association between specific behaviours and specific psychiatric disorders are of particular interest for people with intellectual disability as behaviour problems are the most important cues for psychiatric disorders among people with limited verbal abilities. Several studies have found associations between specific behaviour problems and depression. Hemmings, Gravestock, Pickard and Bouras (2006) found that self-injurious and aggressive behaviours were most associated with affective type symptoms while screaming and destructive behaviours tended to be more associated with autism-related social impairment rather than conventional psychiatric symptoms. They conclude that it may be particularly useful to consider the diagnosis of affective disorders if a person with intellectual disability shows self-injurious or aggressive behaviour. An association between aggressive behaviour and depression was also found by Matson and associates (1999) and by Reiss and Rojahn (1993). Matson and associates found positive correlations between acting out behaviours such as aggression and depressive symptoms, and Reiss and Rojahn found aggressive behaviour problems among about 40 percent of people with depression compared to among ten percent of those without depression. Davis, Judd and Herrman (1997b) found behavioural change with marked aggressive behaviour for half of the depressed persons.

The link between aggressive behaviour and depression has been most marked in people with more severe intellectual disability. Marston, Perry and Roy (1997) found that with increasing disability, there was a move towards behavioural depressive equivalents such as aggression, screaming and self-injurious behaviour, and Meins (1995) found that psychomotor agitation and irritable mood was common among depressed people with more severe intellectual disability. In a review from 1997, Davis, Judd and Herrman (1997a) concluded that the clinical features of depression appeared to vary with level of disability. Irritability, anger, self-injury and aggressive behaviour were observed among people with more severe intellectual disability rather than classic depressive symptoms.

Contrary to the findings of Davis *et al.* (1997b), Tsiouris, Mann, Patti, and Sturmey (2003) did not find close associations between behaviour problems and depression. They concluded that assessment of depression among people with intellectual disability should focus on DSM-IV core symptoms. According to Tsiouris (2001), depressive equivalents can be used as critical behaviours or potential indicators

to alert clinicians of the possibility of underlying depressive disorders, but not as core characteristics of depression.

Associations between behaviour problems and personality disorders have also been reported. Kishore, Nizamie and Nizamie (2005) found that aggression and rebellious behaviour were more common among people with personality disorders and affective disorders than among people with other psychiatric disorders. Flynn, Matthews and Hollins (2001) found that 39 percent of the sample consisting of 36 adults with mild/moderate intellectual disability and severe behavioural problems met the criteria for severe personality disorder, and Bihm, Poindexter and Warren (1998) found that aggression was most consistently predicted by dependent personality and psychosis and that persons showing aggression were more likely than others to be impulsive, attention-seeking, dependent, socially inadequate and anxious.

The use of psychotropic medication for people with intellectual disability and behaviour disorders

Psychotropic medication is reported to be frequently used in relation to behaviour problems. In their study of the receipt of psychotropic medication among 500 people with intellectual disability living in different forms of residential provisions in the UK, Robertson, Emerson, Hatton, Kessissoglou and Hallam (2000) found that whilst the prescription of antidepressants was predicted by symptoms of psychiatric disorders, the prescription of both anti-psychotics and hypnotics/anxiolytics was predicted by variables related to challenging behaviour. People with autism seemed to be given more anti-psychotic medication than others. In Norway, Nøttestad and Linaker (2003) found that the main predictor variable for neuroleptic dosage both before and after deinstitutionalization was challenging behaviour, and no major changes in the use of neuroleptics were found after deinstitutionalization. In a study of psychoactive drug use among people with intellectual disability living in various residential facilities, Intagliata and Rinck (1985) found that between two and three-quarters were receiving psychoactive medication and that medication was more likely to be used with persons who exhibited various behaviour problems. Molyneux, Emerson and Caine (1999) studied the prescription of drugs to 357 people with intellectual disability and found that seven percent were recorded as having a psychiatric illness while 21 percent were receiving neuroleptic medication. In a study of a group 66 people with autism and intellectual disability and 99 controls, Tsakanokos, Costello, Holt, Sturmey and Bouras (2006) found that people with autism had higher rates of behaviour problems and more frequent use of anti-psychotics than matched controls and that physical aggression and problems such as pestering staff independently predicted use of anti-psychotics. Holden and Gitlesen (2004b), in their study of psychotropic medication in 300 adults with intellectual disabilities living in Hedmark County in Norway found that 37 percent were using psychotropics, mostly neuroleptics, and a lot of these prescriptions had not

been indicated by diagnosis. In Sweden, Gustafsson (2003) found that in a sample of 181 adults with intellectual disability, 59 percent received some sort of psychopharmacological treatment, and the most common prescribed medication was anti-psychotic drugs (41%).

Gualtieri and Keppel (1985) reported a widespread concern that too many people with intellectual disability were on chronic neuroleptic therapy. In a review from 1999, Branford (1999) expressed similar concerns. Branford noted that antipsychotic drugs remained widely subscribed to people with intellectual disability, despite the continuing concern about the potential over-prescribing and serious side effects associated with the drugs.

