

# Mild intellectual disability

Diagnostic and outcome aspects



Ida Lindblad

Institute of Neuroscience and Physiology  
at Sahlgrenska Academy  
University of Gothenburg





# **Mild intellectual disability: Diagnostic and outcome aspects**

Ida Lindblad

Gillberg Neuropsychiatry Centre  
Institute of Neuroscience and Physiology  
Sahlgrenska Academy at University of Gothenburg



UNIVERSITY OF GOTHENBURG

Gothenburg 2013

Cover illustration: by Siv Bogren, after an idea of psychologist Ingrid Adolfsson

Mild intellectual disability: Diagnostic and outcome aspects

© Ida Lindblad 2013

[ida.lindblad@gnc.gu.se](mailto:ida.lindblad@gnc.gu.se)

ISBN 978-91-628-8803-9

Printed in Gothenburg, Sweden 2013

Ale Tryckteam AB

To Olof, Edvin, Arvid and Vidar

My inspiration and support



# Mild intellectual disability: Diagnostic and outcome aspects

Ida Lindblad

Gillberg Neuropsychiatry Centre, Institute of Neuroscience and Physiology  
Sahlgrenska Academy at University of Gothenburg, Sweden

## ABSTRACT

The aim of the thesis was to describe mild intellectual disability (ID) from various neurodevelopmental and neuropsychiatric perspectives in children and young adults.

**Paper I** The objective of the first paper was to analyse coexisting neurodevelopmental disorders/problems and diagnostic concerns in a population-based group of 33 school age children with mild ID. The instrument used was the Five-To-Fifteen questionnaire. The prevalence of mild ID in the study area was found to be 0.85%. High rates of problems were reported regarding motor skills, executive function/attention, social and emotional/behavioural functioning. It was concluded that school age children with mild ID are in need of a comprehensive work-up covering not only general cognitive abilities, but also many other areas.

**Paper II** In the second paper adaptive functioning was compared between the group of 33 school age children with mild ID (Paper I) and a referral group of 27 school age children with ADHD. The instrument, administered to teachers, was the Adaptive Behavior Assessment System, Second Edition (ABAS-II). At total group levels, the group with ADHD had even lower adaptive functioning compared to the group with mild ID. The difference between the groups was significant in children 12 years or older. The finding has implications for diagnostic concerns and indicates that the level of adaptive functioning cannot be used to differentiate between mild ID and ADHD.

**Paper III and IV** In the third and fourth papers a population based group of 42 children – now young adults – born to mothers with ID was explored with regard to life experiences. Three of the 42 individuals (0.68%) had died before the age of 8 years, one had moved abroad and seven declined participation. Ten individuals were personally interviewed and 21 were searched for in different registers. When the interview and register groups were collapsed, it was found that 11 of the 31 individuals (35%) had mild ID and 9 (29%) had ADHD. Sixteen children (52%) had not been primarily raised by their biological mother. Children born to mothers with ID are exposed to several risks. These include an increased risk of neglect and abuse in the family and also an increased risk for the child to have mild ID and other neurodevelopmental disorders, including ADHD. Individuals with ID who become parents need tailored support from social services and their children need early assessment so as to develop physically, mentally and socially in an optimal way.

**Keywords:** Mild Intellectual Disability (ID), ADHD, comorbidity, adaptive functioning, mothers with mild Intellectual Disability, neglect and abuse, ABAS-II

ISBN: 978-91-628-8803-9

<http://hdl.handle.net/2077/34073>





# SAMMANFATTNING PÅ SVENSKA

Lindrig utvecklingsstörning är en funktionsnedsättning som numera inte är lika uppmärksammas som till exempel ADHD och Autism. Den huvudsakliga funktionsnedsättningen innebär brister i den kognitiva förmåga som rör abstrakt/teoretiskt tänkande. Andra kognitiva funktioner som rör planering, flexibilitet och minne är oftast också påverkade. Förekomsten av lindrig utvecklingsstörning brukar i Norden anges till mellan ca 0.5-1.5%. Samexisterande funktionsnedsättningar är vanligt, särskilt ADHD. Lindrig utvecklingsstörning definieras enligt DSM-5 (Diagnostic and Statistical Manual of Mental Disorders, American Psychiatric Association, 2013) med tre kriterier (A-C); A: Brister i intellektuell funktion; problemlösning, abstrakt tänkande och teoretisk inläring, som bekräftas både genom standardiserad testning och vid klinisk bedömning. B: Brister i adaptiv funktion (dagligt fungerande; kognitivt, socialt och avseende praktiska förmågor – i relation till ålder och kulturell grupp). C: Svårigheterna har sitt ursprung under individens utvecklingsperiod.

Lindrig utvecklingsstörning är en svår diagnos att ställa och funktionsnedsättningen är inte lätt att leva med i ett samhälle som ställer ökande krav på kognitiva förmågor. Tillståndet upplevs av många som stigmatiserande, särskilt för dem som får diagnos i tonåren. Rätt diagnos är avgörande för att: 1) kunna ge adekvat information och en förklaring till de svårigheter som föreligger, 2) få tillgång till de stödinsatser som skolan och samhället erbjuder, 3) planera en adekvat medicinsk bedömning och 4) för att kunna få en uppföljning över tid; medicinskt och avseende andra stödinsatser.

Avhandlingsprojektet innehåller fyra delstudier. I *delstudie I* var frågeställningen att kartlägga frekvensen av samtidigt förekommande funktionsnedsättningar och funktionsproblem hos skolbarn med lindrig utvecklingsstörning i två kommuner. Ett nordiskt formulär, "Fem-Till-Femton" (FTF) användes. Förekomsten av lindrig utvecklingsstörning i de studerade kommunerna var 0.85%. Andelen barn och ungdomar med samexisterande funktionsproblem var hög, 55-80% av barnen med lindrig utvecklingsstörning hade betydande svårigheter inom områden som motorik, exekutiv funktion, social förmåga och emotioner/beteende. För ungefär hälften fanns indikationer på samtidig ADHD. Studien visar att barn och ungdomar med lindrig utvecklingsstörning behöver utredas

avseende sannolika tilläggsproblem så att stöd och insatser kan anpassas individuellt.

I den *andra delstudien* jämfördes dessa skolbarn med lindrig utvecklingsstörning (från delstudie I) med en grupp skolbarn med ADHD avseende förmågor i det dagliga livet (adaptiv förmåga). Ett särskilt frågeformulär användes till barnens lärare, "Adaptive Behavior Assessment Scales" (ABAS-II). Studien visade en tendens till att den totala gruppen av barn med ADHD hade mer påtagligt nedsatta funktioner i det dagliga livet jämfört med gruppen som hade lindrig utvecklingsstörning. Skillnaden var signifikant när grupperna med barn över 12 år jämfördes. Barn och ungdomar med lindrig utvecklingsstörning får idag lagstadgade stödinsatser i samhället, medan gruppen med ADHD i allmänhet inte får sådan hjälp. Studien ger också stöd för att man vid utredning och diagnostisering av lindrig utvecklingsstörning behöver beakta att ADHD, mer kan påverka det adaptiva fungerandet, än lindrig utvecklingsstörning.

I *delstudierna tre och fyra* var syftet att undersöka livssituationen för barn – nu unga vuxna (18-25 år) – till mödrar med utvecklingsstörning. Studien omfattade 42 individer. Tre hade avlidit under barndomen, en hade flyttat utomlands och sju avböjde deltagande. Tio individer deltog i en intervjustudie och för 21 söktes information i olika register. I den sammanslagna undersökningsgruppen hade 11 av 31 individer (35%) lindrig utvecklingsstörning och 9 (29%) ADHD. Sexton barn (52%) hade placerats i familjehem eller haft kontaktfamilj under uppväxten. Resultaten från studien visar att barn till mödrar med utvecklingsstörning utgör en sårbar grupp. De är utsatta för "dubbla risker"; dels på grund av en ärftlig sårbarhet för utvecklingsneurologisk/neuropsykiatrisk funktionsnedsättning och dels för risker relaterade till bristande föräldrastöd, vård och omsorg.

# LIST OF PAPERS

This thesis is based on the following studies, referred to in the text by their Roman numerals.

- I. Lindblad I, Gillberg C, Fernell E. ADHD and other associated developmental problems in children with mild mental retardation. The use of the "Five-To-Fifteen" questionnaire in a population-based sample. *Res Dev Disabil.* 2011;32(6):2805-9.
- II. Lindblad I, Svensson L, Landgren M, Nasic S, Tideman E, Gillberg C, Fernell E. Mild intellectual disability and ADHD; a comparative study of school age children's adaptive abilities. *Acta Paediatr.* 2013;102(10):1027-31.
- III. Lindblad I, Billstedt E, Gillberg C, Fernell E. An interview study of young adults born to mothers with mild intellectual disability. *J Intellect Disabil*, Oct. 2013. [Epub ahead of print].
- IV. Lindblad I, Billstedt E, Gillberg C, Fernell E. A register study of life events in young adults born to mothers with mild intellectual disability. Submitted.



# CONTENT

ABBREVIATIONS .....	VII
1 INTRODUCTION.....	1
1.1 Some historical notes.....	1
1.2 Terminology .....	2
1.3 Current definition of ID.....	3
1.4 Prevalence of mild ID.....	7
1.5 Mild ID - diagnostic aspects.....	7
1.5.1 Intelligence .....	8
1.5.2 Adaptive function .....	9
1.6 How intelligence and adaptive function relate to each other.....	11
1.7 Cognitive functions .....	12
1.7.1 Abstract/theoretical thinking.....	12
1.7.2 Executive functions.....	12
1.8 Common coexisting disorders in mild ID.....	13
1.8.1 ADHD.....	14
1.8.2 ASD .....	15
1.8.3 Cerebral palsy (CP) and epilepsy in mild ID .....	15
1.9 Borderline intellectual functioning (BIF).....	15
1.10 ESSENCE.....	16
1.11 Aetiologies.....	17
1.12 School.....	18
1.13 Community support.....	18
1.13.1 Act Concerning Support and Services for Persons with Certain Functional Impairments (SSF) (LSS).....	19
1.14 Risks related to mild ID.....	19
1.14.1 Socio-economic status .....	19
1.14.2 Abuse and bullying.....	20
1.14.3 Attitudes.....	20

1.15	ID and parenthood .....	21
1.15.1	Pregnancy and delivery.....	21
1.15.2	Abuse and neglect of children who have parents with ID .....	22
1.15.3	Parents at risk.....	23
1.15.4	Child-focused approach .....	23
2	AIMS.....	25
3	PARTICIPANTS AND METHODS .....	26
3.1	Participants .....	26
3.1.1	Study I.....	26
3.1.2	Study II .....	27
3.1.3	Study III and Study IV .....	28
3.2	Measurements .....	30
3.2.1	FTF.....	30
3.2.2	ABAS-II.....	31
3.2.3	The interview .....	32
3.2.4	SF-36.....	33
3.2.5	The registers.....	33
3.3	Ethical approvals .....	33
3.4	Statistical analyses.....	34
4	RESULTS.....	35
4.1	Overall findings .....	35
4.1.1	Study I.....	35
4.1.2	Study II .....	37
4.1.3	Study III .....	38
4.1.4	Study IV .....	40
5	DISCUSSION .....	44
5.1	General findings .....	44
5.2	Limitations and strengths.....	45
5.2.1	Study I.....	45
5.2.2	Study II .....	45

5.2.3	Study III and IV .....	45
5.3	Discussion of results obtained .....	47
5.3.1	Mild ID and co-occurring problems/other ESSENCE conditions.....	47
5.3.2	Prevalence of mild ID .....	47
5.3.3	Adaptive function .....	48
5.3.4	Young individuals of mothers with ID – recruitment process..	49
5.3.5	Mortality .....	49
5.3.6	Adverse events and experiences in individuals born to mothers with ID .....	49
5.3.7	SF-36.....	50
5.3.8	ESSENCE .....	51
5.3.9	The need for support and protection .....	51
5.3.10	Double hazards .....	51
5.4	Conclusions and implications for clinical practice.....	52
	ACKNOWLEDGEMENTS .....	55
	REFERENCES .....	59





# ABBREVIATIONS

AAIDD	American Association on Intellectual and Developmental Disabilities
AAMR	American Association on Mental Retardation
ABAS	Adaptive Behavior Assessment System
ADHD	Attention-Deficit/Hyperactivity Disorder
ADD	Attention-Deficit Disorder
APA	American Psychiatric Association
ASD	Autism Spectrum Disorder
BIF	Borderline Intellectual Functioning
BPSMR	Board for Provision of Services to the Mentally Retarded
CD	Conduct Disorder
CON	Conceptual domain
CP	Cerebral Palsy
DSM	Diagnostic and Statistical Manual of Mental Disorders
ESSENCE	Early Symptomatic Syndromes Eliciting Neurodevelopmental Clinical Examinations
FTF	Five-To-Fifteen questionnaire
ICD	The International Classification of Diseases

ICF	The International Classification of Functioning, Disability and Health
ID	Intellectual Disability
IDD	Intellectual Developmental Disorder
IQ	Intelligence Quotient
LSS	Lag om Stöd och Service till vissa funktionshindrade (see SSF)
MR	Mental Retardation
MMR	Mild Mental Retardation
ODD	Oppositional Defiant Disorder
PPS	Prison and Probation Services
PRA	Practical domain
SD	Standard Deviation
SFS	Svensk Författningssamling (Swedish law)
SOC	Social domain
SSF	Support and Services for Persons with Certain Functional Impairments (see LSS)
WHO	World Health Organization
WISC	Wechsler Intelligence Scale for Children

# 1 INTRODUCTION

## 1.1 Some historical notes

Intellectual disability (ID) is related to how well people learn. The disability has existed throughout history, but the terminology, attitudes and manner in which individuals with ID have been perceived – from being excluded to having received legal rights and participation in society – have changed considerably (Bray, 2003; Grunewald, 2009).

During the 1600s and 1700s thoughts of education and learning for individuals with ID were raised by John Locke (1632-1704) and Jean Jacques Rousseau (1712-1778). During the 1870s, education for “feeble-minded” children started in Sweden at institutions named “school homes”. A pioneer was Emanuela Carlbeck who in 1875 started an institution for “feeble-minded” children in Mariestad, a town in south-western Sweden.

The first intelligence test was developed by the French psychologist Alfred Binet in 1905. The aim of developing an intelligence test was to get a tool to find out which children needed special help at school (Bray, 2003). The test became a prototype for forthcoming intelligence tests. The knowledge that now emerged was that intelligence is not a characteristic that is equal for everyone but that intelligence varies between individuals.

Concerns regarding parenting skills among individuals with for example; ID, psychiatric disorders, criminality and other abnormal behaviours have been raised and debated (Grunewald, 2009). The first law for sterilizing of individuals with ID appeared in the US in 1907, in Denmark 1929, and in Sweden 1934, and a law that allowed forced sterilization lasted until 1976 in Sweden (Grunewald, 2009).

The Boards for Provision and Services to the Mentally Retarded (BPSMR) were implemented in the mid-1950s in Sweden and were established in order to identify and register all people with intellectual disabilities (Umb Carlsson, 2008). The boards’ assignments were to provide special services and support to individuals with ID.

Until the late 1960s a common phenomenon in Swedish society was to hide and protect the public from people with major disabilities, especially those with ID. Therefore, many individuals with disabilities were cared for in institutions. In 1968 the Act of services to the mentally retarded

(Swedish Omsorgslagen, Svensk författningssamling, SFS) was developed to implement normalization and integration of individuals with ID. This law should also guarantee all children the right to education. During the 1970s - and '80s the large institutions were closed, a process that was accelerated by a revised legislation in 1986. In 1994, a revision and extension of the law was performed, now named Act Concerning Support and Services for Persons with Certain Functional Impairments (SSF) (Swedish LSS, SFS).

In the agrarian society, many individuals with ID had regular employment, but with industrialization many of those with ID became unemployed (Grunewald, 2009). Today's society places increasing demands on cognitive skills. Labour and employment conditions require well developed cognitive skills, including executive functions, and there are fewer practical jobs available. It can be assumed that individuals with mild ID, with an intelligence quotient (IQ) close to borderline intellectual functioning (BIF), a few decades ago had an easier time finding a suitable job, compared with the situation of today.

## 1.2 Terminology

The terminology for what we now call ID (Diagnostic and Statistical Manual of Mental Disorders 5<sup>th</sup> edition, DSM-5) has shifted over time (Table 1, from Bray 2003). A main reason for this change of expressions has been that the terms have become perceived as derogatory and therefore not acceptable. Common, recently used terms, besides the DSM-5 terminology (American Psychiatric Association, APA, 2013) ID and intellectual developmental disorder (IDD), include mental retardation (MR), learning disability, learning difficulty and slow learner. The main term used in DSM-5, ID, was already used by the American Association on Intellectual and Developmental Disabilities (AAIDD) (Schalock et al., 2010) since 2006. In the previous edition, DSM-IV (APA, 2000) the term mental retardation was used. In the World Health Organization (WHO) classification system; International Classification of Diseases (ICD) 10, the term MR is still used. In the upcoming ICD-11, the proposed terminology is IDD (Salvador-Carulla et al., 2011). IDD is already used in the current DSM-5, i.e., ID/IDD.

*Table 1. Labels that have been used for ID, in alphabetical order (adapted from Bray, 2003)*

Backward
Cretin
Educable
Educationally subnormal
Feeble-minded
Idiot
Imbecile
IDD
ID
Intellectual disadvantage
Intellectual handicap
Learning difficulty
Learning disability
Mental deficiency
Mental handicap
MR
Mental subnormality
Moron
Slow learner
Trainable

### 1.3 Current definition of ID

ID refers to an intellectual, cognitive and developmental disability (Harris, 2006). The main cognitive deficit relates to the ability of abstract/theoretical thinking. According to the DSM-5 (APA, 2013) ID is defined as 1) a deficit in intellectual functions (criterion A), 2) a deficit in adaptive functions (criterion B) and 3) with an onset during the developmental period (criterion C). The deficit in intellectual functioning (criterion A) has to be confirmed by both clinical assessment and intelligence testing. The psychometric definition means that individuals with ID have scores of approximately 2 SDs or more below the population mean of 100, including a margin for measurement error (generally  $\pm 5$  points). Thus, the cut-off point will correspond to a score of 65-75 ( $70 \pm 5$ ). The second criterion, referring to adaptive functioning (criterion B) involves adaptive functioning in three domains: The conceptual domain (CON), the social domain (SOC) and the practical domain (PRA). The adaptive functioning is assessed by using both “psychometrically sound measures” and clinical evaluation. Criterion B is met when at least one of the three domains, CON, SOC and PRA is sufficiently impaired in one or

more life settings. The third criterion (criterion C) emphasises the onset during the developmental period, i.e., during childhood or adolescence (Table 2). DSM-5 also includes paragraphs about associated features, development and course, risk and prognostic factors and differential diagnosis.

