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## Growing up with Dyslexia

### Cognitive and Psychosocial Impact, and Salutogenic Factors

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Growing up with Dyslexia:  
Cognitive and Psychosocial Impact,  
and Salutogenic Factors.

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2007



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*To my sister and nephew  
Lena and Kristofer*

## Abstract

The studies in this doctoral thesis report aspects of cognitive and socio-emotional development in a group of teenagers and young adults with dyslexia. The 75 subjects, between 14 and 25 years of age, had been diagnosed in the latter half of the 1990s, and the collection of quantitative and qualitative data was performed in 2003–04 .

Study I investigated the stability of intelligence. Earlier research had shown contradictory results. Participants, who were 12 years old on the average at the first test, were retested after a mean period of 6½ years. There was a significant relative decrease in Verbal IQ, interpreted as an effect of the dyslexic individuals having less experience with reading and writing, and as a consequence, a lag in verbal ability. Performance IQ improved significantly and the tentative interpretation was that of a compensatory process. Dyslexic children might develop a more visual, intuitive and creative way to process information and solve problems, leading to an improvement in non-verbal intelligence.

Study II involved interviews about school experiences in terms of well-being, educational achievement, self-esteem, peer relations, and future beliefs. Earlier studies suggest that secondary emotional problems are common. Early on, school was experienced as full of distress and failure for a majority. Peer relations were good for the majority though. With time, problems became more limited to reading and writing activities, interpreted as an effect of compartmentalization of the disability along with suitable choices of school curricula and occupations. Academic self-esteem seemed low and the most optimistic subjects were those who had finished school and were permanently employed.

In Study III, the first of its kind in Scandinavia, the purpose was to uncover factors important for a favourable socio-emotional outcome, so-called salutogenic factors. The subjects and parents were interviewed. Subjects' global self-worth and sense of coherence were measured. Dyslexia was found to be a risk factor for low global self-worth when associated with poor peer relations and low parental support, typical for a group of 'resigned' subjects. External salutogenic factors were; having significant others who believe in the subjects' capacity to cope with the situation, together with good peer and family relations, and having a hobby or being good at sports. Important internal factors were a special talent, the ability to compartmentalize the disability and a personal trait of persistence. The emergence of the latter was discussed.

**Key words:** Developmental dyslexia, cognitive stability, socio-emotional outcome, salutogenic factors, resilience

## List of papers

The present thesis is based on the following studies, which will be referred to in the text by their Roman numerals:

- I.** Ingesson, S. G. Stability of IQ Measures in Teenagers and Young Adults with Developmental Dyslexia. *Dyslexia* 2006; 12: 81-95.<sup>1</sup>
- II.** Ingesson, S. G. Growing up with Dyslexia. Interviews with Teenagers and Young Adults. Manuscript accepted for publication in *School Psychology International*.<sup>2</sup>
- III.** Ingesson, S. G. Psychological Adjustment to Dyslexia—a Salutogenic Approach. Revised manuscript submitted for publication.

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## **Sammanfattning på svenska**

# **Att växa upp med dyslexi – kognitiv och psykosocial inverkan och salutogena faktorer**

Avhandlingens delstudier omfattar kvantitativa och kvalitativa data rörande en grupp tonåringar och unga vuxna med dyslexi. Såväl kognitiva som psykosociala faktorer undersöktes. Gruppen bestod av 75 ungdomar mellan 14 och 25 år som fick diagnosen dyslexi någon gång mellan 1994 och 1999. Datainsamlingen genomfördes 2003 – 2004 . Intervallet mellan diagnostillfället och uppföljningen var i genomsnitt 6½ år.

Syftet med den första delstudien var att undersöka om gruppens resultat på intelligenstest hade förändrats signifikant under perioden mellan diagnos- och uppföljningstillfället. Kliniska erfarenheter och tidigare forskning rörande barn med inlärningssvårigheter (learning disabilities) pekade på att ungdomar med dyslexi ”halkar efter” sina jämnåriga när det gäller verbal förståelse och uttrycksförmåga, men forskningsresultaten gällande barn med dyslexi var motsägelsefulla. Gruppen testades med Wechslers intelligenstest och resultaten jämfördes med tidigare testresultat. Jämförelsen visade på en signifikant relativ försämring i verbal IQ, vilket tolkades som en följd av att barn med dyslexi får betydligt mindre läs- och skriverfärdigheter än sina jämnåriga och av det skälet ”halkar efter” i verbal intelligens. En motsvarande och t o m större signifikant förbättring i performance IQ, eller icke-verbal intelligens, uppmättes, och en försiktig tolkning var att, som en följd av kompensatoriska processer utvecklar barn med dyslexi mera visuella, kreativa och intuitiva metoder att lära sig och att lösa problem, och på så vis förbättras deras icke-verbala intelligens.

Den andra delstudien syftade till att genom intervjuer låta ungdomarna själva komma till tals och undersöka hur de upplevt sin skoltid med särskild fokus på dyslexin. Tidigare forskning har visat att sekundära problem i form av låg självkänsla, dåliga kamratrelationer, ångest och nedstämdhet är vanliga. Resultaten visade att de första sex åren i skolan upplevs som svåra för barn med dyslexi. Det är en tid som präglas av frustration, förvirring och förödmjukelse. De flesta hade goda kamratrelationer, men en del hade blivit mobbade och upplevde fortfarande att dyslexin påverkade dem mycket negativt. Med tiden hade emellertid problemen för majoriteten av ungdomarna kommit att inskränka sig till läs- och skrivsituationer, och de trivdes allt bättre i skolan, framför allt i gymnasiet, där de

också i hög grad upplevde att de lyckades väl. Detta tolkades som ett resultat av dels förmågan att se dyslexin som endast en del av självet, och dels att ungdomarna hade gjort val när det gällde utbildning och yrke som var i linje med deras begåvning och talanger. Många hade valt ett yrkesförberedande program i gymnasiet eller ett specialprogram med idrotts- eller musikinriktning. De som hade slutat skolan och arbetade uttryckte större optimism än de som fortfarande studerade. Det "akademiska" självförtroendet bedömdes som lågt, eftersom endast en mycket liten del av gruppen jämfört med befolkningen i övrigt hade valt att läsa vidare efter gymnasieskolan.

Den tredje delstudien, som är den första av sitt slag i Skandinavien, syftade till att avtäcka "salutogena" faktorer för dyslektiker, d v s vilka faktorer som är betydelsefulla för att ungdomar med dyslexi skall få en god självkänsla och inte drabbas av sekundära emotionella problem. Genom två frågeformulär, intervjuer med dem själva och en av deras föräldrar kunde tre grupper av individer urskiljas, vilka betecknades som de "obekymrade", de "uppgivna" och "kämparna". En relativt hög generell självkänsla och känsla av sammanhang (KASAM) kännetecknade de "obekymrade" och "kämparna".