Research on the effect of psychopharmacological interventions has primarily focussed on people without intellectual disability, and there is little research related to psychopharmacology in people with intellectual disability (Matson *et al.*, 2000). In their review of the literature on randomised controlled trials on anti-psychotic medication for challenging behaviour, Brylewski and Duggan (1999) concluded that the three randomized controlled trials that could be included in their study did not provide evidence as to whether antipsychotic medication does or does not help adults with intellectual disability and challenging behaviour. Clarke's review (1998) of the published literature on psychopharmacology of severe self-injury reported evidence for the efficacy of opiate antagonist in the management of severe self-injury, and Barnard, Young, Pearson, Geddes and O'Brian (2002), in their review of the use of atypical antipsychotics in people with autism, concluded that there is indication that risperidone may be effective in reducing hyperactivity, aggression and repetitive behaviours, often without inducing severe adverse reactions. Singh, Matson, Cooper, Dixon and Sturmey (2005), however, in their review on the use of risperidone, conclude that the effectiveness of risperidone in targeting psychopathology and challenging behaviours for individuals with intellectual disability is questionable at the present, while Malfa, Lassi, Bertelli and Castellani (2006) conclude that the methodological integrity of scientific studies that support the use of antipsychotics in people with intellectual disability is often lacking, but that risperidone seems to be the drug with the highest efficacy in the management of behaviour problems, especially aggressiveness. All the studies reported by Malfa and associates (2006) focused on the use of anti-psychotics in people with intellectual disability presenting behaviour problems.

In their ten-year review of the literature pertaining to psychopharmacology in intellectual disability, Matson and associates (2000) conclude that most medications were given to suppress a myriad of behaviour problems thus chemically restraining the person. Tsaknikos and associates (2006) suggest that there may be pressures to prescribe medication in cases of greater complexity even in the absence of overt clinical psychopathology, and this especially seem to apply to intellectually disabled adults with autism. The findings of Nøttestad and Linaker (2003) and Holden and Gitlesen (2004b) indicate that such a pressure also may exist in Norway.

Present project

The present project is rooted in a clinical setting; that is at Psykiatrisk innsatsteam at Nordlandssykehuset. Psykiatrisk innsatsteam provides services for people with intellectual disability in the Northern Health Region in Norway (the counties of Nordland, Troms and Finnmark). The majority of persons referred to Psykiatrisk innsatsteam have severe behaviour problems, and the team works ambulatory with assessment, consultation and supervision in the municipalities where the persons with behaviour problems live. The team was established after the deinstitutionalization of services for people with intellectual disability in 1991. In 1999 a project to develop better assessment methods related to the behaviour problems among people with intellectual disability was initiated by Psykiatrisk innsatsteam. The project was formally accepted as a doctoral project in 2001.

Aims of the thesis

The general aim of the present thesis has been to contribute to the knowledge of the relationship between behaviour problems and psychiatric disorders among people with intellectual disability living in community settings.

Specific objectives have been:

- To examine the prevalence of behaviour problems in a representative sample of people with intellectual disability, with an emphasis on prevalence rates among people with intellectual disability living in community settings and to discuss methods for reporting prevalence rates that may facilitate comparisons of prevalence rates across regions or countries (Paper I).
- To examine the associations between behaviour problems and psychiatric disorders, and whether associations between behaviour problems and psychiatric disorders differ among people with mild/moderate and people with severe/profound intellectual disability. (Paper II)
- To compare the outcome and to evaluate the concordances between the screening instruments for psychiatric disorders among people with intellectual disability, focussing on the concordances between comparable diagnostic categories on the instruments (Paper III).

Methods

The total sample studied

A total of 181 persons with intellectual disability participated in the study. Seventy-five of these participants had been referred to Psykiatrisk innsatsteam at Nordlandssykehuset. There are ten habilitation teams at the hospitals in the Northern Health Region, and all these teams provide ambulatory services in the municipalities they serve. The teams are generally well informed about people with intellectual disability in their catchment area, and this especially applies to people with behaviour problems as this is a group in need of services from the habilitation teams. When the habilitation teams needs assistance related to individuals with severe behaviour problems they refer the patients to Psykiatrisk innsatsteam. The participants referred to Psykiatrisk innsatsteam were probably among the individuals with the most severe behaviour problems in the Northern Heath Region.