Table 2. *Diagnostic criteria for ID/IDD according to the DSM-5 (APA, 2013)*

Intellectual disability (intellectual developmental disorder) is a disorder with onset during the developmental period that includes both intellectual and adaptive functioning deficits in conceptual, social, and practical domains. The following three criteria must be met:

A. Deficits in intellectual functioning, such as reasoning, problem solving, planning, abstract thinking, judgment, academic learning and learning from experience, confirmed by both clinical assessment and individualized, standardized intelligence testing.

B. Deficits in adaptive functioning that result in failure to meet developmental and sociocultural standards for personal independence and social responsibility. Without ongoing support, the adaptive deficits limit functioning in one or more activities of daily life, such as communication, social participation, and independent living, across multiple environments, such as home, school, work, and community.

C. Onset of intellectual and adaptive deficits during the developmental period.

ID should be specified as regards severity, i.e., mild, moderate, severe or profound (APA, 2013). The severity is defined in accordance with adaptive functioning level;

*Mild* An individual with mild ID needs support with academic skills, i.e., abstract thinking and executive functioning. The individual can often live independently within their community, however with additional support. This support may include assistance with life decisions, money managing and “*support is typically needed to raise a family*” (p. 34; DSM-5).

The WHO uses two classifications of ID/MR: one pertaining to the diagnosis of ID (ICD-10) and the other for the classification of function (the International Classification of Functioning, Disability and Health, ICF). ICD-10 (WHO, 1992) (Table 3) uses a multiaxial system to describe different aspects of ID. ICD-10 stresses the complexity of diagnosis.

Table 3. *Diagnostic criteria for mild MR according to the IDC-10 axis I*

Clinical description

Mildly retarded people acquire language with some delay but most achieve the ability to use speech for everyday purposes, to hold conversations, and to engage in the clinical interview. Most of them also achieve full independence in self-care (eating, washing, dressing, bowel and bladder control) and in practical and domestic skills, even if the rate of development is considerably slower than normal. The main difficulties are usually seen in academic school work, and many have particular problems in reading and writing. However, mildly retarded people can be greatly helped by education designed to develop their skills and compensate for their handicaps. Most of those in the higher ranges of mental retardation are potentially capable of work demanding practical rather than academic abilities, including unskilled or semiskilled manual labour. In a sociocultural context requiring little academic achievement, some degree of mild retardation may not itself represent a problem. However, if there is also a noticeable emotional and social immaturity, the consequences of the handicap, e.g. inability to cope with the demands of marriage or child-rearing, or difficulty fitting in with cultural traditions and expectations, will be apparent.

In general the behavioural, emotional, and social difficulties of the mildly mentally retarded, and the needs for treatment are more closely akin to those found in people of normal intelligence than to the specific problems of the moderately and severely retarded. An organic aetiology is being identified in increasing proportions of patients, although not yet in the majority.

Diagnostic guidelines

If the proper standardized IQ tests are used, the range 50 to 69 is indicative of mild mental retardation. Understanding and use of language tend to be delayed to a varying degree, and executive speech problems that interfere with the development of independence may persist into adult life. An organic aetiology is identifiable in only a minority of subjects. Associated conditions such as autism, other developmental disorders, epilepsy, conduct disorders, or physical disability are found in varying proportion. If such disorders are present, they should be coded independently.

The ICF describes the actual life of people within the areas of; mental and physical functioning, activities and participation and environmental factors (WHO, 2001).

The AAIDD has a wide-ranging definition that focus mainly on functioning, adaptive behaviour and support. Their definition of ID is: “significant limitations *both* in intellectual functioning and in adaptive

behaviour as expressed in conceptual, social, and practical adaptive skills. This disability originates before age 18” (Schalock et al., 2010) (Table 4).

Table 4. *AAIDD criteria for ID*

**Intellectual Functioning**

*Intellectual functioning*—also called intelligence—refers to general mental capacity, such as learning, reasoning, problem solving, and so on.

One way to measure intellectual functioning is an IQ test. Generally, an IQ test score of around 70 or as high as 75 indicates a limitation in intellectual functioning.

**Adaptive Behaviour**

*Adaptive behaviour* is the collection of conceptual, social, and practical skills that are learned and performed by people in their everyday lives.

Conceptual skills—language and literacy; money, time, and number concepts; and self-direction.

Social skills—interpersonal skills, social responsibility, self-esteem, gullibility, naïveté (i.e., wariness), social problem solving, and the ability to follow rules/obey laws and to avoid being victimized.

Practical skills—activities of daily living (personal care), occupational skills, healthcare, travel/transportation, schedules/routines, safety, use of money, use of the telephone.

Standardized tests can also determine limitations in adaptive behavior.

**Age of Onset**

This condition is one of several developmental disabilities—that is, there is evidence of the disability during the developmental period, which in the US is operationalized as before the age of 18.

**Additional Considerations**

But in defining and assessing intellectual disability, the AAIDD stresses that additional factors must be taken into account, such as the community environment typical of the individual’s peers and culture. Professionals should also consider linguistic diversity and cultural differences in the way people communicate, move, and behave.

Finally, assessments must also assume that limitations in individuals often coexist with strengths, and that a person’s level of life functioning will improve if appropriate personalized supports are provided over a sustained period.

Only on the basis of such many-sided evaluations can professionals determine whether an individual has intellectual disability and tailor individualized support plans.



## 1.4 Prevalence of mild ID

The prevalence of mild ID in children varies according to the definition of “mild”, which psychometric measures that have been used, whether an adaptive criterion has been included or not, age group studied and the demographic characteristics, i.e., socioeconomic status of the region under study. Nordic studies published between 1981 and 1998 reported a prevalence for children with mild ID between 0.38 % and 1.3 % (Blomquist, Gustavson, & Holmgren, 1981; Fernell, 1996; Gillberg, Svenson, Carlstrom, Waldenstrom, & Rasmussen, 1983; Hagberg, Hagberg, Lewerth, & Lindberg, 1981; Strømme & Valvatne, 1998). The lowest prevalence was found by Hagberg and colleagues (1981). They used a definition of mild ID that combined individuals receiving or who had received services from the BPSMR with other sources, such as hospital records and information gathered from school nurses and school psychologists. In an age-group of 8-12 year-old individuals they found a prevalence of 0.37%. Blomquist and colleagues (1981) reported a prevalence of 0.38% in 8-19 year-old children in a northern Swedish county. The authors encompassed individuals receiving or who had received services from the BPSMR or similar help from the community. Gillberg and colleagues (1983) studied the prevalence of mild ID in children 8-9 year old, based on data in the BPSMR and a sample of children with perceptual, motor and attention deficits who were assessed to have an IQ of 50-73. They found a prevalence of 0.56. A higher prevalence (1.28%) was found by Fernell (1996) in a population based study among children aged 9-15 years. The method included both a psychometric criterion and an adaptive, clinical criterion. The author discussed that this prevalence could reflect the relatively low socioeconomic status in the municipality under study and perhaps also the fact that testing had been more acceptable in schools (Fernell, 1996). In the Norwegian study by Strømme and Valvatne (1998), carried out in an area with a high socioeconomic status a prevalence of 0.35% was found for mild ID in childhood.

## 1.5 Mild ID - diagnostic aspects

Preschool problems, indicative of mild ID, are usually in the domain of a general “developmental delay”, with delayed speech and language and/or motor development, and attention problems. In some cases, symptoms suggestive of clear cognitive impairment have been noted in the preschool period. Many children with mild ID start mainstream schooling and are

identified with learning difficulties only during their first school-years, or later, as demands on cognitive skills increase.

According to a Swedish study (Fernel & Bremberg, 1996), only 22% of the children with mild ID had been diagnosed before school start. The majority of the children had been diagnosed between 10 and 12 years of age.

The psychologist's assessment of the child's cognitive functions requires knowledge and experience of child development, clinical training in the test instruments and testing procedure and of summing up and drawing conclusions from all available information gathered (Nyman, 2011). A close collaboration between the psychologist and a physician with experience in the field is necessary for the complete clinical assessment. In many cases there is also a need for additional investigations of the child; regarding for example motor functions, speech and language abilities, and educational/academic functioning.

The complete assessment requires considerations also of aetiology, evaluation of co-occurring conditions (medical, mental, emotional and behavioural) (APA, 2013; WHO, 1992).

### **1.5.1 Intelligence**

Intelligence is often divided into two main areas, designated by the terms "fluid" and "crystallized" talent (Smedler & Tideman, 2009). "Fluid" talent is often described as a primarily biological condition, logic thinking and problem solving in novel situations, independent of acquired knowledge. "Crystallized" intelligence involves knowledge that comes from prior learning and past experiences. This type of intelligence is based upon facts and rooted in experiences. As we age and accumulate new knowledge and understanding, crystallized intelligence becomes stronger.

Assessing intellectual functions in children and adolescents requires knowledge of child development in general and also in children with neurodevelopmental deviations and disorders (Ek, 2012). There is a wide variation in "the normal development of children", which is visualized by the normal distribution graph (Figure 1).

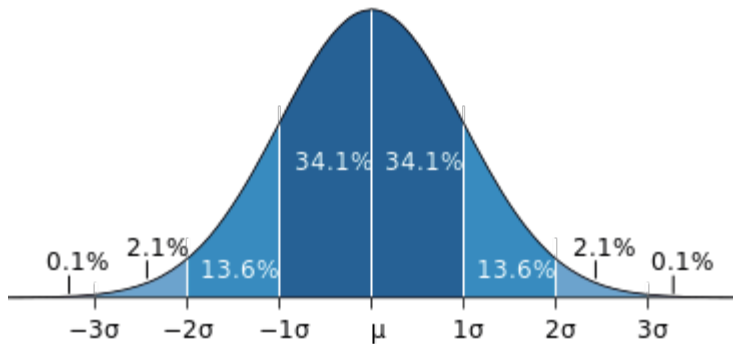


Figure 1. The normal distribution graph

Different test instruments are used to assess intelligence. What kind of instrument is selected depends on different aspects, including the age of the child, the child's developmental age and language development (Ek, 2012). The test instruments used measure theoretical talent, including various domains, such as verbal/logic reasoning, cognitive/perceptual function, working memory and processing speed.

The most common intelligence tests used today in school age children are the Wechsler Intelligence Scale for Children (WISC) (currently WISC-IV) (Wechsler, 2003) and the Leiter-R scales (Leiter, 1979) (Smedler & Tideman, 2009). The Wechsler scales include both a verbal and a non-verbal domain, while the Leiter-R is a non-verbal test.

The test procedure also should include a general assessment of the child's well-being, mood and ability to cooperate in the test. Moreover, any specific impairment that could negatively affect the child's ability to cooperate, motor impairment, visual or hearing impairments or specific behavioural problems needs also to be considered.

### 1.5.2 Adaptive function

ID is associated with impairments in adaptive functioning and this factor is considered on an equal footing as measured IQ (Intelligence Quotient) in the diagnostic process. These adaptive, functional impairments or limitations may exist throughout the lifespan. In 1983 the American Association on Mental Retardation (AAMR), now AAIDD since 2006, stated that adaptive behaviour is related both to development and to cultural expectations (Grossman, 1983). A further development of the

definition of adaptive functions then emerged and in 1992 AAMR highlighted 10 adaptive skills that would constitute adaptive behaviour: communication, community use, functional academics, home and school living, health and safety, leisure, self-care, self-direction, social, and work. By incorporating these ten skills, with requirements for different ages, AAMR (2002) has now collapsed these 10 skills and identified three areas that identify the multidimensional components of adaptive function; CON, SOC and PRA (Luckasson et al., 2002) (Table 5). This definition of adaptive functioning is also used in the DSM-5.

Table 5. *Adaptive skills and domains according to AAIDD*

<b>Domains</b>	<b>Adaptive skills</b>	<b>Associated skills</b>
CON	Communication	Speech, language, and listening skills needed for communication, including vocabulary, responding to questions, and conversation skills
	Community use	Skills needed for functioning in the community, including use of community resources, shopping skills, and traveling in the community
	Functional academics	Basic reading, writing, mathematics, and other academic skills needed for daily, independent functioning, including telling time, measurement, and writing notes or letters
SOC	Home/School living	Skills needed for basic care of a home, living setting or school, including cleaning, organizing, maintaining and repairing property, preparing food, and performing chores
	Health and safety	Skills needed for the protection of health and to respond to illness and injury, including following safety rules, using medicines, and showing caution
	Leisure	Skills needed for engaging in and planning leisure and recreational activities, including playing with others, engaging in recreation at home, and following rules in games
PRA	Self-care	Skills needed for personal care including eating, dressing, bathing, toileting, grooming, and hygiene
	Self-direction	Skills needed for independence, responsibility, and self-control, including starting and completing tasks, keeping a schedule, following time limits, following directions, and making choices
	Social	Skills needed to interact socially and get along with other people, including having friends, showing and recognizing emotions, assisting others, and using manners
	Work	Skills needed for successfully holding a job and functioning in a part-time or full-time work setting, including completing work tasks, working with supervisors, and following a work schedule

The history of systematically measuring adaptive functions started already in 1936 with the Vineland Social Maturity Scale (VSMS) (Doll, 1936). In 1968 the first standardized assessment instrument was published, the Adaptive Behaviour Checklist (Nihira, Foster, Shellhaas, & Leland,

1968). This instrument was then revised to Vineland Adaptive Behavior Scales in 1984 (Sparrow, Balla, & Cicchetti). There are now about 200 scales for measuring adaptive behaviour (Schalock, 1999). According to Schalock and collaborators (2010) and to Tasse and collaborators (2012) only four have psychometrically sound measures; Adaptive Behavior Assessment System, Second Edition (ABAS-II) (Harrison & Oakland, 2003), Adaptive Behaviour Scale – School, Second Edition (ABAS-S:2) (Lambert, Nihira, & Leland, 1993), Scales of Independent Behaviour, Revised (SIB-R) (Bruininks, Woodcock, Weatherman, & Hill, 1996) and Vineland Adaptive Behavior Scales – Second Edition (VABS-II) (Sparrow, Cicchetti, & Balla, 2005; Tasse et al., 2012). All four are standardized in the U.S. on individuals with and without ID, have evidence of reliability and validity and are based on the three-factor structure of adaptive behaviour (CON, SOC and PRA).

ABAS-II is constructed according to the definitions prepared by APA and AAMR/AAIDD and has been clinical validated in Sweden on controls and on a small group with mild ID (ABAS-II, 2008).

## 1.6 How intelligence and adaptive function relate to each other

Intelligence and adaptive capability are related, but still represent separate concepts (ABAS-II, 2008). Intelligence reflects the *maximum* performance, while adaptive behaviour refers to everyday behaviours and should reflect the *typical* performance. The correlation between adaptive behaviour, measured for example with ABAS-II, and measured IQ is approximately 0.3-0.5 (Sattler & Hodge, 2006). The communication skill, as part of the adaptive behaviour CON domain, measured with ABAS-II, has been shown to be associated with IQ, more than other skills for adaptive function (Harris, 1989).

Several aspects have been found to relate to adaptive functioning. Matson and collaborators (2009) studied autism spectrum disorder (ASD) and what they called psychopathology and found that these conditions affect adaptive functioning more than ID. Papazoglou and colleagues (2013) found that adaptive impairment was comparable between a group characterized by low intelligence and a group with average intelligence but with significant behavioural dysregulation. They concluded that adaptive functioning should be considered across various co-occurring disorders.

Stein and colleagues (1995) compared adaptive functioning in groups of children with ADHD (Attention-Deficit/Hyperactivity Disorder), ADD (Attention-Deficit Disorder) and in children with pervasive developmental disorders or mild ID. They found that *“the level of adaptive functioning relative to IQ in the areas of Socialization, Communication and Daily Living was significantly lower for the ADD and ADHD groups. These deficits in adaptive functioning that characterize children with ADHD and ADD may help explain the poor long-term prognosis of ADHD, suggesting that increased attention should be paid to the assessment and treatment of adaptive functioning in individuals with ADHD and ADD”* (p. 663; Stein et al., 1995).

## **1.7 Cognitive functions**

### **1.7.1 Abstract/theoretical thinking**

Abstract or theoretical thinking is a cognitive skill that helps to understand concepts that are not immediately obvious. It includes complex reasoning, problem solving, symbolic thinking and the ability to think about objects, principles, and ideas that are not physically present. Abstract/theoretical thinking is fundamentally impaired in ID and is measured with IQ tests (see above). These cognitive tests include verbal and non-verbal components, and in some individuals the abilities may differ considerably between the two. The verbal IQ reflects the ability to make analyses, reasoning and to draw conclusions and the performance IQ measures spatial thinking and various aspects of non-verbal reasoning.

### **1.7.2 Executive functions**

Executive functions are usually agreed to be defined as the skills necessary for purposeful, goal-directed activity (Anderson, 1998; Shallice, 1982; Spreen, Risser, & Edgell, 1995; Stuss & Benson, 1986). Another definition suggested is *“cognitive abilities necessary for goal-directed behaviour and adaption to a range of environmental changes and demands”* (p. 64; Loring, 1999). Executive functions consists of a cluster of skills that are well coordinated for the purpose of assisting the goal-directed behaviour (Molfese & Molfese, 2002). The executive functions are general control mechanisms for coordinating and integrating information, activity and attention (Fors & Tideman, 2007). Neuropsychological studies suggest that these skills are largely controlled from the frontal lobes (Duffy & Campbell, 2001; Duke & Kaszniak, 2000; Stuss & Benson, 1986).