En slutsats var att ungdomar med dyslexi som har en särskild talang eller ett starkt intresse och med en familj utan "skolambitioner" med tiden anpassar sig väl. Detta karaktäriserade de "obekymrade". Dyslexi bedömdes vara en riskfaktor för låg självkänsla och emotionella problem i de fall då individerna även upplevde dåliga kamratrelationer och lite stöd från föräldrar, något som karaktäriserade de "uppgivna" ungdomarna. De tio individer som uppvisade högst självkänsla och KASAM bland "kämparna", de "bäst anpassade", studerades närmre i syfte att identifiera salutogena faktorer. Dessa individer syntes ha gått igenom alla stadier av accepterande av de dyslektiska svårigheterna.

Externa positiva faktorer var betydelsefulla vuxna, oftast mödrar, som trodde på ungdomarnas möjlighet att klara sig bra, goda kamrat- och familjerelationer, samt ett starkt intresse, en hobby eller sport. Viktiga interna faktorer var en talang för sport, konst, musik eller teknik, att kunna isolera dyslexin till en mindre del av självet samt den personliga egenskapen "envishet". Envishet är ett drag som även förts fram som betydelsefullt i internationell forskning, och uppkomsten av detta karaktärsdrag diskuterades.

De tio individer som bedömdes som "bäst anpassade" hade inte förlorat i verbal förmåga lika mycket som de övriga, och det var en signifikant skillnad i jämförelse med de "obekymrade" och de "uppgivna". Detta tolkades som ett resultat av att de varit mycket ambitiösa i sitt skolarbete.

## Abbreviations

ADD	Attention Deficit Disorder
ADHD	Attention Deficit Hyperactivity Disorder
BDA	British Dyslexia Association
DAMP	Dysfunction of Attention, Motor and Perception
FDB	Föräldraföreningen för Dyslektiska Barn
FMLS	Förbundet funktionshindrade Med Läs- och Skrivsvårigheter
FSIQ	Full Scale IQ
IDA	International Dyslexia Association
LD	Learning Disability
MR	Mental Retardation
NICHHD	National Institute of Child Health & Human Development, U.S.
PIQ	Performance IQ
SEM	Structural Equation Modeling
SOC	Sense Of Coherence
SOU	Statens Offentliga Utredningar
SPSS	Statistical Package for the Social Sciences
VIQ	Verbal IQ
WAIS-R	Wechlser Adult Intelligence Scale – Revised ed.
WAIS III	Wechlser Adult Intelligence Scale – 3 <sup>rd</sup> ed.
WISC-R	Wechlser Intelligence Scale for Children – Revised ed.
WISC III	Wechlser Intelligence Scale for Children – 3 <sup>rd</sup> ed.
WISC-III <sup>s</sup>	Wechlser Intelligence Scale for Children – 3 <sup>rd</sup> ed. Swedish Standardization Version
WPPSI	Wechsler Preschool and Primary Scale of Intelligence

## Preface

In my work as a psychologist in a small dyslexia clinic between the years 2000 and 2005, I stumbled across some phenomena that aroused my curiosity and raised some of the questions that this thesis tries to answer. One of them had to do with test-retest differences. Several of the children who came to the clinic had been subjected to examination and tests long before they were referred to the clinic. It was quite common that a school psychologist had performed a WISC test a couple of years earlier. For different reasons, the child was then referred to the clinic where I worked, either because the school required a renewed assessment, or because the child's parents or teachers felt the need for a second opinion. Testing the child, I found that the results were often quite different, and lower, than at first test. Talking to colleagues and teachers, I found a widespread conception that dyslexic students tend to lag behind their peers in the course of the school years. They maintained that this was the case not only as to the pupil's proficiency in different school subjects, but in their general cognitive ability. Going through the published research on this subject, I found contradictory results in children diagnosed as dyslexic. Hence I decided to find out whether this widespread 'hunch' was valid not only in the individual case, but in a larger group of dyslexic individuals.

Interestingly enough, in spite of the limited research done on this phenomenon, the definition of dyslexia accepted by the International Dyslexia Association (IDA) includes the following statement: 'Secondary consequences may include problems in reading comprehension and reduced reading experience that can impede growth of vocabulary and background knowledge'. This implies a 'lag' in verbal ability over time. In the commonly-used intelligence tests, half of the scales are measurements of verbal ability, and consequently, if verbal ability does not develop normally, intelligence is affected, at least as intelligence is measured by tests.

Another phenomenon that caught my interest was the socio-emotional outcome of dyslexia. In talking to parents, members of different dyslexia organizations (the Swedish FDB and FMLS) and professionals working in the dyslexia field, there seemed to be a consensus about the detrimental effects of dyslexia on children's general self-esteem, peer relations, and some also put forward the risk of anti-social behaviour and related problems. Once again, turning to the research domain, I found an overwhelming amount of books and articles on the negative effects of dyslexia on social and emotional development. However, I and everyone else know that not all children with reading impairments turn into psychic wrecks or juvenile delinquents, which is why I decided to find out what

the factors would be that bring out happy and normally functioning dyslexic individuals. I found this perspective more useful in future contacts with young people with reading difficulties and their parents and teachers. It turned out that most of the young people that I met in this research project displayed an impressive persistence and ability to cope with their situation in the long run.

After having started the research project, there emerged several other phenomena during the data collection and interpretation that I found very interesting, such as the young people's experiences of school, especially their account of how they had experienced the first years of school.

## **Ethics**

All subjects were asked to agree on participating in the study orally as well as by letter. In the cases where subjects were below 18 years of age, parents' permission was also required. The study was approved by the Medical Ethical Committee of Lund University (LU 722-02).

## **Introduction**

There are several features or problems associated with dyslexia, the most obvious being a difficulty in the use of the written language. This thesis will not deal with this phenomenon, however, but with the possible secondary effects of dyslexia. It will treat the possible cognitive changes over the years in young people with dyslexia (Study I). It will also go into the socio-emotional effects of the disability, with two specific focal points. The first is how dyslexic young people themselves feel about the effect of their dyslexic difficulties when they grow up (Study II). The second focus is on factors that create resilience to negative socio-emotional consequences of dyslexia (Study III).

Several circumstances and concepts need some presentation before the empirical studies are described and discussed. First, the Swedish school system needs some attention. Swedish school policy and research with relevance to the thesis are treated in short. Then the clinic, where the research was carried out, is described.