One-hundred-and-six participants were recruited from five of the 44 municipalities in Nordland County. These participants were adolescents and adults with administratively defined intellectual disability. People with intellectual disability who have behaviour problems are likely to be known to the administrators in the municipalities and the group with administratively defined intellectual disability was therefore believed to include people with behaviour problems who are the main focus of the present thesis. In each of the five municipalities, meetings were arranged to inform members of organizations for persons with intellectual disability and their families, leading members of staff, and managers of the social and health services about the study. People with moderate to profound degrees of intellectual disability generally have some kind of support or care organized and funded by the municipality. The invitation to participate in the study was mediated by representatives from the local social and health services, who contacted persons with an “administrative” intellectual disability (i.e., who received services from the municipality) and their families or guardians. A total of 155 individuals were contacted and 117 individuals and/or their guardians gave their consent and/or assent to participate in the study (75.5 percent). Two of these 117 individuals were already included in the study because they had been referred for behaviour problems. Nine others were excluded for various reasons: one person did not have an intellectual disability, one person died before the data collection was started, the assessment instruments were considered inappropriate for three persons who had severe visual or auditory impairment and for four persons with advanced stages of dementia.

Samples in the studies

Sample study I (n = 140)

In study I, the prevalence of behaviour problems among people with administratively defined intellectual disability in five municipalities in Nordland County were examined. The sample in this study consisted of 140 participants and included all people with intellectual disability who were recruited from the five municipalities as well as all people with intellectual disability from these five municipalities who had been referred to Psykiatrisk innsatsteam.

Sample study II (n = 142)

In study II, a group with moderate and severe behaviour problems was compared to a group with no behaviour problems or mild problems only. The Aberrant Behavior Checklist (Aman & Singh, 1986, 1994) was used to assess behaviour problems among the participants and the results were used to allocate the participants to either a behaviour problem group (moderate or severe behaviour problems) or a comparison group (no behaviour problems or mild problems). Of the 181 participants, 98 were rated on the Aberrant Behavior Checklist as showing at least one moderate or severe behaviour problem, while 83 participants were rated to have no behaviour problems or mild problems. The participants in the group with moderate and severe behaviour problems on the Aberrant Behavior Checklist were matched individually with individuals in the group with no or mild problems, according to level of intellectual disability – and as far as possible in accordance with gender and age, in that order of priority. The matching resulted in a behaviour problem group of 71 people and a comparison group of 71 people.

Sample study III (n = 181)

The total sample of 181 participants was included in study III.

Instruments

Four checklists for psychiatric disorders in people with intellectual disability were used, the Reiss Screen (Reiss, 1988), the Mini Psychiatric Assessment Schedule for Adults with Developmental Disability, Mini PAS-ADD (Prosser, Moss, Costello, Simpson &

Patel, 1997), the Diagnostic Assessment for the Severely Handicapped-II, DASH-II (Matson, 1995), and the Assessment of Dual Diagnosis, ADD (Matson & Bamburg, 1998).

The Reiss Screen for Maladaptive Behavior (Reiss, 1988) has 38-items, each relating to a symptom, and it is designed to identify persons who should be referred for further evaluation of possible psychiatric disorders. The 38 symptoms are rated on a three point scale: 1) no problem, 2) problem or 3) major problem and summed up in eight diagnostic categories relating to mental health problems. These categories are based on factor analysis and are termed: 1) aggressive behaviour, 2) autism, 3) psychosis, 4) paranoia, 5) depression (behavioural signs), 6) depression (physical signs), 7) dependant personality disorder, and 8) avoidant personality disorder. In addition to the diagnostic categories, there are six maladaptive behaviour items. The identification of possible psychiatric disorders is based on a) the total score on the Screen, b) the scores on the eight diagnostic categories, and c) the scores on the six maladaptive behaviour items. The cut-off or referral scores for all diagnostic categories on the Reiss Screen, except for Autism, are about two standard deviations above the mean for a group without a diagnosis used in the standardization by Reiss (Reiss, 1988). The mean score for 14 subjects with a diagnosis of autism was set as the cut-off for the Autism scale. The cut-off point for the total score was the mid-point between the average score for the group without a psychiatric diagnosis and the average score of various diagnostic groups (Reiss, 1988). According to Reiss, a score above cut-off means that the subject is likely to have mental health problems and should be referred to a psychiatric service. A score below the cut-off means that the person is likely to be mentally healthy.

The Mini PAS-ADD (Prosser, Moss, Costello, Simpson & Patel, 1997) is based on ICD-10 (World Health Organization, 1992). The Mini PAS-ADD is a structured interview, and care-persons who know the person well are informants. The assessment schedule can be used to detect symptoms of psychiatric disorders and to make informed referrals to psychiatric services. The Mini PAS-ADD consists of 86 items that are assessed on a four-point scale: 0) symptoms not present, 1) mild symptoms, 2) moderate symptoms or 3) severe symptoms. The scores are summed up into seven symptom scales or categories for psychiatric disorders: 1) depression, 2) anxiety, 3) hypomania/mania, 4) obsessive/compulsive disorder, 5) psychosis, 6) unspecified disorder, and 7) autism (DD1, DD2 and DD3). The symptom scales are provided with threshold or referral scores and it is necessary to have at least one core symptom of a disorder to reach the referral score. According to Prosser and associates (1997), a score above this level indicates that the person may have mental health problems in that area and should be referred for further psychiatric investigation.