The prefrontal regions are relatively immature during childhood, but continue to develop into early adolescence (Anderson, 1998). The executive functions are not considered to be fully developed until adulthood (Fors & Tideman, 2007). Individuals with developmental disabilities are unlikely to develop the executive functions fully, which in turn could have an impact on the development of adaptive skills (Anderson, 1998).

Friedman and collaborators (2006) investigated the relationship between IQ and executive functions; measured as inhibition, shifting and updating working memory, in a population with normally distributed cognitive abilities. The results showed that IQ was related to only one of the three executive functions measured; updating working memory. These findings indicate that there is an association between IQ and working memory, which is consistent with earlier findings (Carpenter, Just, & Shell, 1990; Engle, Tuholski, Laughlin, & Conway, 1999). Danielsson and collaborators (2010) found that adults with ID had difficulties in working memory-related executive control. There are relatively few studies of executive functioning in children with mild ID.

## **1.8 Common coexisting disorders in mild ID**

Approximately 30-50% of individuals with ID have coexisting neurodevelopmental/neuropsychiatric disorders (Dekker & Koot, 2003; Einfeld, Ellis, & Emerson, 2011; Emerson & Einfeld, 2010; Emerson & Hatton, 2007a; Gillberg, Persson, Grufman, & Themner, 1986).

Children with mild ID had been found to be at increased risk for social problems, attention problems, and aggressive behaviour (Dekker, Koot, Ende, & Verhulst, 2002). Einfeld and Tonge (1996) found that disruptive behaviour and antisocial behaviours were more common among children with mild ID compared to children with more severe ID.

Gillberg and colleagues compared children and adolescents with mild and severe ID and found that those with mild ID had higher rates of depressive feelings, emotional disorder and antisocial behaviour than the group with severe ID where ASD was more common (Gillberg et al., 1986). In a US study depressive disorder was found to be the most common psychiatric disorder among children with mild ID (Hurley, Folstein, & Lam, 2003).

Despite the high prevalence of coexisting disorders, Einfeld and Tonge (1996) found that only 9% of the children with ID combined with a

psychiatric disorder had received specialist assistance. In a Swedish study (Gustavson, Umb-Carlsson, & Sonnander, 2005) of individuals with ID, only about 50% of the individuals had had an appropriate psychiatric assessment.

### **1.8.1 ADHD**

ADHD is a disorder that impacts the life of children and adolescents due to significant symptoms within three central areas; attention, impulsivity and activity regulation (APA, 2013). Social difficulties are often also associated with ADHD (Barkley, Fischer, Edelbrock, & Smallish, 1991; Hinshaw, 1992). The main cognitive deficit consists of impaired executive functions (Barkley, 1998, 2010). The prevalence of ADHD in children is about 5% (Faraone, Sergeant, Gillberg, & Biederman, 2003). In most instances childhood ADHD is combined with other neurodevelopmental/neuropsychiatric disorders (Kadesjo & Gillberg, 2001). Studies of adults with ADHD have revealed a high prevalence of co-occurring psychiatric disorders (Kessler et al., 2006), criminal behaviour (Rasmussen & Gillberg, 2000) and of substance abuse (Kessler et al., 2006; Rasmussen & Gillberg, 2000). In prison inmates the prevalence of ADHD was found to be about 40% (Ginsberg, Hirvikoski, & Lindefors, 2010).

ADHD occurs more commonly in children with ID but there is a risk that ADHD is not identified when it coexists with ID, i.e., coexisting disorders may easily be over-looked in children with ID (Fuller & Sabatino, 1998). Dekker and Koot (2003) found a prevalence of ADHD of 15% in children with ID.

Simonoff and collaborators (2007) studied emotional and behavioural problems, including ADHD symptoms, using the SDQ (Strengths and Difficulties Questionnaire) (Goodman, 1997) in a representative sample of 12–15-year-old children of different intellectual levels. They demonstrated that symptoms of ADHD were very frequent in children with ID and that the presence of ADHD symptoms was linearly related to lower IQ.

The group of children with the combination of mild ID and ADHD appears to be a severely impaired group with increased rates of conduct disorder (CD) and oppositional defiant disorder (ODD) symptoms, in comparison with the groups of “only” ID and “only” ADHD separately (Ahuja, Martin, Langley, & Thapar, 2013). Lindsey (2002) has suggested



that guidelines for identifying inattention, overactivity and impulsivity in individuals with ID are needed.

### **1.8.2 ASD**

ASD with its main problem in the area of social communication often co-occurs with ID. In younger, population-based, age-groups of children with ASD, the rate of ID is about 50% (Fennell et al., 2011). In representative groups of school-age children, in which the number of milder ASD types (without ID) have been recognized and diagnosed, the rate of co-occurring ID is about 15-20% (Gillberg, 2010).

### **1.8.3 Cerebral palsy (CP) and epilepsy in mild ID**

In the Swedish population-based study of children with mild ID by Hagberg et al (1981), epilepsy was found in 12% and CP in 9%. The authors also analysed psychiatric disturbances in this group and found the prevalence to be 31%. In a study 15 years later in Sweden (Fennell, 1996) the prevalence of CP in children with mild ID was found to be 6%. In a population-based study from southern Sweden, comprising more than 360 children, 18% had mild ID (Lauruschkus, Westbom, Hallstrom, Wagner, & Nordmark, 2013). The prevalence of epilepsy in school children with ID was analysed in a Swedish study by Steffenburg et al (1995). In children with mild ID 15% had active epilepsy.

## **1.9 Borderline intellectual functioning (BIF)**

BIF is neither an intellectual disorder nor a disability (Ferrari, 2009). Under the DSM-IV-TR (APA, 2000) BIF was defined as an IQ in the range between 70-84 (i.e. -1 to -2 SD below the mean of 100).

There are few studies addressing BIF (Fennell & Ek, 2010). One study including children with BIF, as well as children with mild ID, reported an increased risk for psychopathology (Volkmar & Klin, 2004). Fennell and Ek (2010) examined adolescents in special school/upper secondary school for pupils with mild ID and found that a considerable number of the children diagnosed with mild ID did not meet the combined IQ and adaptive criteria for the disorder. The authors suggested that this partly could be due to lack of school alternatives for children with BIF. Some of these adolescents also had definite attention problems that had influenced (“lowered”) their total IQ score.

## 1.10 ESSENCE

The co-occurrence of symptoms across different neurodevelopmental/psychiatric disorders has been demonstrated in several studies (Chawarska, Klin, Paul, Macari, & Volkmar, 2009; Einfeld et al., 2011; Emerson & Einfeld, 2010; Emerson & Hatton, 2007a; Kadesjo & Gillberg, 2001; Kantzer, Fernell, Gillberg, & Miniscalco, 2013; Reiersen, Constantino, Volk, & Todd, 2007). Despite this, many child and adolescent clinics are specialized and directed to specific disorders, i.e., ADHD or ASD or Speech and Language Impairments (Gillberg, 2010). This may lead to combinations of developmental problems not being adequately recognised, and that proper assessment and interventions may not be initiated. The problem was expressed by the late Donald Cohen; “*the children haven’t read the text books*” (p. 873; Volkmar & Klin, 2004).

ESSENCE (Early Symptomatic Syndromes Eliciting Neurodevelopmental Clinical Examinations) was coined by Gillberg (2010) to emphasise the importance of examining children with developmental deviations “*in the fields of; (a) general development, (b) communication and language, (c) social interrelatedness, (d) motor coordination, (e) attention, (f) activity, (g) behaviour, (h) mood, an/or (sleep)*” (p. 1544; Gillberg, 2010). Children with symptoms in one or more of these fields need tailored multidisciplinary assessment.

ESSENCE is an umbrella term for different syndromes listed in Table 6. It is important to point out that ESSENCE is not a diagnosis in itself.

Table 6. *Syndromes included in ESSENCE (modified from Gillberg, 2010)*

<b>Syndrome</b>	<b>Prevalence</b>
ADHD	5%
Developmental coordination disorder	5%
ODD	4%
ID	1.5%
Speech and language impairment	2-4%
ASD	1%
Tic disorders/Tourettes syndrome	1%
Bipolar disorder	1%
Reactive attachment disorder	0.5-1%
Behavioural phenotype syndromes	1%
Rare epilepsy syndromes	0.01%
Total taking overlap into account	7-10%

## 1.11 Aetiologies

Efforts to identify the aetiology of mild ID are important (Shea, 2006). When ID/mild ID has been diagnosed, a medical assessment must follow. This assessment includes a detailed history regarding family background, parents' medical and psychiatric history, other prenatal and also peri – and postnatal factors and an assessment of the child with regard to height, weight, head circumference, hearing, vision, general function, associated impairments, minor physical anomalies and other signs that could give indications as to aetiology. If a specific aetiology is identified, this provides the opportunity to discuss specific treatment, prognosis and also genetic factors, including recurrence risk (Moeschler, 2008).

Identifying the aetiology could also make social support and information more accessible for the family and professionals; i.e. in some instances diagnose-specific guidelines are made available (Moeschler, 2008). It is also suggested that an aetiological diagnosis may contribute to a feeling of control for the family: *“As physicians we have experience with other children who have the same disorder, access to management programs, knowledge of the prognosis, awareness of research on understanding the disease and many other elements that when shared with the parents will*

*give them a feeling that some control is possible*” (p. 2; Rosenbaum, 1988).

## **1.12 School**

School attendance is compulsory for all children living in Sweden (The Swedish National Agency for Education, 2013). Children with ID can choose to attend mainstream school or programmes for students with ID. “Special schooling” consists of 9 to 10 years of schooling. After compulsory school adolescents with ID can attend 4 years of special upper secondary school.

In 2011, a reform was implemented and the focus for the compulsory school for pupils with ID now changed (The Swedish National Agency for Education, 2010). Former evaluations at school of children with ID were based on the individual’s functional abilities. The new reform implies that children and adolescents with ID now will be judged by academic knowledge. Grades should be given only at the request of a student or parent/carer in school-year 6 and 9.

## **1.13 Community support**

In the 1950s social support and service to individuals with ID were given from county council authorities (i.e. the BPSMR) (Umb Carlsson, 2008). In these authorities all individuals with diagnosed ID were registered and were provided with different kinds of service. At the end of the 1960s a concept termed “the normalization process” was introduced and with this concept the service now changed from being county based authorities to local, community-based authorities (providing day care, group homes and day centres). Individuals with ID are eligible to receive LSS/SSF service (see below) provided optionally on the request of the persons concerned or their proxy. The service and support given by LSS/SSF are expected to be individualized and planned in cooperation with the individual concerned and/or their proxies.

Individuals with ID obtain their health care from the public health system in Sweden and the same applies for individuals in the UK (Lindsey, 2002). Individuals with ID have a higher proportion of co-occurring disabilities (see above) and are in need of tailored considerations with regard to aetiology (see above). Lindsey (2002) highlighted the risks that special health care for individuals with ID, despite these needs, was not

provided; i.e., individuals with ID need to be aware of their own special needs to get tailored support. It has also been pointed out that professionals, meeting individuals with ID with different types of illnesses, may not be fully specialized or aware of the specific needs of this patient group. Lindsey (2002) therefore emphasised the need for comprehensive health care services for individuals with ID.

Nowak and colleagues (2013) conducted interviews with parents of children in Sweden to investigate the parents' experiences of received support. The study revealed that parents had encountered difficulties to obtain information about available services and that these services had not been easy to get access to.

### **1.13.1 Act Concerning Support and Services for Persons with Certain Functional Impairments (SSF) (LSS)**

The teams organised under the SSF provide services for children and adults with different kinds of disabilities (National Board of Health and Welfare, 2013). LSS (Swedish term) is targeted to three defined categories of functionally impaired individuals (1 to 3). Individuals with ID and/or ASD comprise the first of these categories. The services consist of ten different types of interventions: Counselling and other personal support, Personal assistance, Companion service, Contact person, Relief service in the home, Short stay away from home, Short period of supervision for schoolchildren over age of 12, Contact family (children), Supported housing (adults) and Daily activities. The municipalities are responsible for most of the interventions. The most common services provided for individuals in category 1 are Daily activities, the Supported housing and Contact person.

## **1.14 Risks related to mild ID**

### **1.14.1 Socio-economic status**

Low socio-economic status has been found in a higher prevalence among parents of children with mild ID than among parents of children with more severe ID (Strømme & Magnus, 2000).

Emerson and Hatton (2007a) found a significant association between ID in children and social and environmental risk factors; poverty, one-parent family, exposure to negative life events and households with no paid

employment were all more common in families with a child with mild ID. Sidebotham and collaborators (2006) found that socio-economic status was associated with child abuse and neglect.

An increased risk of socio-economic disadvantage has been found among mothers of children with ID (Emerson & Hatton, 2007b). In another study socioeconomically disadvantaged women, had at least a five-fold increase in the risk of having a child with mild or moderate ID (Leonard et al., 2005).

### **1.14.2 Abuse and bullying**

Children with disabilities are at increased risk of all types of abuse compared to children without disabilities (Svensson, Bornehag, & Janson, 2011). The risk of abuse has been found to be at least three times higher in disabled children than in children in the general population (Child Welfare Information Gateway, 2012; Sullivan & Knutson, 2000).

In a review of studies regarding abuse among children with ID, Jones and colleagues (2012) found that children with ID or mental disabilities had a higher risk to be victims of violence than children with other disabilities. The risk was increased for physical violence, emotional abuse and sexual violence. This accords well with the findings by Spencer and colleagues (2005) reporting that the most vulnerable group for abuse and neglect were children with learning difficulties. They also found that children with CD were at many times greater risk for these adverse experiences than typically developed peers or children with ADHD. Jones and collaborators (2012) have pointed out the dearth of research in this area despite the awareness of the issue.

### **1.14.3 Attitudes**

In spite of the introduction of central concepts in society regarding social inclusion and community participation for individuals with ID, there are still reports that there are suspicions and even hostility to integrating persons with ID (Antonak & Harth, 1994; McCaughey & Strohmer, 2005; Yazbeck, McVilly, & Parmenter, 2004). Important factors for creating positive attitudes and for increasing acceptance are active interactions between individuals in the general population and individuals with ID (Lau & Cheung, 1999).

A recent study (Morin, Rivard, Crocker, Boursier, & Caron, 2013) showed that public attitudes now generally have become more positive

than reported in earlier studies (Antonak & Harth, 1994; McCaughey & Strohmer, 2005; Yazbeck et al., 2004), but still there are reports that individuals with ID feel discomfort and that attitudes tend to be negative towards this group of individuals (Morin et al., 2013).

## **1.15 ID and parenthood**

Almost all individuals with ID who become parents have mild ID (Bager, 2003; IASSID, 2008; Willems, de Vries, Isarin, & Reinders, 2007). In Australia, it was estimated that 1–2% of families with children aged 0–17 years included at least one parent with ID (Lamont & Bromfield, 2009). The estimated population prevalence of individuals with ID who become parents vary across countries. In the Netherlands, Willems and colleagues (2007) found that parenthood occurred in 1.5% of adults with ID. In Sweden, Bager (2003) found a prevalence of at least 0.14% of children born to women with ID. In another Swedish study, Weiber and collaborators (2011) found that approximately 0.21% of the general population of children were born to women with ID per year. The authors highlighted that this means that there are about 4050 children (aged 0–18 years) in Sweden born to women with ID. These prevalence rates are likely to be extreme underestimations given that probably only a portion of cases with “real” ID are to be found in official registers, and that “unregistered” women with ID are likely to often become parents.

Parents with ID face problems that make parenthood more difficult (IASSID, 2008). Individuals with ID are more often exposed to poverty and prejudice and may also have other disabilities. Lewellyn and colleagues (2003) examined mothers with ID and their health status and found them being at risk for poor health. Parents with ID have also been found to report higher levels of stress, depression and poorer mental health than parents without ID (Feldman & Walton-Allen, 1997; Tymchuk, 1994).

Mothers with ID are often socially isolated (Llewellyn & McConnell, 2002). This accords with findings of more restricted social support networks in parents with ID (Feldman, Varghese, Ramsay, & Rajksa, 2002; Llewellyn & McConnell, 2002).

### **1.15.1 Pregnancy and delivery**

Höglund and collaborators (2012) found teenage births to be more common in Swedish women with ID than in women in general (18.4% vs. 3.3%). The authors also found that a higher proportion of the women with

ID were single, worked less and that their pregnancies more often had a gestational length of less than 37 full weeks. This is in accordance with a finding also in Australia (McConnell, Llewellyn, Mayes, Russo, & Honey, 2003).

A UK study showed that women with ID had limited knowledge about sexual health issues and reproduction (Aunos & Feldman, 2002; McCarthy, 2009) and that the use of contraceptives was low among them (Aunos & Feldman, 2002; Servais et al., 2002).

### **1.15.2 Abuse and neglect of children who have parents with ID**

Children of mothers with mild ID are at a high risk of child abuse and neglect (Crain & Millor, 1978; Feldman & Walton-Allen, 1997; Ronai, 1997; Seagull & Scheurer, 1986).

Parents with ID are overrepresented in child protection and legal proceedings in courts (Booth, Booth, & McConnell, 2005; McConnell, Llewellyn, & Ferronato, 2000). About 40-50% of all children born to parents with ID are removed from their parents (Emerson, Malam, Davies, & Spencer, 2005; Gillberg & Geijer-Karlsson, 1983; Morch, Skar, & Andersgard, 1997).

In an Australian study of court proceedings, involving parents with ID, the most common concern raised by the child protection workers was developmental delay in the child (McConnell et al., 2000). The authors discussed that this might, in Australia, have led to discriminatory actions by the legal system, meaning that children of parents with ID are assessed in a greater extent (McConnell & Llewellyn, 2000). However, children with disabilities, and with parents with ID, do seem to have an increased risk for maltreatment; neglect, physical abuse and sexual abuse (Sullivan & Knutson, 2000). These results are in line with several other studies (Jones et al., 2012; Svensson et al., 2011; Turner, Vanderminden, Finkelhor, Hamby, & Shattuck, 2011).