Dyslexia is not an unambiguous concept and the definitions of dyslexia and their distinctive features are treated next, as well as how dyslexia was defined in the present study.

Research on the stability of intelligence is presented with relevance to Study I. Then there are several concepts with relevance to studies II and III that are considered, such as shame, self-esteem, self-efficacy, locus of control and sense of coherence. The research on socio-emotional problems associated to dyslexia is then presented as well as a model of the process of acceptance of the disability. Finally, the research on resilience is presented.

## **National and Local Issues and Settings**

### **The Swedish school system**

In Sweden, all children between the ages of seven and sixteen must attend school. If the parents wish, a child can start school one year earlier, at the age of six. The compulsory school is traditionally divided into three stages; elementary school (age 7–10 years), middle school (age 10–13 years) and secondary school (age 13–16 years). In upper secondary school there are 17 national programmes, all of which are 3-year programmes. The programmes provide a broad general education and eligibility to study at the university or post-secondary level. There are several programmes with vocational courses. Upper secondary school is not compulsory, but an overwhelming majority of the students who leave secondary

school attend upper secondary school (97.9 % in 2005). Students aged 20 or older may attend municipal adult education (Komvux, Folkhögskola) programmes at the upper secondary level, an option which is being chosen more and more, not seldom in order to improve marks from upper secondary school.

### **Swedish school policy and research**

Over the past few decades there has been a considerable research interest in dyslexia in Sweden, and major efforts have been made to remedy children's difficulties, as well as to work to improve society's attitudes to learning disabilities. The explicit goal has been to create a 'school for all', outlined in the Swedish government report 'Att lämna skolan med rak rygg' ('Walking tall after leaving school', author's translation, SOU 1997:108).

Interestingly enough, although the importance of self-esteem is stressed, even in the title of the report, there has been little research in the field of self-image, self-esteem and associated concepts on Swedish students with dyslexia. Research in Sweden relevant to the present study was performed by Taube (1988), who showed that young students' reading and spelling performance can affect their self-concept of ability. Zetterqvist-Nelson (2003) found that labelling children as dyslexic might have ambiguous effects on their self-image. Westling-Allodi (2002) analysed interactions between the comprehensive school organisation and students involved in special educational activities. Among other things, she found that good peer relations compensated for students' difficulties. Swalander (2006) showed that self-regulation and academic self-concept influence reading ability in a normal population of Swedish pupils, and that self-regulation and self-concept in turn is influenced by family circumstances. In the study by Olofsson (2002), the students diagnosed as dyslexic in childhood, had chosen school subjects and programmes that demanded lower levels of reading skills. None had taken any university courses and had no such plans for the future either. Olofsson found that the students had reading skills that would allow university studies, but motivation, low self-esteem and perceived self-efficacy made them choose not to enter tertiary education.

### **The dyslexia clinic in Lund, SKED**

(Skånes Kunskapscentrum för Elever med Dyslexi)

The clinic is situated in Lund, Sweden, and children from the whole county of Skåne come for consultation. From the beginning, it was part of the psychiatric clinic for children, but is at present organized with other units serving children with disabilities. Since the start in 1994, hundreds of children have been referred to the clinic for different purposes. Assessment of dyslexia is one, and has often been

carried out in cases when resources for assessment have not been adequate or sufficient in the child's school or local community. Hence, there is a rather unique collection of test protocols and medical records of children with reading and writing difficulties.

Referral practices have been generous, and children have come to the clinic on the initiative of parents, teachers, paediatricians, school psychologists, etc. One of the effects of this practice is that many of the referred children have not been diagnosed as dyslexic.

The author of this thesis was employed as a psychologist and head of the clinic 2000–2006 .

## **Definitions of Dyslexia**

Accurate identification of dyslexia requires that key symptoms and characteristics be specified. A definition of the deficit is required. An operational definition is furthermore essential for research purposes. More specifically, without the well-defined subject selection criteria that an operational definition provides, research examining the causes and consequences of reading disability typically cannot be interpreted, replicated and generalized.

Regrettably, there is no unambiguous or undisputed definition of dyslexia. Professionals still argue about what dyslexia is, and how or if it is different from general reading difficulties. Among those who accept that there is a specific reading disability as opposed to general difficulties, the argument involves the issue of which aspect of dyslexia is the most characteristic, or the aspect that could define the disability. It is obvious that, since there is no agreement on what dyslexia is, the process of assessing the deficit is also under discussion.

Historically, early definitions of reading disability or dyslexia have been exclusionary. Within this context, reading disability is identified if the difficulty in reading exists in the *absence* of other problems (e.g. mental retardation or socio-cultural deprivation) that could explain it. This so-called discrepancy theory states that, if there is a substantial difference between the student's level of reading, writing and spelling abilities on the one hand and his or her general cognitive abilities, measured by an intelligence test, on the other, one can assume that he or she has a specific reading and writing disability, or dyslexia. This definition leans on the fact that there is a correlation between intelligence and reading ability, somewhere between .40 and .60, depending on the study (Siegel, 1992; Snowling, 2000).

In the last decades there has been a great amount of research published about characteristic phonological weaknesses associated with dyslexia. This research suggests that difficulties in phonological processing constitute the core symptoms of dyslexia (Bradley & Bryant, 1978; Caravolas & Volin, 2001; Felton, Naylor & Wood, 1990; Fletcher *et al.*, 1994; Frith, 1999; Hatcher, Snowling & Griffiths, 2002; Manis, Custodio & Szeszulski, 1993; Pennington, Van Orden, Smith, Green & Haith, 1990; Snowling, 2000; Svensson & Jacobson, 2006).

Phonological awareness appears to be the most deficient language skill in disabled readers. In a practical sense, phonological awareness is essential in enabling children to map, or translate, printed symbols (letters and letter patterns) into sound, commonly known as the grapheme-to-phoneme coding skill. If a child cannot perceive the sounds in spoken words, for example, if they cannot 'hear' the 'ar' sound in 'car' and 'bar' and perceive that the difference between these sound segments lies in the first sound, they will have difficulty decoding words accurately and fluently. Dyslexics are slow at rapid automatic naming, poor at non-word repetition, they have poor phoneme awareness, and they have difficulties in segmenting phonemes and difficulties in object naming (Bradley & Bryant, 1978; Denckla & Rudel, 1976; Kamhi & Catts, 1986; Lundberg & Høien, 1997; Lundberg, Olofsson & Wall, 1980; Manis *et al.*, 1993; Snowling, 2000).

Consequently, the two main lines of argument can be defined as on one hand the 'discrepancy' definition, and on the other hand, the 'phonological' definition. The approaches are not necessarily exclusive, but professionals tend to agree with only one of them.