The DASH-II (Matson, 1995) has 84 items relating to psychiatric symptoms. This rating scale is designed to identify psychiatric disorders in adults with severe and profound intellectual disabilities. The DASH-II is derived from the DSM-III-R classification system (American Psychiatric Association, 1987). The checklist is a structured interview, and the informants rate the frequency, the duration and the severity of the symptoms on a three-point scale. The frequency is rated as 0) no

occurrence at all, 1) has occurred between one and ten times the last two weeks or 2) has occurred more than ten times the last two weeks, the duration is rated as 0) less than one month, 1) one to twelve months or 2) over twelve months, and the severity is rated as 1) caused no disruption or damages, 2) caused no damages, but interrupted activities of others at least once or 2) caused injury or property damage at least once. The symptom scores on the DASH-II are summed up in 13 diagnostic categories: 1) impulse control, 2) organic syndromes, 3) anxiety, 4) mood, 5) mania, 6) PDD/ autism, 7) schizophrenia, 8) stereotypies, 9) self injurious behaviour, 10) eliminating disorders, 11) eating disorders, 12) sleep disorders and 13) sexual disorders. The 13 diagnostic categories are provided with cut-off scores indicating when a diagnosis should be considered. For the first eight scales Matson set the cut-off point for diagnosis at a score of one standard deviation above the mean of the standardization sample. For the last five scales at least one subscale item must have been rated a severity level of 1 or 2 to reach the cut-off point (Matson, 1995).

The Assessment of Dual Diagnosis (ADD) is designed to screen psychiatric disorders in adults with mild and moderate intellectual disabilities and has 79 items relating to psychiatric symptoms (Matson & Bamburg, 1998). The ADD is based on the DSM-IV (American Psychiatric Association, 1995). This checklist is a structured interview, and the informants rate the frequency, the duration and the severity of the symptoms on three-point scales identical to the scales on the DASH-II. The ADD contains 13 diagnostic categories: 1) mania, 2) depression, 3) anxiety, 4) PTSD, 5) substance abuse, 6) somatoform disorders, 7) dementia, 8) conduct disorder, 9) pervasive developmental disorder, 10) schizophrenia, 11) personality disorders, 12) eating disorders, and 13) sexual disorders. In contrast to the other checklists, the ADD does not have cut-off scores.

The Aberrant Behavior Checklist (Aman & Singh, 1986, 1994) is a rating scale for behaviour problems in children and adults with intellectual disability. The checklist has 58 items, and the informants are supposed to fill in the questionnaire. Each item is rated on a four-point scale as 0) no problem, 1) slight problem, 2) moderate problem or 3) severe problem. The items are summed up in five subscales: I) Irritability (15 items), II) Lethargy (16 items), III) Stereotypy (7 items), IV) Hyperactivity (16 items), and V) Inappropriate Speech (4 items).

Vineland Adaptive Behavior Scales, Expanded Form (Sparrow, Balla & Cicchetti, 1985) was used to measure adaptive functioning. Vineland Adaptive Behavior Scales measures adaptive functioning in four specified domains called "communication" (receptive, expressive and written), "socialization" (interpersonal relationships, play and leisure time, and coping skills), "daily living skills" (personal, domestic and community) and "adaptive behaviour composite" (total score). Leiter International Performance Scale-Revised (Roid & Miller, 1997) and Wechsler Intelligence Scale for Children-Revised-III (Wechsler, 2003a) and Wechsler Adult Intelligence Scale-III (Wechsler, 2003b) were used to assess level of intellectual disability. Leiter-R is a non-verbal intelligence test and the Wechsler tests includes both verbal and performance items. A checklist developed for the project was used to assess service needs. This checklist contains 66 items relating to a) accommodation, b) work

and school, c) leisure activities, d) family and relatives, e) social network, f) health issues, g) economy, h) staff assistance, i) written plans, j) the person's participation in meetings concerning her or his situation, and k) meetings and supervision for staff members.

Procedure

All the participants were assessed with the Reiss Screen, the Mini PAS-ADD and the Aberrant Behavior Checklist. The DASH-II and the ADD are designed for use with different populations and each participant was given the checklist that was considered appropriate for his or her degree of intellectual disability. 126 participants were assessed with the DASH-II and 54 participants were assessed with the ADD.

Two individuals (care staff or family) performed the ratings on the Mini PAS-ADD, the DASH-II and the ADD. Qualified mental health professionals, trained in the use of the schedules, administered the assessments. The data collection related to the group of 106 persons from the five municipalities was performed by two research assistants who worked full-time with the project in two years from 2002 to 2004. The research assistants had bachelor level of education, one as a special nurse and one as social worker specialised in psychiatry. The data-collection for the 75 individuals that were referred to Psykiatrisk innsatsteam was performed by team members and was part of the standard assessment of all referred patients. The research assistants were located in the premises of Psykiatrisk innsatsteam and followed the same procedures for training in the use of the assessment instruments as the team members.