In a study in New Zealand, Conder and colleagues (2008) found that parents with ID who had a child or children in foster care were in general unclear about the reasons why their child had been removed. Furthermore parents seemed to think that they needed to master a set of behaviours to have their children be returned.



### 1.15.3 Parents at risk

McGaw and colleagues (2010) identified risk factors affecting parents with ID and found high-risk and low-risk parents with ID. Risk factors among these parents were a history of own experiences of abuse and/or neglect. Parents' experiences of physical neglect and emotional abuse related to an increased risk of inflicting abuse on their own children. In parents with a dual diagnosis of psychopathology and ID the children were at an increased risk of mental and cognitive problems (McGaw, Shaw, & Beckley, 2007).

IQ of the mother's with ID partner has also been studied with regard to the risk of child abuse/neglect. If the partner's IQ was higher than 85 the risks for child abuse/neglect was 9 times higher compared to when the partner had an IQ<70 (McGaw et al., 2010). This association has also been shown in an early study by Mickelson (1947). Another significant risk related to the mother's partner is a history of criminality and/or anti-social behaviour (McGaw et al., 2010). The inability of mothers with ID to protect themselves and their children from abuse has been recognized in court proceedings (Booth & Booth, 2000).

### 1.15.4 Child-focused approach

Parents with ID often need to learn a set of skills related to parenting i.e., healthcare, how to stimulate the child's development and handling child problem behaviour (Tymchuk, 1992; Tymchuk & Feldman, 1991). There are also many rapidly changing situations that the mother needs to adapt to and that require new decisions. The ongoing development of the child can also be challenging in different periods.

Kjellmer (Kjellmer, 2013) recently wrote that "*no person has the right to have children, but children have the right to have parents*" (p. 725; Kjellmer, 2013).

Several studies (Feldman, 1994; Wade, Llewellyn, & Matthews, 2008) have shown that parents with ID can learn and maintain parenting skills but unfortunately the effects of the interventions on child outcomes have seldom been considered (Wade et al., 2008).

To support this already vulnerable parental group, the social support systems need to be well developed and coordinated and adapted to this group. However, this does not always apply (Aunos, Feldman, & Goupil, 2008; Willems et al., 2007).

In DSM-5 (APA, 2013) this aspect regarding support for individuals with mild ID is expressed: “*Support is typically needed to raise a family*” (p. 34; APA, 2013). To be able to get help the parent needs to be aware of their own needs, and to recognize their shortcomings in identifying those (Hindberg, 2003). However, this view may mean that some families that do not recognize their own needs will not receive appropriate intervention from social service.

## 2 AIMS

Mild ID is a disorder that has attracted less research attention – with regard to several aspects – than many other neurodevelopmental disorders. The aims of this thesis therefore were to:

- 1) describe coexisting neurodevelopmental symptoms and disorders, especially in “the ADHD spectrum”, in children with mild ID (Paper I);
- 2) compare adaptive functioning, in a group with mild ID with that of a group with ADHD (Paper II);
- 3) elicit information about the personal experience of childhood, upbringing and current life situation through interventions with a group of young adults born to mothers with ID (Paper III);
- 4) study life events in those young adults who could not be reached for interview, by performing a register study (Paper IV).

## 3 PARTICIPANTS AND METHODS

### 3.1 Participants

This thesis is based on three sets of data; one from a group of children with mild ID (Paper 1, at the time of the study referred to as the mild mental retardation, MMR, group), one from a group of children with ADHD (ADHD group) and two from a group of children – now young adults – born to mothers with ID. This group was divided into 1) a group of individuals who had given their consent to being interviewed (Interview group) and 2) one who could not be reached for interview (Register group). An overview is given in Table 7. The recruitment processes and the participants' characteristics will be described separately for each study group.

Table 7. *Overview of the participants in the four papers.*

	<i>MMR group</i>	<i>ADHD group</i>	<i>Interview group</i>	<i>Register group</i>
Study	I, II	II	III	VI
Total (n)	33	27	10	21
Male:female	21:12	18:9	6:4	14:7
Mean age (years)	12.6	12.9	21	23

#### 3.1.1 Study I

The 33 participants (21 boys and 12 girls, age 6-15 years) with mild ID were recruited from special schools for pupils with mild ID in two municipalities in the south-western part of Sweden. They were identified through files at the school health units.

A letter containing an outline of the study, including an invitation to participate, was sent to all parents/carers of children with mild ID (birth-years 1994-2002) in these two municipalities (n=53 children). To increase the sample size, 9 pupils born in 1993, younger than 16 years of age, were also included. Of the collapsed total of 62 eligible pupils, 39 had parents (63%) who participated in the study by completing the Five-To-Fifteen (FTF) questionnaire (Kadesjo et al., 2004) and by allowing the child's health care record at school to be included for review. Of these 39 pupils,

6 were found not to entirely meet criteria for mild ID with respect to the IQ and adaptive criteria (see below), leaving 33 for inclusion in Study I.

Parents of the 33 children agreed to letting their child's teacher fill out the ABAS-II (Harrison & Oakland, 2003), i.e., a questionnaire pertaining to children's abilities in social functioning, communication and daily life skills (see below).

The review of the school health records was performed by two of the authors (IL and EF) in terms of cognitive test results/reports and medical data to evaluate the accuracy of the diagnosis according to IQ test data and the assessment of the child's adaptive functioning, according to ABAS-II, filled out by the child's teacher. The validity of the diagnosis MMR/mild ID was established for all included pupils.

### **3.1.2 Study II**

The mild ID group was the same as in Study I. The ADHD group, consisted of 27 children (18 boys and 9 girls), ages 6-16 (mean 12.9) years, and was recruited from a consecutive series of patients with ADHD at a specialized paediatric unit in the south-western health care region of Sweden. To this unit, schools and general paediatric out-patient clinics in the region refer children with suspected ADHD for comprehensive assessments and decision about intervention. As part of the assessment the ABAS-II was used and given to parents and teachers for completion by them. Although only a minority of the referred children's teachers received the ABAS-II, there was no selection with regard to severity of the child's ADHD or comorbidity status in this procedure. The group referred to this unit was considered representative of children with at least moderately severe ADHD, in which pharmacological treatment often is part of the total treatment/intervention.

When the study data were compiled, children who in addition to ADHD had mild ID or ASD were excluded, and all children already on pharmacological ADHD treatment before the ABAS-II questionnaire had been filled out, were also excluded.

Of the 27 children 26 were diagnosed with combined ADHD and one with mainly inattentive subtype ADHD. The children's IQ distribution was as follows: 10 (38%) had BIF, and 17 (62%) had average IQ.

Although exclusion of associated disorders such as mild ID and ASD, 23/27 (85%) had at least one additional impairment/developmental

problem, including dyslexia, speech and language impairment, ODD, Tourette syndrome, autistic traits and depression.

### **3.1.3 Study III and Study IV**

The children – now young adults – born to mothers with ID, comprised 31 individuals (20 males and 11 females, ages 18-25 years). They were recruited in a south-western geographical and administrative Swedish health care region with appr. 275,000 inhabitants. Bager (2003) identified all children (n=53), born in the years 1986-1995, by finding their mothers with ID (n=37), registered with the county authorities responsible for supporting people with ID. All individuals with ID for whom any societal help is provided in Sweden are listed in this register. The children were ascertained through these mothers' registration. Almost ten years later, in 2011-2012, 42 of these 53 children were 18 years of age or older (birth years 1986-1993) and were targeted for follow-up at this young adult age. As it turned out 3 of the 42 children had died and 1 had moved abroad.

Contact details/addresses of these young people were identified in the public Swedish population register. Thereafter a letter of information about the study was sent to the 38 individuals. The letter included an outline of the study and information that a personal contact (telephone) would be made within a week by the psychologist responsible for the study (IL).

Of the 38 individuals (Figure 2), only 17 could be reached by telephone. Seven of these did not want to participate and 10, representing 8 mothers, were willing to participate in the interview. The remaining 21 individuals could not be reached at all; 13 had no telephone listed landline and mobile number, and 8 did not answer any of 10 or more telephone calls made over a two month period from different “open” listed telephone numbers.

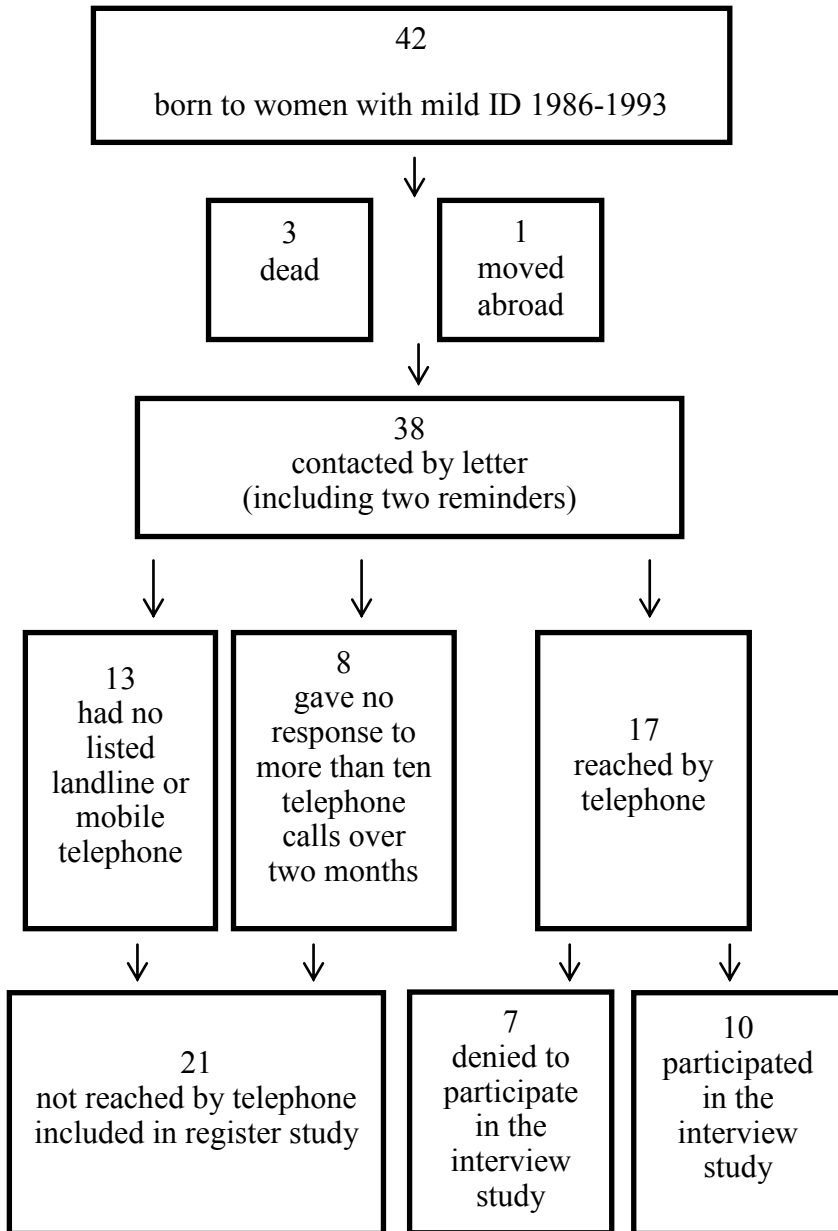


Figure 2. Flowchart showing the procedure of the contacts with the individuals in Study III and Study IV

## **Interview group**

Mean age of the 10 individuals (6 males and 4 females) that agreed to participate was 21 years (range 19 to 23 years). One of the participants was accompanied by an assistant at the supported housing at the face-to-face interview. In one case the individual accepted to be interviewed, but only if the questions were presented by the personal assistant at the supported housing. In that case the research psychologist handed written questions to the assistant and the answers were then noted by the assistant and handed back to the psychologist. One interview was performed over the telephone. The remaining interviews were performed face-to-face.

## **Register group**

Twenty-one individuals (14 males, 7 females), representing 16 mothers could not be reached at all; 13 had no telephone listed landline and mobile number, and 8 did not answer any of 10 or more telephone calls made over a two month period from different “open” listed telephone numbers.

To get information about the current situation for the 21 individuals that had not been possible to make contact with at all, the ethics committee was contacted and after a new application, approval was given for a register study.

## **3.2 Measurements**

### **3.2.1 FTF**

The FTF (Kadesjo et al., 2004) is now widely used, clinically and in research, in the Nordic countries. It was developed by a Scandinavian and Finnish group to serve as a tool for screening of neurodevelopmental-neuropsychiatric disorders or problems in the following areas; ADHD, ASD, tic disorders, developmental coordination disorder, ODD, CD, emotional disorder, learning problems, or symptoms in these areas (Kadesjo et al., 2004; Trillingsgaard et al., 2004). The questionnaire contains 181 items (179 of which pertain to difficulties) divided into 8 subdomains (motor skills, executive functions/ADHD, perception, memory, language, learning, social skills/autism and emotional/behavioural problems). The executive domain includes all the symptoms of ADHD that accord with the DSM-IV criteria (APA, 1994).

Each item is scored as 0 when the statement “does not apply”, 1 when it “applies sometimes or to some extent” or 2 when it “definitely applies”. The clinical validity and usefulness of the FTF have both been supported



in several large-scale epidemiological and smaller clinical studies (Kadesjö et al., 2004). The questionnaire has been used in a stratified sample of 854 Swedish children from the general population, subdivided into 3 age groups. Medians, means, 75th, 90th and 95th percentiles for domain scores have been published for boys and girls of this Swedish norm group. A score between the 75<sup>th</sup> and 89<sup>th</sup> percentile indicates a minor problem and a score above the 90th percentile is an indication of a definitive problem in the domain assessed.

In order to validate the parental FTF results in our study group of children with mild ID, three of the domains were selected for completion also by the child's teacher (motor function, executive functions/ADHD and social skills/autism). Since the teacher version of the FTF has not been evaluated in norm groups the teachers' reports were used only for checking if the problems noted by parents accorded with the teacher reports for these domains. To specifically evaluate ADHD symptoms in more detail, the teacher ratings of these symptoms were compared with the parent ratings in the domain of executive functions. In the domain of executive functions the teachers were also asked to comment on whether the symptoms had an impact on the child's daily life.

### **3.2.2 ABAS-II**

The instrument used for comparison of adaptive functioning in the two groups was the ABAS-II (Harrison & Oakland, 2003), a validated questionnaire for assessment of adaptive behaviour. The questionnaire has norm-referenced scaled scores for 10 skill areas (9 included in the three domains for children), with a mean of 10 (SD 1.5) and provides norm-referenced standard scores for three domains: CON, SOC, and PRA and a merged score: GAC (M 100, SD 15) with 90% and 95% confidence intervals and percentile ranks. The CON includes Communication, Functional Academics and Self-Direction, the SOC includes Leisure skills, and Social skills and the PRA includes Community Use, Home/School Living, Health and Safety and Self-Care). Work skills are also assessed but not included in any of the three domains.

The respondent rates the observed behaviour frequency of various skills using a four-point Likert scale; "not able", "never", "sometimes" and "always" and are also provided an option to mark the item as "guessed". At the end of each domain section additional comments can be added if desired. Every item is formulated into positive statements and high scores indicate good functioning. Examples are: "Shows realistic idea of the

value of money” (CON), “Customize clothing for the weather” (PRA) and “Treat young children with an understanding of their lower level of maturity” (SOC).

The ABAS-II includes two separate forms; Parent/Primary caregiver and Teacher/Daycare provider and both are for the ages of 5:0 to 21:11 years. In the present study only teacher report form was used. In the group of children with mild ID we had ABAS-II from teachers and not from parents. Therefore we used the teachers’ ABAS-II reports also for the ADHD group.

Test-retest and inter-rater reliability of the GAC are all in the .89 - .90s. The test-retest reliability coefficients of the 10 skill areas are slightly lower, mainly in .80s to .90s and the inter-rater reliability coefficients for the skill areas generally are in the .60s and .70s (Harrison & Oakland, 2012).

### **3.2.3 The interview**

The interview consisted of a semi-structured schedule that was made up of certain central themes. The research group has long clinical experience of developmental disabilities, including mild ID, and relevant themes for the interview were discussed and developed by the research group before the interviews started. The aim was to document these young individuals’ perceptions and experiences concerning their 1) family situation, 2) school situation and school achievement, 3) support and important persons during childhood, 4) adverse experiences, 5) psychiatric/developmental assessments and 6) current life situation. Examples of questions were: “I would like you to tell me about your family when you grew-up?” and “Could you tell me about your school situation from the time you started school and until you finished?” The participants were asked to describe as much as possible within the different themes and the interviewer used a computer to write down the information that was given. No audio-recorder was used. The interview lasted in general between 2 to 3 hours, depending on the participants’ ability to cooperate in the dialogue at the meeting. The interview took place at a hospital or at the participants’ supporting housing. In 2 cases the informant was accompanied by his or her assistant at the interview.

The interviewer read and analysed the transcriptions and structured the text into the different themes. The transcripts were also read by two independent raters (EB and EF) who reached the same conclusion.

### 3.2.4 SF-36

SF-36 is a 36-item short self-administered form for reports of different dimensions of health (Ware, 2000). The form is divided into eight health concepts; physical function (PF, 10 items), role limitations caused by physical problems (RP, 4 items), bodily pain (BP, 2 items), general health perception (GH, 5 items), vitality (VT, 4 items), social functioning (SF, 2 items), role limitations caused by emotional problems (RE, 3 items), mental health (MH, 5 items) and health transition (1 item). The last item, health transition, does not contribute to any of the scale scores. Each part is scored from 0 to 100 and a higher score accords with a better health status.

However, since the SF-36 has not been sufficiently validated for people with cognitive impairments, and considering that six of the ten interviewed had been given a diagnosis of mild ID, we found the items to be too cognitively demanding. Therefore we chose to use only two of the items that were easy to understand: Number 1: “In general, would you say that your health is”: “excellent”, “very good”, “good”, “fair” or “poor” and number 2: “How much bodily pain have you had during the past 4 weeks:” “none”, “very mild”, “mild”, “moderate”, “severe” or “very severe”.