## **Definition problems**

For several reasons, the IQ/reading achievement discrepancy is a problematic marker for reading disability. The first problem is its exclusionary character. It says nothing of what the problem is, it only claims that the individual reads and writes at a lower level than would be expected from their level of general cognitive abilities. From this definition it is not possible to make a valid prediction of an individual's potential to learn to read and write normally.

Furthermore, the definition lacks a theoretical explanation of the disorder.

Another dilemma is that it is not clear how IQ/achievement discrepancies are to be operationalized and defined. For example, which IQ score and which IQ measure should be employed? Is the Full Scale IQ the most appropriate metric, or should the Verbal or Performance IQ be used as the measure of aptitude or potential ability to read?

A fourth problem is that the discrepancy method requires students to fail or fall behind for a substantial period of time before they are identified as dyslexic

(Lyon *et al.*, 2001). This requirement for an ‘accumulation of failure’ acts as a barrier to early help and a risk for possible secondary effects such as loss of self-esteem. There is scientific evidence of the importance of early identification in order to avoid secondary emotional consequences (Hellendoorn & Ruijsenaars, 2000; Humphrey, 2002; Høien & Lundberg, 1999; Rogan & Hartman, 1990). If the child must wait until failing, the risk of suffering from academic and emotional strains of failure is obvious (Lyon *et al.*, 2001).

Yet another problem is that the discrepancy definition eliminates the possibility of individuals with lower cognitive abilities having specific reading and writing problems, which is not self-evident (Andersson, 2003; Høien & Lundberg, 1999; Lyon *et al.*, 2001; Siegel, 1992).

For the phonological weakness to be used as a positive criterion of dyslexia, phonological impairments, no matter how subtle, must be identified only in true dyslexics, and should not be observed in individuals who are not dyslexic. This has not been shown. Høien and Lundberg (1999) have surveyed the research on the prediction of reading difficulties from phonological weaknesses in smaller children. Children at risk were those who had parents with reading difficulties and who showed phonological difficulties in kindergarten, but the predictive value was only around 80%. This means that, in the individual case, the presence of phonological difficulties cannot be a sole reliable predictive variable.

As Stanovich (1991) has pointed out, the critical task will be to identify the most valid predictor of an individual's potential to read at the single-word level.

### **The IDA definition**

The definition of dyslexia seemingly most accepted internationally is the IDA definition. On August 3, 2002, the IDA (International Dyslexia Association) and NICHD (National Institute of Child Health & Human Development, USA) convened a scientific consensus meeting to bring the research definition, used by NICHD since 1994, in line with recent research:

Dyslexia is a specific learning disability that is neurobiological in origin. It is characterized by difficulties with accurate and/or fluent word recognition and by poor spelling and decoding abilities. These difficulties typically result from a deficit in the phonological component of language that is often unexpected in relation to other cognitive abilities and the provision of effective classroom instruction. Secondary consequences may include problems in reading comprehension and reduced reading experience that can impede growth of vocabulary and background knowledge.

This definition was subsequently approved by the IDA board of directors and is currently in use by NICHD. As can be seen, the IDA definition is a combination of the discrepancy definition ('...is often unexpected in relation to other cognitive abilities') and the hypothesis of phonological weaknesses ('...result from a deficit in the phonological component of language').

### **The Definition of dyslexia in the present study**

At the time of the initial assessment of the group which is the subject of the present study, the discrepancy diagnostic criterion was used, in accordance with the ICD-10 (1992) and DSM-IV (APA, 1995) diagnostic manuals. In these cases a prediction of reading level was made from the Full Scale IQ (FSIQ), and in cases where the reading and spelling attainment was two or more years below, the children were diagnosed as dyslexic. This criterion is no longer in use in the clinic where the study was performed.

As in many disciplines, there is a lag between scientific research and clinical practice, and as a consequence, phonological deficits were not used as a diagnostic criterion at the time of the first assessments in this study. Some would argue that there might be individuals in the studied group who would not be diagnosed as dyslexic today. However, a closer look at the objections to the discrepancy definition, as outlined above, reveals that it is not criticized because of its over-inclusive character, but rather because it is under-inclusive.

There is very little research done on the overlap between the two criteria, but John Rack at the York Dyslexia Institute presented two studies at the BDA Conference in 2004 (e-mail communication, July 5, 2005). In the first, the pupils of a whole school were screened for dyslexia and the subjects who showed a discrepancy between reading ability and non-verbal intelligence tended to show a profile of difficulties in phonological processing and memory. In the SPELLIT study, Rack and his colleagues selected children with literacy difficulties and there was no selection on a discrepancy criterion. However, it turned out that most of the subjects showed both a discrepancy in relation to general ability, both verbal and non-verbal, and weaknesses on tests of phonological processing and memory.

In conclusion, bearing in mind that follow-up studies are usually afflicted with the problem of significance shifts of concepts used, it seems plausible that all members of the studied group would have been diagnosed as dyslexic even if they had been assessed according to the standards used at present.

## **Intelligence Stability in Normal and Exceptional Children**

Stanovich (1986) considers slow reading acquisition to have cognitive, behavioural and motivational consequences that in turn slow the development of other cognitive skills and inhibit performance on many academic tasks. He refers to this phenomenon as the 'Matthew Effect' ('For unto every one that hath shall be given, and he shall have abundance; but from him that hath not shall be taken away even that which he hath'. Matthew XXV: 29).

One of the basic assumptions considering intelligence is that it is constant over time. Intelligence, as measured with the Wechsler scales in samples of normally achieving individuals, has been shown to be stable over time (Ellzey & Karnes, 1990; Moffit, Caspi, Harkness & Silva, 1993; Neyens-Lidwien & Aldenkamp, 1996; Tuma & Appelbaum, 1980; Wechsler, 1974, 1981 and 1992).

Tuma & Appelbaum (1980) found a high stability in the WISC-R when testing a group of normal children with a test-retest interval of six months. Neyens-Lidwien & Aldenkamp (1996) performed the WISC-R (Wechsler Intelligence Scale for Children-Revised) and the WPPSI (Wechsler Preschool and Primary Scale of Intelligence) three times, with a test-retest interval of six months in a group of 59 normal Dutch children. They found that the stability of Verbal IQ (VIQ) and Full Scale IQ (FSIQ) was excellent ( $> .78$ ) and that the reliability of Performance IQ (PIQ) was fair to good ( $.68$ ).

The stability of the WISC-R and the WISC-III (Wechsler Intelligence Scale for Children, 3<sup>rd</sup> ed.) have been repeatedly investigated, both in groups of normal children and in groups of exceptional children.