Generally, there were two informants for each person to be rated. Close family were informants for 8 participants, care staff for 149 persons, and family members and care staff together were informants for 24 participants. The care staff had known the person for an average of 110 months, ranging from 3 to 356 months. For the checklists that were presented as structured interviews (Mini PAS-ADD, DASH-II and ADD), the administrator of the interview read the items to the informants and asked for their ratings. The Mini PAS-ADD has a glossary, and this could be used whenever clarification was needed. The Reiss Screen is self-administered and the informants filled in the forms themselves and the two informants completed the rating independently. The Aberrant Behavior Checklist was completed by one informant, either a member of care staff or family, who knew the person with intellectual disability well. In most cases, all instruments were completed on the same day. Generally, a rating started up with the Mini PAS-ADD, followed by the Reiss Screen and the Aberrant Behavior Checklist. After a break, rating with the DASH-II or the ADD was done. Including the break, these rating sessions lasted about three hours.

Leiter-R was administered individually to 77 participants, the WISC-III was used with one and the WAIS-III with two participants. Vineland was completed for all participants except one person, with members of the support staff or the persons'

families as informants, and the Vineland scores were used for estimating level of intellectual disability in the participants who were not assessed with the Leiter-R or the Wechsler tests. For the participant who had not been assessed with Vineland or the other tests, the level of intellectual disability was estimated clinically. The checklist used to assess service needs was generally left with one informant who filled it in and returned it within a two weeks period. This checklist was filled in together with the person to be assessed whenever that was possible.

Statistical analyses

In all three studies, group differences were tested with Fishers Exact Test or by independent samples t-test. In addition, Pearson's correlations were used to investigate relationships between scores for behaviour problems and scores for psychiatric disorders in Paper II. In Paper III reliability was analysed with Cronbach's alpha and associations between variables were analysed using Spearman correlations.

Ethical considerations

The Regional Committee for Medical Research Ethics approved the study. Most of the participants in the project had moderate, severe or profound degrees of intellectual disability. This implies that the majority of the participants did not have the capacity to understand and make informed decisions regarding the participation in the project and the informants could not be released from their professional secrecy by the participants. An exception from the secrecy thus was required to go through with the project, and after consulting the Council for Professional Secrecy and Research (Rådet for taushetsplikt og forskning) the Directorate for Health and Social Affairs (Helse- og Sosial Direktoratet) gave the assistant staff and care staff exception from professional secrecy and allowed them to give the information that was requested. In addition to the exception from secrecy granted by the Directorate for Health and Social Affairs, assent to participation also was obtained from close relatives or guardians. The Data Inspectorate granted a license for the use of health information.

Summary of papers

Paper I: The prevalence of behaviour problems among people with intellectual disability living in community settings.

Aim of the study

The aim of the study was to contribute to the accumulation of knowledge related to behaviour problems among people with intellectual disability living in different community settings. A group of 140 people with administratively defined intellectual disability living in five municipalities in Nordland County in Norway participated in the study. Comparisons of behaviour problems among people living in regions or countries with different service structures may be important to evaluate possible impacts of service structures on behaviour problems and the study discuss methods for reporting prevalence rates that may facilitate comparisons.

Main results

Behaviours rated as problems by family and care staff was common in the individuals with administratively defined intellectual disability. Twenty-eight people were reported to have severe behaviour problems, and on the average, people showing challenging behaviour had seven behaviours rated as severe problems. Those with severe behaviour problems were perceived to be significantly less satisfied with their life-situation than people without severe behaviour problems.

When calculated relative to the corresponding age group in the general population, the prevalence rate corresponded to 63.6 people per 100 000 base population. The prevalence rate found in the present study was in accordance with prevalence rates found in the limited number of comparable studies that have used similar methods for reporting prevalence rates. The results suggest that the conditions that may facilitate or prevent behaviour problems, related to for example the structure and content of services, are comparable in the mainly Norwegian and British settings that have been studied.

Paper II: Psychiatric disorders and behaviour problems in people with intellectual disability

Aim of the study

The aim of the study was to examine the associations between behaviour problems and psychiatric disorders. The prevalence of psychiatric disorders was examined as well as the distribution of psychiatric disorders among people with mild/moderate and severe/profound intellectual disability. In addition, associations between specific psychiatric disorders and specific behaviour problems were examined. It was hypothesized that participants with behaviour problems would show more psychiatric symptoms than participants without behaviour problems, and that the pattern of psychiatric symptoms would vary with degree of intellectual disability.

Main results

The majority of the participants with moderate and severe behaviour problems had symptoms of psychiatric disorders, and this group showed significantly more symptoms of psychiatric disorders than the comparison group. The participants with mild and moderate intellectual disability showed more symptoms of psychosis and depression than the participants with severe and profound intellectual disability. The group with mild/moderate intellectual disability also showed a somewhat different pattern of associations between behaviour problems and psychiatric symptoms than the group with severe/profound intellectual disability. Depression was associated with screaming and aggression in the participants with severe and profound intellectual disability, and with self-injury in the participants with mild and moderate intellectual disability. The finding that the majority of the participants with behaviour problems showed symptoms of psychiatric disorders suggests that proper assessment and treatment of psychiatric disorders should be an important aspect of the health services for this population.