### 3.2.5 The registers

The 21 individuals who had not been possible to reach were searched for in the following registers: Social Services Act, SSF, Social Insurance Office, Child Psychiatry Service, Adult Psychiatry Service, Medical Clinic and the Swedish Prison and Probation Service (PPS). The three individuals that had deceased during childhood were searched for with regard to cause of death in the national Mortality Register.

All authorities and clinics were contacted by letter and personally by I.L.

## 3.3 Ethical approvals

The four studies were approved by the Ethics Committee in Gothenburg. The individuals of MMR/mild ID group (Study I and II) and the individuals in the interview group (Study III) provided informed consent. For the ADHD group (Study II), ethical approval had been given to analyse the clinically used ABAS-II data for research. In the register group (Study IV), the participants could not be reached personally. Instead ethics approval was obtained for a register study.

## **3.4 Statistical analyses**

In study II, descriptive statistics with medians and quartiles were used for the three ABAS domains and for the GAC. The Mann–Whitney U-test was used for statistical analyses. SPSS v. 20 for Windows (SPSS Inc., Chicago, IL, USA) was used for all statistical data handling.

## 4 RESULTS

### 4.1 Overall findings

Children and adolescents with mild ID displayed several co-occurring neurodevelopmental conditions. Approximately half the group had symptoms that were consistent with ADHD/subthreshold ADHD.

Children with ID exhibited lower adaptive functions than children in general, thus their adaptive criteria were met. However, children and adolescents with ADHD had at least as low adaptive functioning as those with mild ID and the group with ADHD, of 12 years and above, had significantly lower adaptive functioning than children with mild ID.

Children of mothers with ID had been subjected to more risk situations, i.e., were exposed to double hazards, than children in general. They had a considerably increased risk of having mild ID, with or without concomitant ADHD. About half the group had not been primarily raised by their biological mother.

#### 4.1.1 Study I

Of the 33 children with mild ID, assessed according to the FTF questionnaire in study I, 18 (55%) had motor problems, 18 (55%) had problems with executive functions/ADHD, 29 (88%) had perceptual problems, 22 (67%) had memory problems, 26 (79%) had language problems, 25 (76%) had social skills dysfunction and 19 (58%) had emotional problems, exceeding the 90th percentile of the general age-matched population (Table 8). Numbers and percentages of the children with problems between the 90th and 97th and above 98th percentile are also indicated in Table 8.

Table 8. *Numbers and percentages of children with associated disorders according to the FTF between the 90<sup>th</sup> and 97<sup>th</sup> percentile, above the 98<sup>th</sup> percentile and the total above the 90<sup>th</sup> percentile*

Domain	No. between the 90 <sup>th</sup> and 97 <sup>th</sup> percentile	Percentages between the 90 <sup>th</sup> and 97 <sup>th</sup> percentile	No. above the 98 <sup>th</sup> percentile	Percentages above the 98 <sup>th</sup> percentile (expected 2%)	No. above the 90 <sup>th</sup> percentile	Percentages above the 90 <sup>th</sup> percentile (expected 10%)
<b>Motor</b>	7	21%	11	33%	18	55%
<b>Executive</b>	12	36%	6	18%	18	55%
<b>Perception</b>	15	45%	14	33%	29	88%
<b>Memory</b>	14	33%	8	24%	22	67%
<b>Language</b>	13	39%	13	39%	26	79%
<b>Learning</b>	10	30%	15	45%	25	76%
<b>Social</b>	18	55%	7	21%	25	76%
<b>Emotional</b>	15	45%	4	12%	19	58%

Parent and teacher FTF ratings in the three domains of motor function, executive function and social skills were compared for the 28 children born in 1994-2002. There were only minor disagreements, i.e., the teachers gave lower scores, in 4/28, 3/28 and 3/28 individuals, respectively.

To explore diagnostic concerns in children with mild ID with a co-occurring developmental disorder of ADHD, the domain of executive function in FTF was used. This executive domain contains the DSM-IV diagnostic criteria of ADHD. Of the 33 children with MMR/mild ID, five (15%) had by this time received a main clinical diagnosis of ADHD after clinical assessment at either a neuropsychiatric or a neuropaediatric clinic. Another three had ADHD combined with ASD. When the parent and the teacher results from the FTF were analysed in detail with respect to the DSM-IV criteria for ADHD, it was found that another five children met criteria for a clinical diagnosis of ADHD and that another four met criteria for subthreshold ADHD. This means that a total of 14 of the 33 pupils with mild ID (42%) actually did have clinically relevant ADHD with cross-situational symptoms at or above diagnostic cut-off level (nine previously diagnosed, with or without comorbid autism and 5 “new” cases). Adding the group with subthreshold ADHD, a total of 18 of the 33 children with mild ID (54%) met criteria for ADHD/ subthreshold ADHD.

The “FTF study” was population-based and therefore the prevalence of mild ID was estimated in the two municipalities under study. The

prevalence was found to be 0.85% in school age children. The figure is in between previous Swedish studies, ranging from about 0.4 to 1.3%.

### 4.1.2 Study II

The group of children with mild ID and the group with ADHD were compared with respect to the diagnostic criteria B in DSM-5: adaptive functioning. For the total groups there were no significant differences across groups. However there was a tendency for children with ADHD to have lower scores on GAC with a median of 63 (quartiles 56-80), compared to children with mild ID with a median of 76 (quartiles 67-90), ( $p=0.05$ ). There were also tendencies for children with ADHD to have lower scores on CON and PRA with median indices on CON 65 (quartiles 53-76) (ADHD) and 74 (quartiles 61-86) (mild ID) ( $p=0.05$ ) and on PRA 67 (quartiles 55-80) (ADHD) and 81 (quartiles 68-91) (mild ID) ( $p=0.05$ ). Median indices on SOC were 66 (quartiles 57-83) and 76 (quartiles 60-95) ( $p=0.21$ ), in ADHD and mild ID, respectively (Figure 3).

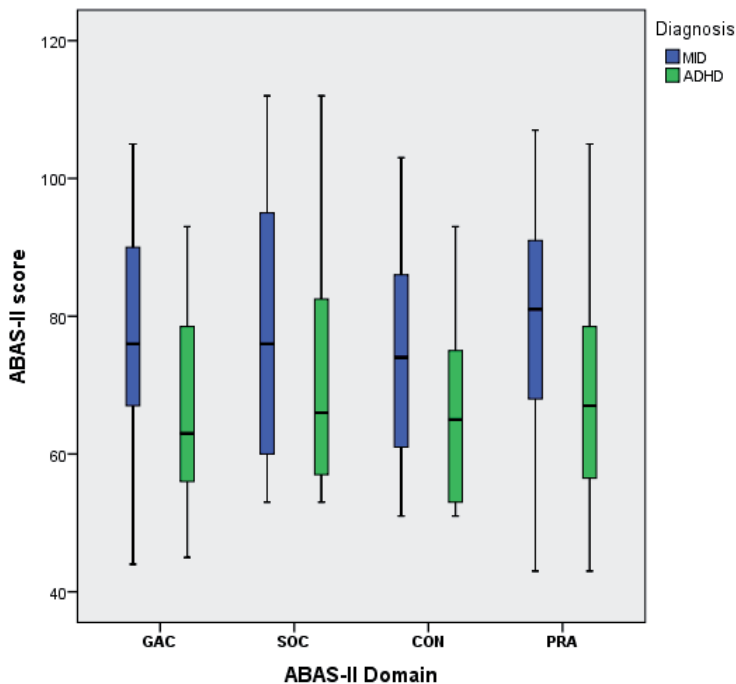


Figure 3. Results on the three ABAS-II domains and the GAC in children with mild ID ( $n=33$ ) and ADHD ( $n=27$ )

When the groups were divided into younger, 11 years and under (ADHD 5 boys, 3 girls; mild ID 7 boys, 1 girl) and those older, age 12 years and above (ADHD 13 boys, 6 girls; mild ID 14 boys, 11 girls) there was no difference between those with mild ID and ADHD in the younger age group. However, in the older group, those with ADHD had lower results on GAC, CON, and PRA ( $p=0.038$ ,  $0.026$  and  $0.049$ ), respectively (Figure 4).

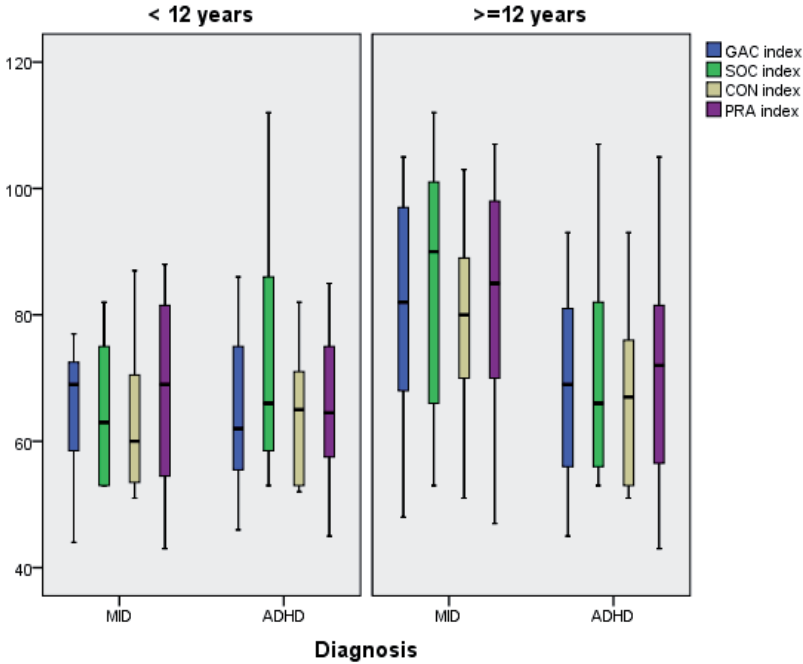


Figure 4. Results on the three ABAS-II domains and the GAC in younger and older children with mild ID (younger=8, older=25) and ADHD (younger=8, older=19)

### 4.1.3 Study III

#### Family situation during childhood

Three of the 10 interviewed young individuals grew up with their parents throughout their entire childhood. Another three had been placed in foster care during their preschool years, one of them had to change and move to another foster family and later moved to an apartment, supported by social services. One individual lived most of the childhood with the father and



mother alternately and was taken into foster care at the age of 17 years. One grew up in a family treatment centre with the mother and was taken into foster care at the age of 4 years. Two years later the child moved to the father, who was supported by social services. One individual lived most of the childhood alone with the mother and another one grew-up with close relatives after the mother deceased.

### **School situation and school achievement**

Four individuals started at a special school for children with mild ID, and two started ordinary school with a lot of support and from middle school age they attended special schools for children with mild ID. Four attended mainstream school, three of them passed in all subjects and one finished school without a degree and had problems of various types and had therefore been assessed by a psychologist since the parents and siblings had mild ID. However, a diagnosis of mild ID could not be confirmed in this individual.

### **Support and important persons during childhood**

Of the 10 individuals, three reported that they had had some important support from a family member/close relative during childhood. Three, including one of those who also reported support from a family member, mentioned that support from Free Church had been of importance during their childhood. Two of those that reported such support from Free Church, mentioned that they had not had any support from a family member/close relative. One mentioned that friends had been of importance and reflected about how childhood might have turned out if more family support had been given. Four individuals reported that they had had no support and no person of importance during their childhood and one of them expressed feeling very lonely during childhood and young adulthood.

### **Adverse experiences**

Six individuals reported or clearly indicated that they had been abused and/or neglected during childhood. For example, one of them described having told the staff at the social services that the parents “hit them like bears”. This individual also reported being sexually abused by the father. Another one reported missing an adult to talk to and someone who would have taken better care of him. “I do not think that anyone should have to have it as I have had it, that is why I’m telling you this”. Of the remaining four, one reported severe conflicts with peers and parents and another two reported being bullied. One individual early taken into foster care did not report any adverse experiences.

## **Developmental assessments and cognitive/psychiatric disorders**

Seven of the 10 participants had had a cognitive assessment and of these, 6 had been given a diagnosis of mild ID. One of these also had ADHD, ASD, depression and anxiety. Another one had in addition to mild ID also DAMP (Deficits in Attention, Motor control and Perception) and another one had depression in addition to mild ID. One individual had a diagnosis of depression.

## **Current life situation**

Of the six individuals with a diagnosis of mild ID, five worked with “municipal supported activities” and one was still attending special upper secondary school. Of the remaining four, two were studying: one attended a nursing education and one a residential college for adult education to become a youth worker in a church. Another one was unemployed and one was on sick leave from an employment as a cleaner.

Three of the interviewed reported meeting their parents sporadically/rarely. Four individuals had a deceased mother and three of these had sporadically contact with their father and one had no contact at all with the father. Another two had no contact with their mothers but contact with their fathers. One individual reported having contact on a regular basis with the parents. Of the six with mild ID, one lived on its own with support from the father and five lived in a supported housing. Of the four individuals with no diagnosis of mild ID two lived on their own, one of them had a young child. One individual lived in a student home at the residential college for adult education and one lived with the foster family.

## **SF-36**

Of the two items that could be used in the SF-36, one individual reported the general health to be “excellent”, three as “very good”, four as “good”, one as “fair” and one reported the general health to be “poor”. Seven scored that they had “none” bodily pain, two that they had “very mild” and one scored “severe” bodily pain. These results were in accordance with the general population.

### **4.1.4 Study IV**

In the present study, 18 of the 21 individuals searched for in registers, had been in contact with different authorities and clinics (Table 9).

Table 9. *Outcome of individuals searched within different registers*

Ind.	Social Services childhood	Social Services adulthood	Support and Service Childhood	Support and Service Adulthood	Social Insurance Office	Child Psychiatry Services	Adult Psychiatry Services	Swedish Prison and Probation Services
1	X	X						
2		X	X	X	X			
3	X	X	X	X	X	X		
4		X				X		
5	X		X	X	X	X	X	
6			X	X	X			
7	X	X						
8	X	X	X		X	X		
9							X	
10	X	X	X		X	X	X	
11						X	X	X
12							X	X
13								
14								
15	X							X
16		X			X			
17								
18	X							
19	X					X	X	
20						X	X	
21	X	X				X	X	X
N	10	9	6	4	7	9	8	4

## Mortality

Three of the original group of 42 children (7%) (1 male, 2 females) had died during childhood. They were searched for in the mortality register, and one had died at birth, one at the age of three and a half year and one had died at seven years of age. The causes of death given in the mortality register were extreme prematurity, severe heart malformation and cerebral tumour, respectively.

## Family situation

Of the total of 21 individuals, 13 had social services acts. It was established that 11 individuals had had contact with social services since childhood and 4 of these had been taken into care (foster family). Six had

had contact families during childhood. One had had contact with social services according to adult psychiatric files and had been taken into a treatment centre. One individual grew up with the father. This means that 12 of the 21 individuals (57%) were not primarily raised by their biological mother. In one case contact with social service was established in adulthood.

According to the files from social services and child psychiatry, four individuals had experienced sexual abuse in their family during childhood. All individuals were abused in their home; two by an elder sibling, one by the mothers' partner and one by the father in the foster care. Three of these had ID and one low borderline intellectual functioning.

### **Neurodevelopmental/neuropsychiatric disorders**

Eleven of the 21 (52%) (9 males and 2 females) individuals had major neurodevelopmental/neuropsychiatric diagnoses according to different registers and clinical files. Five had mild ID; two of whom in combination with ADHD and ASD, and one with ADHD "only". One individual had ASD with ADHD (and no ID), and one had ASD "only" (with borderline intellectual functioning). Another four individuals had ADHD without ID or ASD (Table 10). In a further three cases information given in psychiatric records and other acts gave strong indications of ADHD. However the disorder was not explicitly diagnosed.

The five individuals with mild ID had received support with regard to accommodation and/or personal assistance during childhood, and, as adults, they had "municipal supported activities" under the act regulating SSF/Swedish LSS or social services. Of the two individuals with ASD, but without ID, one had had support (accommodation) from SSF during childhood and one had had support from social services (youth treatment centre) during adolescence. The five individuals with ID had activity compensation from the social insurance office.

Table 10. *Individuals with neurodevelopmental/neuropsychiatric disorders*

<b>Ind.</b>	<b>ID</b>	<b>ASD</b>	<b>ADHD</b>
1			
2	X		
3	X	X	X
4			
5	X		X
6	X		
7			
8	X		
9			X
10		X	
11			
12			X
13			
14			
15			X
16			
17			
18			
19		X	X
20			
21			X
<b>n</b>	<b>5</b>	<b>3</b>	<b>7</b>

### **Criminality and drug abuse**

Four of the 21 individuals (19%) (1 female and 3 males) were registered within the PPS due to various types of crimes; three for violent behaviour and drug possession, and one for drinking-driving. All four had diagnoses of ADHD (and drug abuse). One of the four had committed more than one criminal act, and one had been admitted to prison for more than a year during which time he continued committing crimes.

Another individual with the combination of ID, ADHD and ASD but without any criminal acts had had hospital care due to intoxications (alcohol).

## 5 DISCUSSION

### 5.1 General findings

Mild ID in school aged children was strongly associated with many overlapping problems including very high rates of deficits in motor, attention, language, social and emotional functioning. These ESSENCE associated problems are all amenable to well validated psychological, educational, and/or pharmacological interventions. The findings have clear clinical implications with regard to the need for a broad assessment in the diagnostic process of all children with mild ID, and indeed for the need of follow-up and support throughout the lifespan.

When comparing adaptive function across children with mild ID and children with ADHD without ID, those with ADHD, especially those above the age of 12 years, had even lower adaptive functions than individuals with mild ID. This finding has implications for diagnostic concerns and indicates that the level of adaptive functioning could not be used to differentiate between mild ID and ADHD. Yet, those children with the combination of mild ID and ADHD need special attention and intervention, including specific considerations with regard to their accompanying ADHD. Moreover, the low adaptive function of children with ADHD without mild ID needs to be "taken seriously". This group needs services at least as much as children with mild ID (who are already, at least from the legislative point of view, recognized as being specifically in need of extra societal support).