Quite a few longitudinal studies have been performed with the explicit purpose of investigating the reliability of the WISC-R test with exceptional children. The test-retest stability of the WISC-R for learning disabled (LD) children over short term periods (less than a year) has been evaluated (Covin, 1977; Smith & Rogers, 1978). In these studies the WISC-R proved stable. The stability of WISC results over longer time periods has also been thoroughly examined in clinical samples. Several studies (Elliot *et al.*, 1985; Haynes & Howard, 1986; Horn-Alberge, 1999; Lally, Lloyd & Kulberg, 1987; Naglieri & Pfeiffer, 1983; Oakman & Wilson, 1988; Webster, 1988; Whorton, 1985) show that the three-year stability coefficients compare well with those established during the standardization of the WISC-R (Wechsler, 1974). Ellzey and Karnes (1990) examined 46 gifted students and found no significant differences between the means on VIQ, PIQ and FSIQ with a test-retest interval ranging from one to two years.

In some studies though, a somewhat different picture emerges. Vance, Hankins & Brown (1987) investigated a group of LD and mentally retarded (MR) students over a longer time period. The students were tested with the WISC-R three times with three-year intervals. They found that the stability coefficients were lower for the six-year interval than the coefficients found in studies with shorter intervals between tests. The coefficients obtained by Vance *et al.* (1987) ranged from .53 for PIQ, .75 for VIQ to .81 for FSIQ with a six-year interval. They concluded that, 'This finding seems to substantiate the fact that the shorter the retest interval, the higher the reliability coefficients' (p. 231). Sattler (1992) indicates that a 'reliability coefficient of .80 or higher is generally considered to be acceptable' (p. 25).

Schuerger & Witt (1989) have gathered test-retest reliability data from 79 sources (34 studies) on five intelligence tests, the Stanford-Binet, the WISC, the WISC-R, the WAIS and the WAIS-R, and they found that the interval between tests and age at the time of the first testing were the only two factors that showed a significant relationship to test-retest reliability. The younger the children were at the time of the first testing and the longer the interval between tests, the lower stability, although test-retest intervals of greater than 25 months did not seem to make any substantial difference. Subject status—patient or normal—was not related to test-retest reliability. There was no difference between tests, with the effect of age and interval accounted for. In their study, however, there was no attempt to differentiate between VIQs and PIQs.

In no less than eleven studies, there is a report of a decline in the VIQ score on the WISC-R, when compared over a two- to three-year interval. The samples comprise of LD and MR children, and in some studies behaviourally impaired children and so-called neglected youth as well (Anderson, Cronin & Kazmierski, 1989; Bauman, 1991; Haddad, Juliano & Vaughan, 1994; Lawson, Inglis & Tittmore, 1987; Martin, 1979; Nichols, Inglis, Lawson & MacKay, 1988; Sarazin & Spreen, 1986; Stavrou, 1990; Truscott, Narrett & Smith, 1994; Vance, Blixt, Ellis & Debell, 1981; Weltner-Brunton, Serafica & Friedt, 1988).

In conclusion, there is good support for the notion that VIQ declines over the years in samples of LD and MR children, and it seems that the decline is greater the younger the children are at the time of first test (Bauman, 1991), and the longer the interval between tests.

As for PIQ, in two studies there was a decline in PIQ as well (Sarazin & Spreen, 1986; Stavrou, 1990). In contrast, Lawson, Inglis and Tittmore (1987) and Haddad, Juliano and Vaughan (1994) reported a reliable increase in PIQ in groups of LD children.

None of the studies presented above deals with reading and writing disability exclusively. The studies comprise children with a variety of symptoms or dysfunctions, although the majority involves children with LD. As for LD, it is a rather non-specific designation of a variety of syndromes affecting language, learning and communication. Traditionally, LD is synonymous with the concept of unexpected underachievement, or more specifically, students who do not listen, speak, read, write, or develop mathematics skills commensurate with their potential (Lyon *et al.*, 2001). Most often, LD designates reading and writing difficulties, according to Lerner (1989) in 80% of the cases, but this leaves one-fifth with other kinds of difficulties. Moreover, in the United Kingdom, 'learning difficulties' and 'mental retardation' are often used interchangeably (Finlay & Lyons, 2005).

Considering the cognitive stability of individuals with dyslexia exclusively, there is not much empirical research available. The samples are usually quite small, and results are contradictory.

Bravo-Valdivieso (1995) studied a group of dyslexic children in Chile over a four-year period. He did not find any difference in VIQ, as measured with the WISC-R, but a slight increase in PIQ (3.7 points). Esser & Schmidt (1994) followed a group of 34 pupils with reading and spelling disorders from the age of 8 to the age of 13. The non-verbal intelligence remained constant. There was no record of verbal intelligence measures.

Frauenheim & Heckerl (1983) performed a follow-up study of eleven subjects, who had been diagnosed as dyslexic in childhood (mean age 10½ years). The mean age for the group at the time of follow-up was 27 years (range 25 to 30). They found a significant discrepancy between VIQ's and PIQ's, in favour of the latter on both tests, but no difference over the years. The Verbal, Performance and Full Scale IQ's were essentially the same in the WISC and WAIS-R scores after seventeen years. Bishop & Butterworth (1980) found that the children in their sample who had reading problems at age eight appeared to have lower VIQ than PIQ scores at age eight, but not at age four. Wright, Fields and Newman (1996) discovered, in a group of 17 students aged eight with dyslexia who were retested after five years, that their VIQ declined on the average 2.3 points and their PIQ declined even more (5 points).

Share & Silva (1987) found, in a group of 39 reading disabled children, with test-retest at the age of nine and eleven, respectively, that their average PIQ in the WISC-R improved 7.2 points. They showed a relative decline in the WISC-R Vocabulary score. Share, Silva and Adler (1987) compared a group of 65 children with reading plus spelling retardation at the age of nine and at the age of eleven.

Their PIQ improved with an average of 8.2 on the WISC-R and their VIQ improved slightly also, with an average of 2.2.

Thomson (2003) investigated a group of 76 dyslexic children attending a specialist school for dyslexics. He found a slight increase in both mean VIQ scores (1.6 points) and in mean PIQ scores (3.3 points). The mean VIQ and PIQ were somewhat above average initially, 111.7 and 112.2, respectively, and the follow-up interval exceeded two years. Thomson's conclusion is that, 'It is important to state here that the interpretation of the data is not to argue that Stanovich's (1986) contention concerning the "Matthew" effect is incorrect, but that this I.Q. drop-off can be circumvented with appropriate help' (Thomson, 2003, p. 11).