Paper III: Screening individuals with intellectual disability for psychiatric disorders: Comparison of four measures.

Aim of the study

The aim of the study was to examine the concordances of four of the most commonly used assessment instruments for psychiatric disorders in people with intellectual disability with regard to identification of individuals who might have a psychiatric

disorder. The results of the assessments with the instruments were compared to evaluate the concordances between diagnostic categories on the four instruments.

Main results

The correlations between the participants' total scores on the four instruments were generally high, suggesting that the instruments gave fairly similar indications of the psychiatric health status of the participants. The concordances between individual corresponding scales, however, were lower, suggesting that these scales did not measure the same underlying problems. The results indicate that the checklists are useful as general indicators of psychiatric disorders, but they seem to be of less value for specifying the nature of the disorders in individuals with intellectual disability.

Discussion

A relatively large proportion of people with administratively defined intellectual disability were reported to have severe behaviour problems. One in five showed one or more behaviours that were regarded as severe problems or “challenging”, corresponding to 63.6 people per 100 000 of the general population. Compared to people without severe behaviour problems, those with severe behaviour problems were less likely to live with their family, were less likely to have friends or someone to entrust and were perceived to be less content with their life situation (Paper I). Thus, the presence of behaviour problems seems to have significant negative impact on social inclusion and well being for people with administratively defined intellectual disability and behaviour problems is a major issue related to the quality of life for people with intellectual disability living in community settings.

Paper II demonstrates a significant association between behaviour problems and psychiatric disorders, but also that the association is complex and that the behaviour problems may not be a direct expression of psychiatric disorders. Also some of the participants without behaviour problems scored above the cut-offs for psychiatric disorder, and over 30 percent of the participants with behaviour problems did not score above the cut-off on any of the checklists. It is possible that a difficult life situation, possibly associated with the intellectually disabled persons’ understanding – or lack of understanding – of important events related to their own lives, may contribute to the development of both psychiatric problems and behaviour problems, or that the behaviour problems are secondary to the psychiatric disorder.

People with autism seem especially vulnerable for developing behaviour problems, and this is in accordance with several other studies (Collacot *et al.*, 1998; Mc Clintock *et al.*, 2003). About one third of people with severe behaviour problems had co-morbid autism and profound intellectual disability. Very few participants with Down syndrome had severe behaviour problems, and in the present sample Down syndrome did not seem to be associated with severe behaviour problems. This result is also in accordance with other studies (Tyrer *et al.*, 2006). The differences in prevalence rates among people with autism and people with Down syndrome indicate that biological factors associated with vulnerability or resilience may play a role in the development of behaviour problems.

Generally, more symptoms of psychiatric disorders were found among participants with mild and moderate than among participants with severe and profound intellectual disability (Paper II). The finding that people with milder degrees of intellectual disability are more likely to have psychiatric disorders than people with more severe disability is in accordance with several other studies (Iverson & Fox, 1989; Moss & Patel, 1993; Holden & Gitlesen, 2004a; Kishore, Nizamie, Nizamie & Jahan, 2004). Cooper and Bailey (2001), however, have found that people with more severe intellectual disability were more likely than those with milder disability to have psychiatric disorders. Cooper and Bailey included autism and behaviour disorders

among psychiatric disorders, and these were not included as psychiatric disorders in the present study. As autism and behaviour disorders are most prevalent among people with severe and profound intellectual disability (Cherry, Matson & Paclawskyj, 1997), the inclusion of these diagnoses may explain some of the differences in results.

Specific behaviour problems and specific psychiatric diagnoses

The examination of the relation between specific psychiatric disorders and specific behaviour problems showed that anxiety was correlated with tantrums, and mania was strongly correlated with both tantrums, aggression and screaming (paper II). Self-injury showed the weakest correlations with both general psychopathology and the diagnosis-specific subscales, especially psychosis. None of the correlations between self-injury and the psychosis subscales reached significance.

The pattern of correlations between psychiatric disorders and specific behaviour problems differed somewhat between individuals with mild/moderate and severe/profound intellectual disability. Depression seemed to be associated with aggression, tantrums and screaming in the group with severe/profound intellectual disability and with tantrums and self-injury in the group with mild/moderate intellectual disability. Similar findings are reported in other studies. In a sample with predominately profound intellectual disability, Rojahn and associates (2004) found weak and non-significant correlations between depression and self-injury while Hemmings and associates (2006) found significant correlations between self-injury and a range of symptoms that are usually associated with depression in a sample of people with predominately mild and moderate intellectual disability. Tsiouris and associates (2003) studied a sample where over half had mild and moderate intellectual disability, and found that self-injury was nearly 2.5 times more frequent in the participants who had received a diagnosis of depression than in the participants with other psychiatric diagnosis. The present study and other studies indicate that there are associations between specific behaviour problems and specific psychiatric diagnoses, for example between aggressive behaviour and depression. However, the results also show that level of intellectual disability is important to consider when studying such associations.