The group of young adults, born to mothers with ID, was difficult to reach. Fewer than half of the targeted group was possible to make contact with at all for asking if they would agree to participate in an interview study. Of these, slightly more than half consented to participate in the interview. When results from the personal interview of the young adults of mothers with ID and the register study of those who had not been possible to reach at all were combined, it was found that a large proportion of the young individuals (35%) had mild ID and that the rate of ADHD in the group was considerably higher than in the general population without ID (29%). Half the group (52%) had not been primarily raised by their biological mother and the group as a whole was found to have been exposed to several risks. These included neglect and abuse in the family. Individuals with ID who become parents need tailored support from social services and children of mothers with ID need early assessments with

regard to development and also measures to ensure their right to develop physically, mentally and socially in an optimal way.

## **5.2 Limitations and strengths**

### **5.2.1 Study I**

The major limitation of Study I was that the study group was small, consisting only of 33 children with MMR/mild ID. However, the strengths were that the group was considered representative of the general population of children with mild ID, and that it was thoroughly investigated with respect to the validity of the diagnosis of MMR/mild ID. Another limitation stemmed from the fact that only parents completed the full FTF questionnaires, and we cannot exclude that some parents may have had difficulties due to their own cognitive problems. Nevertheless, this did not seem to influence the results in a significant way for the three FTF domains that were validated against teacher reports. One might argue that teachers would score children in special schools according to norms set by the group of children with cognitive difficulties. However, in the present study, the results reported for individual children were, in general, very similar across teachers and parents.

### **5.2.2 Study II**

The two groups included in Study II were relatively small. However, the group of children with mild ID was population-based, and the group of children with ADHD was drawn from a clinically referred sample of children with ADHD in which no selection occurred other than the exclusion of those with mild ID and those with ASD in combination with ADHD. Moreover, the ADHD group was “representative” of other recently published ADHD patient and population samples as regards associated disorders or “comorbidities”. Even when associated mild ID and ASD had been excluded, a full 85% was found to have at least one additional disorder/developmental problem, which is in accordance with the total population study, performed by Kadesjö and Gillberg (2001).

### **5.2.3 Study III and IV**

Limitations of Study III and Study IV included the fact that only a relatively small group took the in-depth interview. This group represented a subgroup, consisting of those with whom it was possible to get in contact and who wanted and had possibilities to participate in an interview. The various themes in the interview had been determined in

advance by the research group and were intended to reflect different situations and events from childhood to young adulthood. No audio-recorder was used at the interview; instead, the interviewer used a computer for immediate written recording of the information that was given.

The instrument SF-36 that was also used in the personal interview has been validated in two studies in which 20-50% of the respondents were cognitively impaired. The authors found that the higher the proportion of the respondents who had cognitive impairments the poorer validity the instruments showed. Therefore our results, revealing that eight of the 10 participants reported good, very good or excellent health, should be interpreted with caution considering the problem of validity of the instrument in this study group.

Only a relatively small group was possible to search for in registers (due to ethical considerations). Moreover, in the register study, we do not know if we have complete information from social service acts due to the rule that acts are destroyed if a contact has not taken place within a five-year period. This limitation suggests that the rate of individuals who had not been raised “full time” by their biological mothers should be seen as minimum figures. Another limitation was that we had no information about the mothers complete disability profile, i.e., about additional neurodevelopmental-neuropsychiatric disorders, such as ADHD or ASD, and we had no systematic information at all about the fathers of the children.

The strength of Study III and Study IV was the population-based study design; the group of mothers with ID was derived from one Swedish county and information about their children’s personal identification numbers were available. However, the group of mothers with ID consisted of those who had been registered within the BPSMR. Thus only women who had had a thorough cognitive assessment comprised the target group of mothers. It can be assumed that there may be further mothers with ID, women who had never had an accurate cognitive assessment and accordingly had not been given a diagnosis of ID (hence not being registered and receiving support from the BPSMR).



## **5.3 Discussion of results obtained**

### **5.3.1 Mild ID and co-occurring problems/other ESSENCE conditions**

According to the FTF, 55% to 88% per cent of the children with mild ID had definite problems within the areas of motor function, executive function, social skills and emotional/behavioural problems. These findings accord well with earlier studies of children with mild ID (Di Nuovo & Buono, 2007; Emerson, 2003; Gillberg et al., 1986; Goodman, 1997; Simonoff et al., 2007). These problems often overlap and coexist in various degrees of severity and may or may not reach a clinical level that accord with a diagnostic term. This broad field of different developmental problems and disorders has been referred to as ESSENCE (Gillberg, 2010).

Approximately half (18/33) of the children with mild ID met criteria for ADHD/subthreshold ADHD. Of these 18 children, 8 already had a clinically determined diagnosis of ADHD. Thus, the high rates of ADHD in the group of individuals with mild ID (Study I) and in the group of individuals born to mothers with ID (Study III and IV) indicate that individuals with ID - and also their offspring - need assessments that take these aspects into account. Moreover, children with mild ID and co-existing ADHD may benefit from several types of support, including educational, psychological and pharmacological interventions.

### **5.3.2 Prevalence of mild ID**

The group of schoolchildren with mild ID was also included in a prevalence estimate. The prevalence of mild ID in this group was found to be 0.85% in the study area. Considering that, statistically, about 2% of children should have an IQ below 70 – the majority of whom in the area corresponding to mild ID – this figure should be regarded as a minimum prevalence. Furthermore, we do not know the rate of children in the two municipalities under study that had not been referred for cognitive assessment.

The prevalence rate of mild ID varies considerably across studies, even in Sweden and other Nordic countries (Fernell, 1996; Gillberg & Geijer-Karlsson, 1983; Hagberg et al., 1981; Strømme & Valvatne, 1998) and is dependent on several factors, including demographic, methodological, and diagnostic criteria for mild ID.

### 5.3.3 Adaptive function

Children and adolescents with ADHD were found to have more deficits/more impaired adaptive functions than children with mild ID, and the difference between the two groups was significant among those aged 12 years and over. In the educational programmes for Swedish students with ID there is a focus on training of adaptive functions. This may be one factor behind the difference found. Moreover, children with mild ID in this study group had had most of their school years in special school and thus their disability had been identified. This was in contrast to the situation for the group with ADHD. At the time when the ABAS questionnaires were completed by their teachers, children in this group had not received a diagnosis of ADHD, and therefore may not have had their difficulties appropriately met.

No differences were found in adaptive functioning with regard to IQ levels in the ADHD group, i.e., between the group with BIF and those with “average” IQ (85 and above). In the ADHD group as a whole 38% had BIF and 62% had average IQ. However, in the ADHD group a significant difference was found between boys and girls; boys had a significantly lower level of adaptive functioning within three of the four areas; GAC, PRA and SOC. Thus, for the group with ADHD, gender was more important for adaptive functioning than IQ. This finding implicates that boys with ADHD should be specifically considered with regard to their adaptive functioning. When the small subgroup of children with mild ID and *clinically diagnosed* ADHD was compared with the group with mild ID without ADHD no significant difference emerged with regard to GAC, CON, SOC and PRA.

A statement of the child’s adaptive functioning is an important part of the comprehensive evaluation of children with suspected mild ID. The diagnostic criteria for ID include that the child’s adaptive functioning should be impaired. Clinically, the ABAS-II is often used to get a structured evaluation of this ability. Although Barkley (personal communication) for many years has highlighted that children with ADHD function at a considerably lower age level compared to their chronological age, adaptive function has been less emphasised in the assessment procedure of children with ADHD. Our results accord well with Barkley’s report and indicate that the level of adaptive functioning cannot be used to differentiate between mild ID and ADHD. Hence, in the diagnostic differentiation between mild ID and BIF, it is important to consider the possibility of coexisting ADHD in children with BIF, and, that co-

occurring ADHD may be the impairment with the greatest impact on adaptive functioning.

### **5.3.4 Young individuals of mothers with ID – recruitment process**

Of the 38 young individuals targeted for study, it was extremely difficult to reach the majority through conventional letters or telephone calls. In only 17 cases was it possible to make personal contact with at all. Of the 17 who could be reached, 7 declined to participate and 10 were positive to take part in the interview that was conducted by the research psychologist (IL). This group of 10 included 6 individuals with mild ID, and a contributing factor to their participation was that the contact with the research psychologist was with help from their social service officer. The remaining 21 individuals could not be reached at all. However, some information about their life situation – from childhood to young adult age – was obtained from different registers, after ethical approval. The difficulties entailed in recruiting children of mothers with mild ID for interview need to be considered in future research on this at-risk group.

### **5.3.5 Mortality**

Of the original group of 42 individuals born to mothers with ID, three had died before the age of 8 years (7%). In the same county, 0.68% of *all* children died before the age of 8 years, thus there was a 10 times higher rate of early mortality in children born to mothers with ID. One of the children in our total cohort (1/42), 2.3%, had died in the perinatal period which is similar to findings by Höglund and colleagues (2012) reporting an increased perinatal mortality in children born to mothers with ID compared to mothers in general (1.8 vs. 0.4%).

### **5.3.6 Adverse events and experiences in individuals born to mothers with ID**

Individuals born to mothers with ID were at high risk for neglect and/or abuse and for having had adverse life experiences.

In the total study group (interview – and register group) (n=31), 16 (52%) had not lived with their mother “full-time” during childhood and adolescence. Instead, they had been placed into foster care, treatment centres, contact families or, in one case, had lived full-time with their father. These findings accord with those of other studies, i.e., by Gillberg and Geijer-Karlsson (1983) who found that 44% of children born to

mothers with ID had been placed into foster care. Morch and collaborators (1997) reported that 38.5% of children in Norway, born to mothers with ID, were taken into care. Similar findings were also reported by Emerson and colleagues (2005) who found that 48% of the children born to mothers with ID did not live with their mother. The reason in the individual case in our studies was not always possible to trace but five of the 31 individuals reported personally or had reports in their social acts confirming that they had been exposed to sexual abuse.

Of the ten interviewed individuals 6 had been removed from their biological parents during childhood, and 6 reported clear child abuse and/or neglect. The majority of the individuals reported difficulties in their relations with family and in school.

Of the 21 individuals in the register study, four (19%) were found in the criminal register and all of them had a diagnosis of ADHD and also of substance use. These findings accord with those of a recent Swedish study (Ginsberg et al., 2010), in which substance use was reported by all prison inmates with a diagnosis of ADHD. In that study approximately 40% of the adult long-term prison inmates had ADHD. The relation between socio-demographic characteristics, psychiatric co-morbidity and criminal behaviour among the Finnish forensic population with ID was explored in a nationwide study. The authors found that the offenders with a combination of substance abuse, mental illness and ID form a small subgroup of criminal offenders with complex needs. They also emphasised the importance of close, long-term cooperation among specialists in the field of ID, addiction service, mental health services and forensic psychiatry (Mannynsalo, Putkonen, Lindberg, & Kotilainen, 2009).

### **5.3.7 SF-36**

The instrument SF-36 that was used in connection with the personal interview, has been discussed in a review by Riemsma and collaborators (2001). The review indicated that instruments for measurement of general health status are not automatically generalizable to people with cognitive impairment. The finding that 8 of the 10 participants in the interview study reported very good, good or excellent health has to be interpreted with caution considering the problem of validity of the instrument in this study group. These reports of good health did not accord with the clinical impression these individuals conveyed at the interview with the clinically experienced research psychologist (IL).

### **5.3.8 ESSENCE**

Of the collapsed group of 31 individuals (born to mothers who themselves had registered ID) in the interview and register study, 11 (35%) had mild ID and 9 (29%) had ADHD. According to the psychiatric case records and other acts it was evident that another three individuals in the register study also met criteria for ADHD. This would correspond to a rate of 39% with ADHD in the collapsed group. Thus, both disorders (ID and ADHD) occurred at a very much higher rate than in the general population. A complete evaluation of coexisting disorders in this group was not possible to obtain but considering the high co-occurrence of other disorders in individuals with ID and with ADHD it is very likely that several other neurodevelopmental/neuropsychiatric conditions were represented.

### **5.3.9 The need for support and protection**

The group of children, adolescents and adults with mild ID constitute a vulnerable group at home, at school and in society more generally. The total group of 16 individuals who had been subjected to early family interventions represented families willing to receive help, according to the social service registers. According to Hindberg (2003) the Swedish system of today is based on the view that support should be optional and that the individuals themselves should initiate the contact. Hindberg (2003) also noted that the parents themselves have to be aware of their needs for help and support from social services. This could mean that some families who do not recognize their own needs will not receive appropriate intervention from social services.

Willems and colleagues (2007) suggested a “balancing model” to provide successful support for parents. They revealed several factors for positive outcome; the ability and willingness to follow advice, the social network, and the society’s attitudes towards parenting with ID. In conclusion they pointed out the importance of a well-coordinated support system. Tarleton and colleagues (Tarleton, B, Ward, L, & Howarth, J, 2006) suggested that support should be multi-professional and multi-agency and that the priority should be to protect and provide welfare for the children. By providing ongoing support for parents with ID the work will entail both education for the parents and preventive safeguarding for the children.

### **5.3.10 Double hazards**

The concept of “double hazards” refers to children with developmental disorders, raised in families with social disadvantages, i.e., children with

the combination of biological and environmental risks (Aylward, 2006). Children born to mothers with ID may be specifically exposed to these “double hazards”. The social disadvantages are likely to be strongly related to hereditary factors, i.e. to the parents own cognitive/developmental/ESSENCE difficulties. In order to provide support for these children and their parents, this relationship between cognitive deficits and socio-economic status has to be recognized and politically accepted in our society.

## **5.4 Conclusions and implications for clinical practice**

The high rate of other ESSENCE conditions in the group of children with mild ID is clinically important. Children with (suspected and verified) ID should be offered a broad clinical assessment in which also other neurodevelopmental-neuropsychiatric conditions are paid attention to. Moreover, medical aspects, including etiological considerations, need to be included. In many cases, mild ID will be recognized and traced at early school age. After initial developmental assessments within the school health service; by collaboration between the school psychologist, special teacher, school doctor and nurse, the school health team needs to discuss their findings and consider a further referral to a clinic specialized in neurodevelopmental/neuropsychiatric assessments. This clinic would correspond to an “ESSENCE–clinic/unit/team”, working in close collaboration with school health services. Such referral is necessary since the final diagnostic procedure cannot be regarded as being only a school issue. The important task for school health services should be to trace ID in children with learning and other cognitive problems and to perform the primary assessments.

Coexisting ADHD in children with ID is important to diagnose. There are several well validated interventions available for ADHD, including educational adaptations, psychological support, working memory training, and pharmacological treatments that could considerably improve the child’s school achievements and function at home.

In accordance with Simonoff and collaborators (2007), our findings support that clinicians should include systematic questioning about ADHD, as part of the diagnostic assessment of children with ID. Also other neurodevelopmental-neuropsychiatric problems need to be considered in children with ID – motor performance, speech and

language, social and emotional functions – so as to be able to help and support the child in an optimal way.

The findings obtained here should lead to increased awareness in schools that mild ID is not merely an issue with consequences for education and school but has far-reaching implications for life, including medical, psychiatric, and psychological aspects.

The finding that children with ADHD in general had lower adaptive functioning than children with mild ID should be of importance with regard to support and service to this group of children and adolescents. Children and adolescents with ADHD are in general not given support from the special services (LSS and habilitation) in Sweden. Our results indicate that the group with ADHD needs this support at least to the same extent as the group with mild ID.

The higher level of adaptive functioning in the group with mild ID may be due to the support provided, i.e., “training” of adaptive functions, in special school. However, the new school reform, that was implemented in 2011, containing less emphasis on practical training, therefore needs to be carefully evaluated. Traditionally, special schools for children with ID have emphasised training of several adaptive abilities. The now launched school reform in Sweden implies a shifted approach in special school education. The programme now places more weight on subject learning than on teaching and training adaptive skills. It can be speculated that this may influence adaptive functioning in a negative way – and possibly participation in society in the future – for children with mild ID. However children with mild ID needs both adapted subject teaching and training of adaptive skills.

Another aspect of the finding of lower adaptive functioning in the group of children and adolescents with ADHD, compared to the group with mild ID relates to the diagnostic assessment of mild ID. A low adaptive function is one important area among the diagnostic criteria of ID. Our results clearly indicate that low adaptive skills cannot be used for differentiating between mild ID and ADHD. The diagnosis of mild ID is especially challenging when the child receives IQ results in the borderline zone between ID and BIF. It is important to consider that BIF combined with ADHD may yield low adaptive functioning and that a low adaptive function is not unequivocally linked to ID.

Several studies in the past 30 years have recognised that the group of individuals with ID is a vulnerable group in many aspects; for additional psychiatric and emotional disorders (Di Nuovo & Buono, 2007; Emerson, 2003; Gillberg et al., 1986; Goodman, 1997; Simonoff et al., 2007), parenting (Höglund et al., 2012) and outcome/adverse experiences of parenting (Accardo & Whitman, 1990; Bager, 2003; Feldman & Walton-Allen, 1997; Gillberg et al., 1983; McGaw et al., 2010; Rönström, 1981). Despite this, too little research has focused on the situation of children of mothers with ID (Pipping, 2001; Socialstyrelsen, 2005).

The increased risk in children and adolescents with ID of adverse experiences with neglect and abuse was also revealed in our study of children born to mothers with ID. Several of those who had been sexually abused themselves had ID or BIF. Children with disabilities have been found to be more than three times as likely, compared with typically developed children, to have been sexually abused (Benedict, White, Wulff, & Hall, 1990). Murphy (2011) highlighted that, despite this, children with disabilities are not provided with information on human sexuality or with strategies to protect themselves from sexual abuse, which makes them easy targets. Adolescents with ID need to be educated in sexuality and what parenthood means. This recommendation was also given by Bager (2005) and illustrates the need for education in cooperation with Youth Health Centres. Aunos and Feldman (2002) reported that women with ID received little education and support, both from their parents and from school, to make decisions about using contraceptives or becoming a parent. Thus, individuals with ID need education both with regard to their own safety to prevent abuse but also for preparing and making it possible for them to understand how parenting would affect their future life situation.

A considerable minority of children grow up with a mother with ID. Future studies in the field should continue to examine the impact of having a parent with ID. Research on the importance of parents' own coexisting disorders, the role of the father, and how to provide tailored support for the child and the family from social and habilitation services, should all be given highest priority.