There is one Swedish study on the subject (Nydén, Billstedt, Hjelmqvist & Gillberg, 2001). It is a pilot study in which the follow-up time was two years, and the number of subjects with a reading and writing disorder was fourteen—all boys. Their mean age at first test was 10.7 and at the second occasion 12.4. It turned out that VIQ on the WISC-III was stable over the two years, but PIQ increased significantly (7.4 points). At the time of the initial test, VIQ > PIQ, but the relationship was the opposite at the time of follow-up.

In conclusion, the results on IQ stability and dyslexia are contradictory. The available research comprises small numbers of subjects, except Thomson's (2003), and the follow-up time ranges between nineteen months and seventeen years.

### **The 'Flynn effect' and its reverse**

Of relevance for a longitudinal study of intelligence stability is that test performance has tended to improve from one generation to the next. It is now over 20 years since Flynn (1984), in a seminal review, first drew attention to the extensive evidence for rising levels of intelligence test scores in the American population through the preceding decades of the twentieth century. This was followed by a further review in which he demonstrated the same effect to have occurred in other economically developed countries from which relevant evidence was available (Flynn, 1987). The magnitude of the effect, which has come to be known as the 'Flynn Effect', varied in time and place but could generally be summarized to be about 3–5 IQ points per decade.

The effect has been seen most prominently in so-called fluid tests of intelligence, i.e. tests requiring educative reasoning to a logical conclusion from given, usually abstract, information such as is presented in Raven's Progressive Matrices (Raven, 2000). The effect has typically been ascribed to either biological factors, such as improved nutrition and health care, or social factors including educational

developments (Neisser, 1998). Flynn himself does not give any explanation as to the causal factors behind these gains in intelligence. All he says is, 'Environmental factors with a large impact on IQ have not been identified' (Flynn, 1987, p. 190).

Recently, a diminishing IQ growth rate has been observed in the birth cohorts 1940–1980 of Danish male conscripts, over 500 000 young men (Teasdale & Owen, 2005). Performance peaked in the late 1990s and has since declined to pre-1991 levels. In Norway, the trend has been the same—Sundet, Barlaug and Torjussen (2004) report a complete cessation of gains in 'General Ability' from the mid 1990s as well as an end to increase in the performance on Raven's matrices after the mid to late 1990s. In Sweden, Svensson, Emanuelsson and Reuterberg (1997) report that in the 35 year period between 1960 and 1995, verbal ability has declined, and reasoning and spatial ability have risen, but levelled out, the largest part of the increment taking place during the 1960s and 1970s. The decline in verbal ability is explained by vocabulary changes in the time period. Thus it seems that the 'Flynn Effect' is not valid any longer in Scandinavia.

## **Illiteracy, Shame and Low Self-esteem**

Shame is one of the most powerful negative affects or emotions. Nathanson (1992) claims that the very idea of shame is so embarrassing that most people do not even want to talk or hear about it.

Illiteracy is very much related to shame. Even prominent and otherwise highly respected persons in Sweden have been publicly ridiculed because of incidents of misreading or misspelling. Being illiterate is associated with being unintelligent, which is another trait considered shameful. Humphrey and Mullins (2002) reported that children with dyslexia, in contrast to a control group, believed that when one is good at reading, one can be considered intelligent, and *vice versa*. The implications for the feelings of bad readers are clear and has reference to the findings of Study II.

The shame of illiteracy can be observed at all levels, within the individual child who fails to learn to read and write (Burden, 2005; Hellendoorn & Ruijsenaars, 2000). It can also, though it is not so often admitted, be recognized in the instructor who 'fails' to teach a child to read and write. On the national level, reflected by the recurrent international comparisons on literacy, a whole nation may feel humiliated if the population's level of literacy is low.

Shame—our reaction to it and our avoidance of it—becomes the emotion of politics and conformity (Nathanson, 1992). Conformity is something especially important to the child around the age of nine to twelve years. Deviation from the norm—whether it involves being too fat, too skinny or clumsy, having the wrong clothes or not being able to read and write—is a source of humiliation to children in middle childhood. Burden (2005) has illustrated this very vividly through excerpts of his interviews with young dyslexics, describing the confusion and humiliation the boys felt the first years of school.

Shame and low self-esteem are linked together. We feel shame when the failure to meet an important competence is seen as a reflection of some defect in the self such as an inferior ability in a highly valued domain. Shame is a social affect, in the sense that we feel shame in relation to others, but most of the time it is the internal expectation of shame that makes us behave in a shame-avoiding manner.

The emotional pain in terms of shame, humiliation and low self-regard that dyslexic individuals experience is the result of society's devaluation of illiteracy. Herrington and Hunter-Carsh (2001, p. 114) put it like this, 'The dominant paradigm is still one of "in-person" weaknesses rather than one which shows quite clearly that it is the specific values which are attached to particular concepts and standards of literacy and numeracy which largely shape the way in which dyslexia is perceived and experienced. It is substantially these perspectives which make dyslexia disabling.'

## **Self-esteem, Its Development and Dyslexia**

In middle childhood, from the age of around seven, children usually start to look upon themselves in a different and often more 'realistic' way compared to preschoolers, who often reveal unreasonably high thoughts of themselves (Cosden, Brown & Elliott, 2002; Wigfield *et al.*, 1997). At about the same time as children start school, at least in Sweden, they begin to discover that others' views about them are not always congruent with their own self-image. The 'looking-glass self', a concept developed by Cooley (1922), emerges, meaning that others' opinions of the self are gradually included in the self-image. Comparisons to and competitions with others become more important in this age period (Singer, 2005). The ability to utilize social comparison information for the purpose of self-evaluation is founded on cognitive developmental advances, namely the ability to simultaneously compare representations of self and others (Harter, 1999). Erikson (1959) has labelled the socio-emotional conflict of this age period 'industry versus inferiority'.

In the 1960s, self-concept was viewed primarily as a unidimensional construct synonymous with self-esteem. This conceptualization of self-concept and self-esteem changed, however, with a variety of multidimensional models emerging. Although the current major models of self-evaluation define domains differently, each includes separate measures of social competence and acceptance, academic skills, and physical appearance (Cosden *et al.*, 2002). Self-perceptions of academic and non-academic competencies are also clearly separated. Self-esteem or self-worth has been conceptualized by Harter (1993) as the level of global regard that one has for the self as a person. The concept goes back to James (1892) who focused on the individual's cognitive evaluation of competence in relation to perceived value of such competence. James maintained that lack of competence in a domain that is considered unimportant by the person will not affect self-esteem negatively.