Level of intellectual disability and psychiatric disorders

People with administrative intellectual disability represented 0.43 percent of the total population (Paper I). However, the prevalence of behaviour problems and psychiatric disorders in the present sample with administratively defined intellectual disability is

not necessarily comparable to the prevalence among people with intellectual disability in general. This especially applies to people with mild intellectual disability. About two percent of the population are believed to have an intellectual disability (American Psychiatric Association, 1995), and the proportion of people with mild intellectual disability was much lower in the present sample than what would be expected in a representative sample of people with intellectual disability. Those with mild intellectual disability who are known by the administration in the municipalities and consequently are part of samples with administratively defined intellectual disability, are likely to be those who have problems of such a degree that they are in need of special services and support because of their condition. The associations between for example symptoms of depression and self-injurious behaviour found among people with mild/moderate intellectual disability in the present study (Paper II) may not be found among people with mild intellectual disability in general. It may be that depressed people with mild intellectual disability who engage in self-injurious behaviour are more likely than others with depression to be known by the administration because of their behaviour problems. It is therefore possible that depression is not generally associated with self-injury among people with mild intellectual disability even if this is the case for those with administrative intellectual disability.

A factor that may affect the reported disorders among those with more severe disability is the difficulties associated with detecting disorders in people that can not verbalize their symptoms. Consequently few symptoms are found among people with severe/profound intellectual disability. Symptom patterns are more clearly visible and easier to identify in individuals with higher levels of ability and more psychiatric disorders are found in this group than in individuals with more severe intellectual disability (Moss & Patel, 1993). Kishore and colleagues (2004) claim that it is still a matter of debate whether rates of psychiatric disorders in people with severe intellectual disability are really lower or clinicians fail to understand the psychopathology because of poor language and cognitive skills. Thus, the fact that people with mild intellectual disability generally are under-represented in samples and the fact that diagnostics is difficult in people with more severe intellectual disability points to general limitations in the published studies on psychiatric disorders among people with disability.

The association between behaviour disorders and personality disorders

In the present project, behaviour disorder was not included as a psychiatric diagnosis. It may be problematic to include behaviour disorders as a psychiatric disorder, but in some cases this may be justified. According to the "Diagnostic criteria for psychiatric disorders for use with adults with learning disabilities" (DC-LD) it is unlikely that personality disorders can be diagnosed in adults with severe/profound intellectual

disability (Royal College of Psychiatrists, 2001). Torr (2003) has suggested that people with severe or profound intellectual disability tend to receive diagnoses of behaviour disorders whereas people with mild and moderate intellectual disability are more likely to be given a diagnosis of personality disorder.

Even though a diagnosis of personality disorder is seldom used for people with more severe intellectual disability there are theoretical and empirical bases for assuming associations between such disorders and behaviour problems. People with intellectual disabilities have more adverse experiences during upbringing than others (Horner-Johnson & Drum, 2006; Sullivan & Knutson, 2000) and studies have indicated an association between adverse life experiences during childhood and adult personality disorder (Battle *et al.*, 2004; Flynn, Matthews & Hollins 2002; Haugaard, 2004; Minzenberg, Poole & Vinogradov, 2006). If personality disorders are a result of poor environmental conditions during upbringing, some behaviour problems in individuals with intellectual disability may be functionally equivalent with the symptoms of personality disorder shown in individuals who are not intellectually impaired, in the sense that they are caused by similar adverse experiences. Some behaviour problems among people with more severe intellectual disability may thus be inflexible and enduring patterns of relating to the environment that correspond to personality disorders and character based patterns of pathology.

Concordances between checklists

The concordances between each of the comparable scales on the checklists varied considerably (Paper III). In particular for the psychosis scales correlations were moderate. The agreement between the checklists was generally higher for the depression scales, possibly reflecting that observable behaviour has a greater role in the assessment of depression than in the assessment of psychosis.

To a considerable extent, the comparable scales on the four checklists identified different people as having psychiatric disorders and the concordances between the checklists were generally lower for participants with severe/profound than for participants with mild/moderate intellectual disability. This underlines the difficulties related to assessment and diagnosis of psychiatric disorders among people with more severe intellectual disability. According to expert consensus guidelines for diagnosis and assessment it is often not possible to diagnose specific disorders reliably in people with more severe intellectual disability (Aman *et al.*, 2004).