## ACKNOWLEDGEMENTS

I want to express my sincere gratitude to:

- my supervisor, Professor Elisabeth Fernell, for your invaluable help during these past years. Thank you for introducing me to the world of science. Thank you also for being so interested, supportive and encouraging. I am so grateful to you for sharing your knowledge in the field of research and neurodevelopment, for having shown lots of patience with me during these years, and for all the nice times that we have spent together. I hope to have the good fortune to work with you in the future;

-my co-supervisor Professor Christopher Gillberg who has been tirelessly supportive and who has always been willing to share his vast scientific and clinical knowledge and experience in neuropsychiatry. I am most grateful for your enthusiasm and never-failing interest;

-my co-supervisor psychologist, PhD, Eva Billstedt for your encouragement and for sharing your knowledge, and for trusting in my capacity;

I would also wish to thank all members of the Gillberg Neuropsychiatry Centre for all your support, interesting discussions and for caring. A special thank you to Ingrid Vinsa for always being there to offer a helping hand, and to Anna Spyrou for all your help correcting the English language in this thesis and for being supportive during these past years;

My gratitude also goes to:

- former senior consultant in child habilitation, Dr Börje Bager who has contributed the data that made Study III and IV possible;

- school health nurse Annika Johnson for being very helpful by assisting me in collecting data for Study I and Study II. Thank you for your collaboration and all the nice meals in Lidköping;

- my co-authors neuropaediatrician, PhD Magnus Landgren and psychologist Leif Svensson at the Department of Paediatrics, Unit of Neurodevelopmental Disorders, Skaraborg's Hospital, Mariestad, for collaboration. Thank you for sharing your knowledge and helping me in Study II;

- all staff at the Research and Development Centre at Skaraborg Hospital, Skövde. A special thanks to statistician and co-author Salmir Nasic for helping me in Study II;

- co-author, associate professor, psychologist Eva Tidemann for valuable collaboration in Study II;

- the Child Psychiatry Service in Skövde for support during my PhD studies;

- my long-term fellow student and colleague Cecilia Karlsson for being supportive and inspiring during the years. Thank you for sharing both personal and professional experience;

- my dear friends, Mårten och Hanna Bremer, for resplendent friendship. I am most thankful for having you as friends and for knowing that you will always be there for me;

- my friend and supporter, Sara Schönbeck, who embodies the good friend. Your support and thoughtfulness give me strength;

- my beloved sister, and Erik, who have always been so supportive and helpful, both as babysitters and as supporters of my work. I am most grateful for all your support throughout the years;

- my parents, brothers and sisters-in-law for being a supportive network and for the knowledge that you are always there for me;

- my mother-in-law for helping and supporting me. I am most grateful to you for your cover illustration for the cover of this thesis;

My deep gratitude goes to my beloved husband Olof for believing in me and supporting me in good times and bad. You are my best friend and I could not have done this without you – you complete me.

Most of all, my sincerest gratitude goes to my three sons, Edvin, Arvid and, Vidar, for opening my eyes to what is important in life. I love you all.

There are many other individuals who have helped and supported me during the years it has taken me to complete this thesis. I could not have

done this without you. Although only a few have been mentioned above, I am most grateful to everyone who has helped me during these years.

Last, but by no means least, I would like to thank all participants who have been willing to give their time to take part in interviews and tests. My sincere thanks also go to all parents who have been willing to take part in these studies. I wish to also thank all the teachers in special schools in Skara and Lidköping for your collaboration.

Financial support for this research was provided by grants from the Research and Development Centre at Skaraborg's Hospital, Skövde, the Wilhelm and Martina Lundgren Foundation, and The Swedish Child Neuropsychiatry Science Foundation.



## REFERENCES

- ABAS-II. (2008). Adaptive Behavior Assessment System - second edition. Swedish version. Stockholm: Pearson Assessment and Information.*
- Accardo, P. J., & Whitman, B. Y. (1990). Children of mentally retarded parents. American Journal of Diseases of Children 144(1), 69-70.*
- Ahuja, A., Martin, J., Langley, K., & Thapar, A. (2013). Intellectual disability in children with attention deficit hyperactivity disorder. Journal of Pediatrics 163(3), 890-895.*
- American Association on Mental Retardation. (2002). Mental retardation: definition, classification, and systems of supports. Washington, DC: American Association on Mental Retardation.*
- American Psychiatric Association. (1994). Diagnostic and statistical manual of mental disorders (4th ed.): DSM-IV. Washington, D.C.: American Psychiatric Association.*
- American Psychiatric Association. (2000). Diagnostic and statistical manual of mental disorders (4th ed., text rev.): DSM-IV-TR. Washington, DC: American Psychiatric Association.*
- American Psychiatric Association. (2013). Diagnostic and statistical manual of mental disorders (5th ed.): DSM-5. Arlington, Va: American Psychiatric Association.*
- Anderson, V. (1998). Assessing executive functions in children: biological, psychological, and developmental considerations. Neuropsychological Rehabilitation, 8(3), 319-349.*
- Antonak, R. F., & Harth, R. (1994). Psychometric analysis and revision of the mental retardation attitude inventory. Mental Retardation, 32(4), 272-280.*
- Aunos, M., Feldman, M., & Goupil, G. (2008). Mothering with intellectual disabilities: Relationship between social support, health and well-being, parenting and child behaviour outcomes. Journal of Applied Research in Intellectual Disabilities, 21(4), 320-330.*
- Aunos, M., & Feldman, M. A. (2002). Attitudes towards sexuality, sterilization and parenting rights of persons with intellectual disabilities. Journal of Applied Research in Intellectual Disabilities, 15(4), 285-296.*

- Aylward, G. P. (2006). *Treating neurodevelopmental disabilities*. New York: Guilford Press.
- Bager, B. (2003). *Children of mentally retarded mothers-an inventory. Small group at risk with considerable need of assistance during an insecure childhood*. *Läkartidningen*, 100(1-2), 22-25.
- Bager, B. (2005). *Special schools should teach about parenthood*. *Läkartidningen*, 102(11), 885; author reply 886.
- Barkley, R. A. (1998). *Attention-deficit hyperactivity disorder: a handbook for diagnosis and treatment*. New York: Guilford Press.
- Barkley, R. A. (2010). *Differential diagnosis of adults with ADHD: the role of executive function and self-regulation*. *Journal of Clinical Psychiatry*, 71(7), e17. doi:10.4088/JCP.9066tx1c
- Barkley, R. A., Fischer, M., Edelbrock, C., & Smallish, L. (1991). *The adolescent outcome of hyperactive children diagnosed by research criteria-III. Mother-child interactions, family conflicts and maternal psychopathology*. *Journal of Child Psychology and Psychiatry*, 32(2), 233-255.
- Benedict, M. I., White, R. B., Wulff, L. M., & Hall, B. J. (1990). *Reported maltreatment in children with multiple disabilities*. *Child Abuse and Neglect*, 14(2), 207-217.
- Blomquist, H. K., Gustavson, K., & Holmgren, G. (1981). *Mild mental retardation in children in a northern Swedish county*. *Journal of Intellectual Disability Research*, 25(3), 169-186.
- Booth, T., & Booth, W. (2000). *Against the odds: growing up with parents who have learning difficulties*. *Mental Retardation*, 38(1), 1-14.
- Booth, T., Booth, W., & McConnell, D. (2005). *The prevalence and outcomes of care proceedings involving parents with learning difficulties in the family courts*. *Journal of Applied Research in Intellectual Disabilities*, 18(1), 7-17.
- Bray, A. (2003). *Definitions of intellectual disability: Review of the literature*. Report prepared for the National Health Committee. Wellington: Ministry of Health and Donald Beasley Institute Inc.
- Bruininks, R. H., Woodcock, R., Weatherman, R., & Hill, B. K. (1996). *Scales of Independent Behaviour-Revised*. Park Allen TX: DLM Teaching Resources.

- Carpenter, P. A., Just, M. A., & Shell, P. (1990). *What one intelligence test measures: a theoretical account of the processing in the Raven Progressive Matrices Test*. *Psychological Review*, 97(3), 404-431.
- Chawarska, K., Klin, A., Paul, R., Macari, S., & Volkmar, F. (2009). *A prospective study of toddlers with ASD: short-term diagnostic and cognitive outcomes*. *Journal of Child Psychology and Psychiatry*, 50(10), 1235-1245.
- Child Welfare Information Gateway. (2012). *The risk and prevention of maltreatment of children with disabilities*. Washington, D.C.: U.S. Department of Health and Human Services, Children's Bureau.
- Conder, J., Mirfin-Veitch, B., & Sanders, J. (2008). "I've got to think of him...": *Relationships between parents with an intellectual disability and foster parents*. *Developing Practice*, 21, 17-25.
- Crain, L. J., & Millor, G. K. (1978). *Forgotten children: maltreated children of mentally retarded parents*. *Pediatrics*, 61(1), 130-132.
- Danielsson, H., Henry, L., Rönnerberg, J., & Nilsson, L.-G. (2010). *Executive functions in individuals with intellectual disability*. *Research in Developmental Disabilities*, 31(6), 1299-1304.
- Dekker, M. C., & Koot, H. M. (2003). *DSM-IV disorders in children with borderline to moderate intellectual disability II: child and family predictors*. *Journal of the American Academy of Child and Adolescent Psychiatry*, 42(8), 923-931.
- Dekker, M. C., Koot, H. M., Ende, J. v. d., & Verhulst, F. C. (2002). *Emotional and behavioral problems in children and adolescents with and without intellectual disability*. *Journal of Child Psychology and Psychiatry*, 43(8), 1087-1098.
- Di Nuovo, S. F., & Buono, S. (2007). *Psychiatric syndromes comorbid with mental retardation: Differences in cognitive and adaptive skills*. *Journal of Psychiatric Research*, 41(9), 795-800.
- Doll, E. A. (1936). *The Vineland Social Maturity Scale*. Vineland, NJ: Vineland Training School.
- Duffy, J. D., & Campbell, J. J. I. (2001). *Regional prefrontal syndromes: A theoretical and clinical overview*. In S. P. Salloway, P. F. Malloy & J. D. E. Duffy (Eds.), *The frontal lobes and neuropsychiatric illness* (pp. 113-123). Washington, DC, US: American Psychiatric Publishing Inc.

- Duke, L. M., & Kaszniak, A. W. (2000). *Executive control functions in degenerative dementias: a comparative review*. *Neuropsychology Review*, 10(2), 75-99.
- Einfeld, S. L., Ellis, L. A., & Emerson, E. (2011). *Comorbidity of intellectual disability and mental disorder in children and adolescents: a systematic review*. *Journal of Intellectual and Developmental Disability*, 36(2), 137-143.
- Einfeld, S. L., & Tonge, B. J. (1996). *Population prevalence of psychopathology in children and adolescents with intellectual disability: II. Epidemiological findings*. *Journal of Intellectual Disability Research*, 40 (Pt 2)(2), 99-109.
- Ek, U. (2012). *Psychological assessments*. In B. Lagerkvist & C. E. Lindgren (Eds.), *Barn med funktionsnedsättningar* (pp. 319-326). Stockholm: Studentlitteratur.
- Emerson, E. (2003). *Prevalence of psychiatric disorders in children and adolescents with and without intellectual disability*. *Journal of Intellectual Disability Research*, 47(Pt 1), 51-58.
- Emerson, E., & Einfeld, S. (2010). *Emotional and behavioural difficulties in young children with and without developmental delay: a bi-national perspective*. *Journal of Child Psychology and Psychiatry*, 51(5), 583-593.
- Emerson, E., & Hatton, C. (2007a). *Mental health of children and adolescents with intellectual disabilities in Britain*. *The British Journal of Psychiatry*, 191, 493-499.
- Emerson, E., & Hatton, C. (2007b). *Poverty, socio-economic position, social capital and the health of children and adolescents with intellectual disabilities in Britain: a replication*. *Journal of Intellectual Disability Research*, 51(Pt 11), 866-874.
- Emerson, E., Malam, S., Davies, I., & Spencer, K. (2005). *Adults with learning difficulties in England 2003/4*. NHS Health and Social Care Information Centre.
- Engle, R. W., Tuholski, S. W., Laughlin, J. E., & Conway, A. R. (1999). *Working memory, short-term memory, and general fluid intelligence: a latent-variable approach*. *Journal of Experimental Psychology*, 128(3), 309-331.
- Faraone, S. V., Sergeant, J., Gillberg, C., & Biederman, J. (2003). *The worldwide prevalence of ADHD: is it an American condition?* *World Psychiatry*, 2(2), 104-113.



- Feldman, M. A. (1994). Parenting education for parents with intellectual disabilities: A review of outcome studies. *Research in Developmental Disabilities, 15*(4), 299-332.
- Feldman, M. A., & Walton-Allen, N. (1997). Effects of maternal mental retardation and poverty on intellectual, academic, and behavioral status of school-age children. *American Journal of Mental Retardation, 101*(4), 352-364.
- Feldman, M. A., Varghese, J., Ramsay, J., & Rajska, D. (2002). Relationships between social support, stress and mother-child interactions in mothers with intellectual disabilities. *Journal of Applied Research in Intellectual Disabilities, 15*(4), 314-323.
- Fernell, E. (1996). Mild mental retardation in schoolchildren in a Swedish suburban municipality: prevalence and diagnostic aspects. *Acta Paediatrica, 85*(5), 584-588.
- Fernell, E., & Bremberg, S. (1996). [Mild mental retardation is very seldom discovered at child health care centers. Diagnosed in every fifth child prior to the compulsory schoolattendance]. *Lakartidningen, 93*(23), 2237-2239.
- Fernell, E., & Ek, U. (2010). Borderline intellectual functioning in children and adolescents - insufficiently recognized difficulties. *Acta Paediatrica, 99*(5), 748-753.
- Fernell, E., Hedvall, A., Westerlund, J., Hoglund Carlsson, L., Eriksson, M., Barnevik Olsson, M., . . . Gillberg, C. (2011). Early intervention in 208 Swedish preschoolers with autism spectrum disorder. A prospective naturalistic study. *Research in Developmental Disabilities, 32*(6), 2092-2101.
- Ferrari, M. (2009). Borderline intellectual functioning and the intellectual disability construct. *Intellectual and Developmental Disabilities, 47*(5), 386-389.
- Fors, K., & Tideman, P. (2007). Användbarheten av ABAS-II vid kartläggning av adaptivt beteende. Psykologexamensuppsats: Lunds universitet. The Department of Psychology. Lund, Sweden
- Friedman, N. P., Miyake, A., Corley, R. P., Young, S. E., Defries, J. C., & Hewitt, J. K. (2006). Not all executive functions are related to intelligence. *Psychological Science, 17*(2), 172-179.
- Fuller, C. G., & Sabatino, D. A. (1998). Diagnosis and treatment considerations with comorbid developmentally disabled populations. *Journal of Clinical Psychology, 54*(1), 1-10.

- Gillberg, C. (2010). *The ESSENCE in child psychiatry: Early Symptomatic Syndromes Eliciting Neurodevelopmental Clinical Examinations*. *Research in Developmental Disabilities*, 31(6), 1543-1551.
- Gillberg, C., & Geijer-Karlsson, M. (1983). *Children born to mentally retarded women: a 1-21 year follow-up study of 41 cases*. *Psychological Medicine*, 13(4), 891-894.
- Gillberg, C., Persson, E., Grufman, M., & Themner, U. (1986). *Psychiatric disorders in mildly and severely mentally retarded urban children and adolescents: epidemiological aspects*. *British Journal of Psychiatry*, 149, 68-74.
- Gillberg, C., Svenson, B., Carlstrom, G., Waldenstrom, E., & Rasmussen, P. (1983). *Mental retardation in Swedish urban children: some epidemiological considerations*. *Applied Research in Mental Retardation*, 4(3), 207-218.
- Ginsberg, Y., Hirvikoski, T., & Lindefors, N. (2010). *Attention Deficit Hyperactivity Disorder (ADHD) among longer-term prison inmates is a prevalent, persistent and disabling disorder*. *BMC Psychiatry*, 10, 112.
- Goodman, R. (1997). *The Strengths and Difficulties Questionnaire: a research note*. *Journal of Child Psychology and Psychiatry*, 38(5), 581-586.
- Grossman, H. J. (1983). *Classification in Mental Retardation*. Washington, DC: American Association on Mental Retardation.
- Grunewald, K. (2009). *Från idiot till medborgare: de utvecklingsstördas historia*. Stockholm: Gothia.
- Gustavson, K. H., Umb-Carlsson, O., & Sonnander, K. (2005). *A follow-up study of mortality, health conditions and associated disabilities of people with intellectual disabilities in a Swedish county*. *Journal of Intellectual Disability Research*, 49(Pt 12), 905-914.
- Hagberg, B., Hagberg, G., Lewerth, A., & Lindberg, U. (1981). *Mild mental retardation in Swedish school children. I. Prevalence*. *Acta Paediatrica Scandinavica* 70(4), 441-444.
- Harris, J. C. (2006). *Intellectual disability: Understanding its development, causes, classification, evaluation, and treatment*. New York: Oxford University Press.
- Harris, P. L. (1989). *Adaptive Behavior: Research to practice*. *Journal of School Psychology*, 27(3), 301-317.