Later on in middle childhood, children develop domain-specific evaluations of their competence or adequacy, in addition to a more global concept of their worth as a person (Harter, 1993). Such domain-specific evaluations are scholastic competence, athletic competence, social acceptance, physical appearance, and behavioural conduct. Marsh and Yeung (1998) point to the importance of separating academic from non-academic and general domains of self-concept. Empirical studies performed by Harter (1993) support the formulations by James. She showed that the magnitude of self-esteem was dependent on perceived competence on the one hand and the evaluation of such competence on the other, i.e. if a person experienced low competence in scholastic achievement and at the same time judged this domain to be very important, the discrepancy created a low academic, or scholastic, self-esteem.

Competence does not appear to be as critical to preschoolers' self-esteem, nor are young children cognitively able to compare two concepts such as self-evaluations and importance ratings simultaneously (Harter, 1993).

Accordingly, there are two routes to self-esteem enhancement; either raise one's level of competence or depreciate the importance of such competence. However, the evaluation of competence in different domains is dependent on others, notably parents and peers. Reading ability is highly valued in Western societies, and the opposite, not being able to read or write, is often associated with low intelligence and shame, as was mentioned above. As Harter (1993) puts it, it would appear to be extremely difficult for children and adolescents to discount the importance of domains that significant others regard as highly valuable. Children and adolescents judge scholastic competence and behavioural conduct to be most important to parents and social acceptance and physical appearance to be

most important to peers (Harter, 1993). Robinson (1995) too, found that approval from peer groups and classmates had a strong relationship to self-worth.

In sum, when the child starts school, he or she becomes conscious of others' evaluations, and begins to compare their own achievements to those of others. Consequently there are two important factors that put the dyslexic child at risk of a dramatic drop in self-esteem—the awakened awareness of the way others look upon oneself, in combination with the failure to meet the standards of learning to read and write. This has relevance to the findings of both Study II and III.

### **The relationship between academic self-esteem and achievements**

It is clear that there is a relationship between scholastic attainments and academic self-esteem (Harter, 1983; Bandura, 1990; Chapman, 1988, Swalander, 2006). The relationship is reciprocal, i.e. poor attainment can lower self-esteem and low self-esteem can lead to poor achievements. Some researchers claim that academic attainment tends to be the most important factor (Hamachek, 1995; Marsh & Yeung, 1997; Muijs, 1997). However, factors like age can have an impact on this relationship. The research of Skaalvik and Hagtvet (1990) indicated that academic achievement was causally predominant over self-concept in grade 4 but in grade 7 the result was the reverse. Swalander (2006) used structural equation modelling (SEM) to show that academic self-concept influenced reading ability more than reading ability influenced academic self-concept among eighth graders (mean age 14 years). Guay, Larose and Boivin (2004) revealed, also through SEM, that academic self-concept in grades 3, 4 and 5 predicted educational attainment level ten years later.

In sum, it appears that academic self-esteem is founded early on and that older children's academic self-esteem is well established and not as much influenced by actual performance compared to the more attainment-dependent self-esteem in younger children.

## **Self-efficacy, Locus of Control and Sense of Coherence**

### **Self-efficacy**

Bandura maintains that among the mechanisms of human agency, none is more central or pervasive than people's belief in their efficacy to regulate their own functioning and to exercise control over events that affect their lives (Bandura, 1997). Perceived self-efficacy refers to beliefs in one's capabilities to produce given attainments and in school settings it is defined as a person's judgement of confidence to perform academic tasks or succeed in academic activities (Pajares

& Graham, 1999). Self-efficacy deals primarily with the cognitively perceived capability of the self.

Unless people believe they can produce desired effects by their actions, they have little incentive to act or to persevere in the face of difficulties (Bandura, Pastorelli, Barbaranelli & Caprara, 1999). Strong self-efficacy beliefs enhance human accomplishment and personal well-being in many ways (Pajares & Graham, 1999). They influence the choices we make in deciding whether or how to act, the amount of effort we are prepared to invest in any activity, how long we persevere when confronted by obstacles and our level of resilience in the face of adversity. This has relevance to the findings of Study III; perseverance turned out to be a strong factor for a positive adjustment.

A low sense of efficacy to exercise control over things one values can give rise to feelings of futility and despondency. One way is through unfulfilled aspirations, which associates to the Jamesian view of self-esteem described above. The satisfactions people derive from what they do are largely determined by the standards against which they evaluate their attainments (Bandura, 1991). A sense of inefficacy to fulfil the valued standards gives rise to self-devaluation and depression. Failure diminishes motivation and generates a despondent mood when people judge they lack the efficacy to attain difficult standards but continue to demand those attainments of themselves for any sense of satisfaction and self-worth. A second pathway to depression is through a low sense of social efficacy to develop social relationships that bring satisfaction to people's lives and enable them to manage chronic stressors. Social support reduces vulnerability to stress, depression and physical illness (Bandura *et al.*, 1999). This has relevance to the findings of Study III; the 'resigned' group revealed a low sense of self-efficacy beliefs.

### **Locus of control**

The locus of control concept was originally developed by Rotter (1966). This construct has relevance to the results of Study III; the subjects that adjusted well appeared to have an internal control orientation. People tend to ascribe their chances of future successes or failures either to internal or external causes. Persons with an internal locus of control see themselves as responsible for the outcomes of their own actions. These individuals perceive an agreement between their own behaviour and subsequent events (Strickland, 1989). They are often observed to excel in educational or vocational realms (Marks, 1998). Someone with an external locus of control, on the other hand, sees environmental causes and situational factors as being more important than internal ones. These individuals would be more likely to see uncontrollable circumstances rather than

effort as determining whether they succeed or fail in the future, and are more likely to view themselves as the victim in any given situation.

Findley and Cooper (1983) showed that an internal locus of control is associated with higher academic achievement. Research results indicate that dyslexic and LD children display less internal locus of control in the academic context than non-disabled children (Bosworth & Murray, 1983; Chapman 1988). Research findings include significant correlations between endorsing external locus of control and higher levels of psychological distress (Marks, 1998).

Locus of control is related to, but distinct from, self-efficacy. Although someone may believe that how some future event turns out is under their own control (locus of control), they may or may not believe that they are capable (self-efficacy) of behaving in a way that will produce the desired result.