Sum scores of items in a checklist may be used as a general indicator of psychiatric health status. A relatively high correlation was found between the participants sum scores on each checklist, and the checklists thus seemed to give better indicators on global psychiatric health status than on specific psychiatric disorders. Decisions related to referrals to psychiatric services may be based on the results of the

checklists. The present results indicate that it may be useful to have sum scores on the checklists as global indicators of psychiatric health status in addition to scores on the specific diagnostic categories. It may be difficult to attain reliable indications on specific psychiatric disorders (see Aman *et al.*, 2004), and the use of sum scores may serve to avoid under referral to psychiatric services. The Reiss Screen is the only of the four checklists used in the present study that is provided with norms and cut-off points for sum scores.

The four checklists used to measure psychiatric symptoms include somewhat different diagnostic subscales. The DASH-II identified considerable more individuals with psychiatric symptoms than the Reiss Screen which did not identify any in the group with no or mild behaviour problems. Many of the participants were identified as having a psychiatric problem by one checklist only. There was only partial overlap between the individuals identified by the different checklists, making the total number identified considerably larger than if only one checklist had been used. The use of several checklists seems to have increased the percentage of people with behaviour problems identified to have psychiatric problems. In clinical settings, the use of more than one checklist may be appropriate, in particular for those with severe and profound intellectual disability.

Conclusions and implications

Twenty percent of the sample with administratively defined intellectual disability, or 63.6 people per 100 000 people in the general population, were reported to have severe behaviour problems. It was common for those with severe behaviour problems to have more behaviour rated as severe problems and on the average seven behaviours was reported to be severe problems in this group. Outwardly directed behaviours like temper tantrums and aggressive behaviour were most frequent, but behaviours such as self-injury and lack of social responses were also reported to be severe problems for about 10 people per 100 000 of the general population.

Studies of behaviour problems have used varied methods for calculation and reporting of prevalence rates and the figures have therefore not been comparable. Calculation of prevalence rates relative to the corresponding age groups in the general population gives estimates that are comparable across regions or countries, and such comparisons may be important to detect contextual factors that may have an impact on behaviour problems, for example the structure and function of the service systems. Calculation of prevalence rates relative to the general population may therefore add to the progress of research in this field.

Assessment of psychiatric disorders among people with intellectual disability is problematic, especially among people with more severe intellectual disability. The discrepancies between the results on the four instruments used for assessing psychiatric disorders reflect this. Even though the concordances between the overall scores of the assessment instruments were high, the instruments agreement related to specific disorders was limited and the agreement related to psychiatric diagnoses was lower for people with severe and profound intellectual disability than for people with mild and moderate intellectual disability. According to expert consensus (Aman *et al.*, 2004), it is often not possible to diagnose specific diagnoses routinely and reliably in people with more severe intellectual disability. The present result suggests that researchers and clinicians should be careful with making assumptions about the nature of the problems, especially when using screening devices for people with more severe intellectual disability.

People with moderate and severe behaviour problems had more symptoms on psychiatric disorders than the others, and the majority of the participants with behaviour problems had symptoms of the main psychiatric disorders. These findings suggest that many behaviour problems may be indications of psychiatric disorders, and the present study underlines the need for adequate psychiatric health services for people with severe behaviour problems. However, the health services for this group have not been functioning satisfactorily. An evaluation by the Board of Health (Statens helsetilsyn, 2000) has revealed serious shortcomings related to all aspects of the psychiatric health services for people with behaviour problems (Statens helsetilsyn, 2000, p. 32). In 2001, several measures to improve the services were proposed to the Board of Health (Statens helsetilsyn, 2001), but no major changes in the psychiatric services for people with

intellectual disability has occurred since 2001. Thus, the situation today is probable no better for this group than it was in 2001.

Under the heading “Habilitation and rehabilitation”, Article 26 in the United Nation’s Convention on the Rights of Persons with Disabilities (United Nations, 2007) it is stated that the authorities ...”shall take effective and appropriate measures, including through peer support, to enable persons with disabilities to attain and maintain maximum independence, full physical, mental, social and vocational ability, and full inclusion and participation in all aspects of life”. The authorities are required to ...”organize, strengthen and extend comprehensive habilitation and rehabilitation services and programmes, particularly in the areas of health, employment, education and social services, in such a way that these services and programmes: (a) Begin at the earliest possible stage, and are based on the multidisciplinary assessment of individual needs and strengths; (b) Support participation and inclusion in the community and all aspects of society, are voluntary, and are available to persons with disabilities as close as possible to their own communities, including in rural areas”. All countries ratifying the Convention...”shall promote the development of initial and continuing training for professionals and staff working in habilitation and rehabilitation services” and ...”promote the availability, knowledge and use of assistive devices and technologies, designed for persons with disabilities, as they relate to habilitation and rehabilitation”.. The recommendations for improvement of services for people with behaviour problems that was presented to the Board of Health in 2001 (Statens helsetilsyn, 2001) are in accordance with the principles of the UN-Convention. The Convention was signed by Norway in April 2007, and more concern for the psychiatric health needs of people with severe behaviour problems should be a consequence of ratification of the UN-Convention.

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