- Harrison, P. L., & Oakland, T. (2003). *Adaptive Behavior Assessment System Manual (2nd ed.)*. San Antonio, TX: Harcourt Assessment.
- Harrison, P. L., & Oakland, T. (2012). [www.pearsonassessments.com](http://www.pearsonassessments.com)
- Hindberg, B. (2003). *Barn till föräldrar med utvecklingsstörning*. Stockholm: Gothia.
- Hinshaw, S. P. (1992). Externalizing behavior problems and academic underachievement in childhood and adolescence: Causal relationships and underlying mechanisms. *Psychological Bulletin* 111(1), 127-155.
- Hurley, A. D., Folstein, M., & Lam, N. (2003). Patients with and without intellectual disability seeking outpatient psychiatric services: diagnoses and prescribing pattern. *Journal of Intellectual Disability Research*, 47(Pt 1), 39-50.
- Höglund, B., Lindgren, P., & Larsson, M. (2012). Pregnancy and birth outcomes of women with intellectual disability in Sweden: A national register study between 1999 and 2007. *Acta Obstetrica et Gynecologica Scandinavica*.
- IASSID. (2008). Parents labelled with Intellectual Disability: Position of the IASSID SIRG on Parents and Parenting with Intellectual Disabilities. *Journal of Applied Research in Intellectual Disabilities*, 21(4), 296-307.
- Jones, L., Officer, A., Bellis, M. A., Wood, S., Hughes, K., McCoy, E., . . . Shakespeare, T. (2012). Prevalence and risk of violence against children with disabilities: a systematic review and meta-analysis of observational studies. *Lancet*, 380, 899-907.
- Kadesjo, B., & Gillberg, C. (2001). The comorbidity of ADHD in the general population of Swedish school-age children. *Journal of Child Psychology and Psychiatry*, 42(4), 487-492.
- Kadesjo, B., Janols, L. O., Korkman, M., Mickelsson, K., Strand, G., Trillingsgaard, A., & Gillberg, C. (2004). The FTF (Five To Fifteen): the development of a parent questionnaire for the assessment of ADHD and comorbid conditions. *European Child and Adolescent Psychiatry*, 13 Suppl 3, 3-13.
- Kantzer, A.-K., Fernell, E., Gillberg, C., & Miniscalco, C. (2013). Autism in community pre-schoolers: Developmental profiles. *Research in Developmental Disabilities*, 34(9), 2900-2908.
- Kessler, R. C., Adler, L., Barkley, R., Biederman, J., Conners, C. K., Demler, O., . . . Zaslavsky, A. M. (2006). The prevalence and correlates of adult ADHD in the United States: results from

- the national comorbidity survey replication. American Journal of Psychiatry, 163(4), 716-723.*
- Kjellmer, I. (2013). För stor hänsyn till barnlösas önskemål. *Läkartidningen, 110, 724-725.*
- Lambert, M., Nihira, K., & Leland, H. (1993). *AAMR Adaptive Behavior Scales-School (ABAS-S:2). Examiner's Manual (2th ed.). Austin, TX: Pro-Ed.*
- Lamont, A., & Bromfield, L. (2009). Parental intellectual disability and child protection: Key issues. *NCPC issues, No. 31.*
- Lau, J. T.-F., & Cheung, C.-K. (1999). Discriminatory attitudes to people with intellectual disability or mental health difficulty. *International Social Work, 42(4), 431-444.*
- Lauruschkus, K., Westbom, L., Hallstrom, I., Wagner, P., & Nordmark, E. (2013). Physical activity in a total population of children and adolescents with cerebral palsy. *Research in Developmental Disabilities, 34(1), 157-167.*
- Leiter, R. G. (1979). *Instruction manual for the Leiter International Performance Scale. Wood Dale: IL: Stoelting Co.*
- Leonard, H., Petterson, B., De Klerk, N., Zubrick, S. R., Glasson, E., Sanders, R., & Bower, C. (2005). Association of sociodemographic characteristics of children with intellectual disability in Western Australia. *Social Science and Medicine 60(7), 1499-1513.*
- Lindsey, M. (2002). Comprehensive health care services for people with learning disabilities. *Advances in Psychiatric Treatment, 8(2), 138-147.*
- Llewellyn, G., & McConnell, D. (2002). Mothers with learning difficulties and their support networks. *Journal of Intellectual Disability Research, 46(Pt 1), 17-34.*
- Llewellyn, G., McConnell, D., & Mayes, R. (2003). Health of mothers with intellectual limitations. *Australian and New Zealand Journal of Public Health, 27(1), 17-19.*
- Loring, D. W. (1999). *INS Dictionary of Neuropsychology. New York: Oxford University Press.*
- Luckasson, R., Borthwick-Duffy, S., Buntix, W. H. E., Coulter, D. L., Craig, E. M., Reeve, A., . . . Tasse, M. (2002). *Mental Retardation: Definition, Classification and Systems of Support (10th ed.). Washington DC: American Association on Intellectual and Developmental Disability.*

- Mannynsalo, L., Putkonen, H., Lindberg, N., & Kotilainen, I. (2009). *Forensic psychiatric perspective on criminality associated with intellectual disability: a nationwide register-based study. Journal of Intellectual Disability Research, 53(3), 279-288.*
- Matson, J. L., Rivet, T. T., Fodstad, J. C., Dempsey, T., & Boisjoli, J. A. (2009). *Examination of adaptive behavior differences in adults with autism spectrum disorders and intellectual disability. Research in Developmental Disabilities 30(6), 1317-1325.*
- McCarthy, M. (2009). *Contraception and women with intellectual disabilities. Journal of Applied Research in Intellectual Disabilities, 22(4), 363-369.*
- McCaughey, T. J., & Strohmer, D. C. (2005). *Prototypes as an indirect measure of attitudes toward disability groups. Rehabilitation Counseling Bulletin, 48(2), 89-99.*
- McConnell, D., & Llewellyn, G. (2000). *Disability and discrimination in statutory child protection proceedings. Disability and Society, 15(6), 883-895.*
- McConnell, D., Llewellyn, G., & Ferronato, L. (2000). *Parents with a disability and the NSW Children's Court. Lidcombe, NSW: University of Sidney, Family Support and Services Project.*
- McConnell, D., Llewellyn, G., Mayes, R., Russo, D., & Honey, A. (2003). *Developmental profiles of children born to mothers with intellectual disability. Journal of Intellectual and Developmental Disability, 28(2), 122-122.*
- McGaw, S., Scully, T., & Pritchard, C. (2010). *Predicting the unpredictable? Identifying high-risk versus low-risk parents with intellectual disabilities. Child Abuse and Neglect, 34(9), 699-710.*
- McGaw, S., Shaw, T., & Beckley, K. (2007). *Prevalence of psychopathology across a service population of parents with intellectual disabilities and their children. Journal of Policy and Practice in Intellectual Disabilities, 4(1), 11-22.*
- Mickelson, P. (1947). *The feeble-minded parent: a study of 90 family cases. American Journal of Mental Deficiency, 51(4), 644-653.*
- Moeschler, J. B. (2008). *Genetic evaluation of intellectual disabilities. Seminars in Pediatric Neurology, 15(1), 2-9.*
- Molfese, D. L., & Molfese, V. J. (2002). *Developmental variations in learning: applications to social, executive function, language,*

- and reading skills. Mahwah, NJ: Lawrence Erlbaum Associates.
- Morch, W. T., Skar, J., & Andersgard, A. B. (1997). Mentally retarded persons as parents: prevalence and the situation of their children. *Scandinavian Journal of Psychology*, 38(4), 343-348.
- Morin, D., Rivard, M., Crocker, A. G., Boursier, C. P., & Caron, J. (2013). Public attitudes towards intellectual disability: a multidimensional perspective. *Journal of Intellectual Disability Research*, 57(3), 279-292.
- Murphy, N. (2011). Maltreatment of children with disabilities: the breaking point. *Journal of Child Neurology*, 26(8), 1054-1056.
- National Board of Health and Welfare. (2013). Persons with Certain Functional Impairments – measures specified by LSS 2012. Official statistics of Sweden, *Statistics – Social Welfare*, 79.
- Nihira, K., Foster, R., Shellhaas, M., & Leland, H. (1968). *Adaptive Behavior Checklist*. Washington, D.C.: American Association on Mental Deficiency.
- Nowak, H. I., Broberg, M., & Starke, M. (2013). Parents' experience of support in Sweden: its availability, accessibility, and quality. *Journal of Intellectual Disabilities*, 17(2), 134-144.
- Nyman, H. (2011). Psykolog har granskat 715 särskoleutlåtanden. *Psykologtidningen*, 2, 12-13.
- Papazoglou, A., Jacobson, L. A., & Zabel, T. A. (2013). More than intelligence: distinct cognitive/behavioral clusters linked to adaptive dysfunction in children. *Journal of the International Neuropsychological Society*, 19(2), 189-197.
- Pipping, L. (2001). Hur ser hjälpen ut när det gäller föräldrar med en lindrig utvecklingsstörning? C-uppstas vid institutionen för psykologi: Göteborgs universitet. The Department of Psychology. Gothenburg, Sweden.
- Rasmussen, P., & Gillberg, C. (2000). Natural outcome of ADHD with developmental coordination disorder at age 22 years: a controlled, longitudinal, community-based study. *Journal of the American Academy of Child and Adolescent Psychiatry*, 39(11), 1424-1431.
- Reiersen, A. M., Constantino, J. N., Volk, H. E., & Todd, R. D. (2007). Autistic traits in a population-based ADHD twin sample. *Journal of Child Psychology and Psychiatry*, 48(5), 464-472.

- Riemsma, R. P., Forbes, C. A., Glanville, J. M., Eastwood, A. J., & Kleijnen, J. (2001). *General health status measures for people with cognitive impairment: learning disability and acquired brain injury. Health Technology Assessment, 5(6), 1-100.*
- Ronai, C. R. (1997). *On loving and hating my mentally retarded mother. Mental Retardation, 35(6), 417-432.*
- Rosenbaum, P. L. (1988). *Prevention of psychosocial problems in children with chronic illness. Canadian Medical Association journal 139(4), 293-295.*
- Rönström, A. (1981). *Mentally retarded parents and their children. A follow-up study of 17 children with mentally retarded parents. Stockholm: The Swedish save the children federation.*
- Salvador-Carulla, L., Akoury-Dirani, L., Girimaji, S. C., Katz, G., Kwok, H., Luckasson, R., . . . Deb, S. (2011). *Intellectual developmental disorders: towards a new name, definition and framework for "mental retardation/intellectual disability" in ICD-11. World Psychiatry : official journal of the World Psychiatric Association (WPA), 10(3), 175.*
- Sattler, J. M., & Hodge, R. D. (2006). *Assessment of children: behavioral, social, and clinical foundations. San Diego: J.M. Sattler.*
- Schalock, R. L. (1999). *Adaptive behavior and its measurement: Implications for the field of mental retardation. Washington, D.C.: American Association on Mental Retardation.*
- Schalock, R. L., Reeve, A., Shogren, K. A., Snell, M. E., Spreat, S., Tasse, M. J., . . . Luckasson, R. (2010). *Intellectual Disability: Definition, Classification, and Systems of Supports. Eleventh Edition: American Association on Intellectual and Developmental Disabilities.*
- Seagull, E. A., & Scheurer, S. L. (1986). *Neglected and abused children of mentally retarded parents. Child Abuse and Neglect, 10(4), 493-500.*
- Servais, L., Jacques, D., Leach, R., Conod, L., Hoyois, P., Dan, B., & Roussaux, J. P. (2002). *Contraception of women with intellectual disability: prevalence and determinants. Journal of Intellectual Disability Research, 46(Pt 2), 108-119.*
- SFS 1967:940, *Omsorgslagen, Stockholm: Riksdagen.*
- SFS 1993:387, *Lag om Stöd och Service till vissa funktionshindrade, Stockholm: Riksdagen.*

- Shallice, T. (1982). *Specific impairments of planning*. *Philosophical Transactions of the Royal Society of London. Biological Sciences*, 298(1089), 199-209.
- Shea, S. E. (2006). *Mental retardation in children ages 6 to 16*. *Seminars in Pediatric Neurology*, 13(4), 262-270.
- Sidebotham, P., Heron, J., & Team, A. S. (2006). *Child maltreatment in the 'children of the nineties': A cohort study of risk factors*. *Child Abuse and Neglect*, 30(5), 497-522.
- Simonoff, E., Pickles, A., Wood, N., Gringras, P., & Chadwick, O. (2007). *ADHD symptoms in children with mild intellectual disability*. *Journal of the American Academy of Child and Adolescent Psychiatry*, 46(5), 591-600.
- Smedler, A.-C., & Tideman, E. (2009). *Att testa barn och ungdomar: om testmetoder i psykologiska utredningar*. Stockholm: Natur och Kultur.
- Socialstyrelsen. (2005). *Föräldrar med utvecklingsstörning och deras barn - vad finns det för kunskap?: Elektronisk resurs*. Stockholm: Socialstyrelsen
- Sparrow, S., Cicchetti, D., & Balla, D. (2005). *Vineland Adaptive Behavior Scales, Second Edition (Vineland-II)*. San Antonio, TX: Pearson Assessment.
- Sparrow, S. S., Balla, D. A., & Cicchetti, D. V. (1984). *Vineland Adaptive Behavior Scales: Survey form manual*. Circle Pines: MN: American Guidance Service.
- Spencer, N., Devereux, E., Wallace, A., Sundrum, R., Shenoy, M., Bacchus, C., & Logan, S. (2005). *Disabling conditions and registration for child abuse and neglect: a population-based study*. *Pediatrics*, 116(3), 609-613.
- Spreen, O., Risser, A. H., & Edgell, D. (1995). *Developmental neuropsychology*. Oxford: Oxford University Press.
- Steffenburg, U., Hagberg, G., Viggedal, G., & Kyllerman, M. (1995). *Active epilepsy in mentally retarded children. I. Prevalence and additional neuro-impairments*. *Acta Paediatrica*, 84(10), 1147-1152.
- Stein, M. A., Szumowski, E., Blondis, T. A., & Roizen, N. J. (1995). *Adaptive skills dysfunction in ADD and ADHD children*. *Journal of Child Psychology and Psychiatry*, 36(4), 663-670.
- Strømme, P., & Magnus, P. (2000). *Correlations between socioeconomic status, IQ and aetiology in mental retardation:*



- a population-based study of Norwegian children. Social Psychiatry and Psychiatric Epidemiology, 35(1), 12-18.*
- Strømme, P., & Valvatne, K. (1998). *Mental retardation in Norway: prevalence and sub-classification in a cohort of 30037 children born between 1980 and 1985. Acta Paediatrica, 87(3), 291-296.*
- Stuss, D. T., & Benson, D. F. (1986). *The frontal lobes. New York: Raven Press.*
- Sullivan, P. M., & Knutson, J. F. (2000). *Maltreatment and disabilities: a population-based epidemiological study. Child Abuse and Neglect, 24(10), 1257-1273.*
- Svensson, B., Bornehag, C. G., & Janson, S. (2011). *Chronic conditions in children increase the risk for physical abuse - but vary with socio-economic circumstances. Acta Paediatrica, 100(3), 407-412.*
- Tarleton, B, Ward, L, & Howarth, J. (2006). *Finding the right support: a review of issues and positive practice in supporting parents with learning difficulties and their children. London: The Baring Foundation.*
- Tasse, M. J., Schalock, R. L., Balboni, G., Bersani, H., Jr., Borthwick-Duffy, S. A., Spreat, S., . . . Zhang, D. (2012). *The construct of adaptive behavior: its conceptualization, measurement, and use in the field of intellectual disability. American Journal on Intellectual and Developmental Disabilities, 117(4), 291-303.*
- The Swedish National Agency for Education. (2010). *Skola i förändring - om reformerna i den obligatoriska skolan, reviderad version. Stockholm: DanagårdLitho AB.*
- The Swedish National Agency for Education. (2013). *What is the compulsory school for pupils with learning disabilities? Retrieved 10 september, 2013.*
- Trillingsgaard, A., Damm, D., Sommer, S., Jepsen, J. R., Ostergaard, O., Frydenberg, M., & Thomsen, P. H. (2004). *Developmental profiles on the basis of the FTF (Five To Fifteen) questionnaire-clinical validity and utility of the FTF in a child psychiatric sample. European Child and Adolescent Psychiatry, 13 Suppl 3, 39-63.*
- Turner, H. A., Vanderminden, J., Finkelhor, D., Hamby, S., & Shattuck, A. (2011). *Disability and victimization in a national sample of children and youth. Child Maltreatment, 16(4), 275-286.*

- Tymchuk, A. J. (1992). *Predicting adequacy of parenting by people with mental retardation*. *Child Abuse and Neglect*, 16(2), 165-178.
- Tymchuk, A. J. (1994). *Depression symptomatology in mothers with mild intellectual disability: An exploratory study*. *Australia and New Zealand Journal of Developmental Disabilities*, 19(2), 111-119.
- Tymchuk, A. J., & Feldman, M. A. (1991). *Parents with mental retardation and their children: Review of research relevant to professional practice*. *Canadian Psychology/Psychologie canadienne*, 32(3), 486-496.
- Umb Carlsson, Ö. (2008). *Public Special Services Provided to People With Intellectual Disabilities in Sweden: A Life Span Perspective*. *Journal of Policy and Practice in Intellectual Disabilities*, 5(4), 237-244.
- Wade, C., Llewellyn, G., & Matthews, J. (2008). *Review of parent training interventions for parents with intellectual disability*. *Journal of Applied Research in Intellectual Disabilities*, 21(4), 351-366.
- Ware, J. E., Jr. (2000). *SF-36 health survey update*. *Spine (Phila Pa 1976)*, 25(24), 3130-3139.
- Wechsler, D. (2003). *Wechsler Intelligence Scale for Children, Fourth Edition technical and interpretive manual*. San Antonio, TX: Psychological Corporation.
- Weiber, I., Berglund, J., Tengland, P. A., & Eklund, M. (2011). *Children born to women with intellectual disabilities - 5-year incidence in a Swedish county*. *Journal of Intellectual Disability Research*, 55(11), 1078-1085.
- WHO. (1992). *International statistical classification of diseases and related health problems: ICD-10. Vol. 1*. Geneva: World Health Organization.
- WHO. (2001). *International classification of functioning, disability and health (ICF)*. Geneva: World Health Organization.
- Willems, D. L., de Vries, J. N., Isarin, J., & Reinders, J. S. (2007). *Parenting by persons with intellectual disability: an explorative study in the Netherlands*. *Journal of Intellectual Disability Research*, 51(Pt 7), 537-544.
- Volkmar, F. R., & Klin, A. (2004). *Behavioral and learning problems in schoolchildren related to cognitive test data*. *Acta Paediatrica*, 93(7), 872-873.

*Yazbeck, M., McVilly, K., & Parmenter, T. R. (2004). Attitudes toward people with intellectual disabilities. Journal of Disability Policy Studies, 15(2), 97-111.*