### **Salutogenesis and sense of coherence**

Salutogenesis, a concept developed by Antonovsky (1979), focuses on factors that support human health and well-being rather than on factors that cause disease. Antonovsky suggested that instead of asking ‘what causes illness?’, an equally or more important question to pose was ‘what is the origin of health?’. Antonovsky proposed that the key factor in salutogenesis is a person's sense of coherence (SOC). He defined SOC as ‘a global orientation that expresses the extent to which one has a pervasive, enduring though dynamic feeling of confidence that one's internal and external environments are predictable and that there is a high probability that things will work out as well as can reasonably be expected.’ Abundant research has shown that a strong SOC is related to better use of available resources, more adaptive coping, and greater resiliency when applied to people with a variety of illnesses and disabilities (Antonovsky, 1987, 1993; Eriksson & Lindström, 2005; Gana, 2001). People with a strong SOC manage insoluble problems better than those with a weaker SOC. The concepts of salutogenesis and SOC have relevance to the methods and findings of Study III.

Whether SOC is to be considered a predictor variable or a measure of psychological outcome has been disputed. Gana (2001) maintains that if SOC essentially refers to one's resilience and ability to respond to stress, it is more likely to act as a mediator between stressors and mental health outcomes. He used SEM to show that adversity and stressful experiences do not affect psychological well-being directly, but do so indirectly via a mediator, the SOC. Adversity affected well-being only among weak SOC individuals. These persons seemed to be more vulnerable to stressful experiences than those who had a strong SOC. Gana's results demonstrate that the sense of coherence buffers the effect of stressful experiences on psychological well-being.

Thus it appears that SOC is a personal trait that develops during childhood and adolescence rather than being an effect of later experiences in life. In trying to outline how the sense of coherence develops during childhood and adolescence, Antonovsky is not very specific but refers to mainstream developmental psychology, such as the work of Bowlby (1969) and Erikson (1963). He stresses healthy secure attachment and a loving parent-child relationship (Antonovsky, 1987). Egeland, Carlson and Sroufe (1993) found that secure attachment relationship in infancy serves a crucial protective function. The experience of sensitive and emotionally responsive caregiving behaviour in parents plays a central role.

SOC does not refer to 'a specific type of coping strategy, but to factors which, in all cultures, always are the basis for successful coping with stressors' (Antonovsky, 1987). These factors are *Comprehensibility*, *Manageability* and *Meaningfulness*. *Comprehensibility* is a cognitive component and refers to the degree to which individuals perceive information about themselves and the social environment as not only understandable, but also as ordered, structured, and consistent. Perceiving events as comprehensible does not mean that they are completely predictable. *Manageability* is an instrumental component and refers to the degree to which individuals feel that the resources (one's own or external resources) of which they dispose are sufficient to adequately meet the demands imposed by internal and external stimuli. *Meaningfulness* is a motivational component that refers to the extent to which subjects feel that certain areas of life are worthy of time and effort, and to their degree of involvement in various domains of life. It is easy to see that these constructs are related to self-efficacy and locus of control, although not equivalent.

## **Low Self-esteem, Social and Emotional Problems in Children and Youth with Dyslexia**

It is well documented that the specific difficulties do not disappear when the dyslexic child grows older, but the problems with reading, writing and spelling persist into adulthood (Bruck, 1990; Byring & Michelsson, 1984; Jacobson, 1999; Riddick, 1996; Shaywitz *et al.*, 1999).

Bender and Wall (1994), in a research overview, concluded that students with LD suffer from a wide array of social-emotional problems, including lower self-concept, lower social competence and more external attribution orientation than children without LD.

LD is however not the same as dyslexia. LD is sometimes used interchangeably with dyslexia, but in other studies it is a non-specific designation of a variety of syndromes affecting language, learning and communication. The difference is treated above in the section about intelligence stability.

Research has shown over-representations of antisocial and other behaviour problems associated with reading and writing difficulties among children, adolescents and adults (Alm & Andersson, 1997; Esser & Schmidt, 1994; Frisk, 1999; Heiervang, Stevenson, Lund & Hugdahl, 2001; Hunter & Lewis, 1973; Jensen, Lindgren, Wirsén-Meurling, Ingvar & Levander, 1999; Maughan, Gray & Rutter, 1985).

There is evidence of increased risks of low self-concept, learned helplessness, low self-efficacy beliefs, anxiety and depression in young people with dyslexia (Alexander-Passe, 2006; Boetsch, Green & Pennington, 1996; Burden, 2005; Casey, Levy, Brown & Brooks-Gunn, 1992; Humphrey, 2002; McNulty, 2003; Rack, 1997; Riddick, Sterling, Farmer & Morgan, 1999). It should be noted that the terms self-esteem, self-worth, self-image and self-concept are concepts used somewhat interchangeably in the literature.

In a study performed by Undheim (2003), the interviewees described difficulties in maintaining a self-image of a competent person, thus contributing to lower self-esteem. Further, they revealed a history of struggling, problems in being recognized as having dyslexia, poor access to help, and little support and understanding. It had led them to doubt their own abilities and supported a picture of themselves as lazy and slow.

Hughes and Dawson (1995) interviewed a group of adults who described failure, humiliation and lack of understanding as continuing experiences from their school days. In the study of Hellendoorn and Ruijsenaars (2000), the adult subjects reported that they knew something was the matter with them long before they were diagnosed. The majority experienced their difficulties as a strenuous handicap as adults, and the most frequently named problems were uncertainty and a general feeling of being different. Most of them had bad memories from childhood, where feelings of inferiority, shame and isolation and being misunderstood dominated. Gonzalez-Pienda *et al.* (2000) found that LD children had a more negative self-image in both academic and social areas and attributed failures more to internal than to external causes.

Children with LD, whether specific or general, are furthermore at an increased risk for bullying and teasing (Eaude, 1999; Singer, 2005; Whitney, Nabuzoka & Smith, 1992), which can be devastating for the developing self-concept (O'Moore, 2000; Sharp, 1996). Humphrey (2002) showed a significant difference between dyslexic and normal subjects in self-esteem with special reference to

popularity. In the study of Hellendoorn and Ruijsenaars (2000) most participants reported that they had few or no friends as children, and that they were bullied frequently. In the Taube (1988) study, the underachievers were less popular and had a lower social status in the class as compared to other children. Nabuzoka and Smith (1993) found LD children less likely to be judged popular by peers and in addition, tending to be shy, help-seeking, and victims of bullying. In a recent study by Lackaye, Margalit, Ziv and Ziman (2006), students with LD reported lower social self-efficacy than their non-LD peers.

It has however been demonstrated that in several cases the self-esteem of young people with dyslexia improves remarkably when they grow older (Boetsch, Green & Pennington, 1996; Maughan, 1995; McNulty, 2003). Moreover, there are reports of adults who in spite of persisting dyslexic difficulties have been very successful (Scott, Scherman & Phillips, 1992). This research has relevance to the findings of Studies II and III.

When children grow older, their self-esteem develops from a relatively undifferentiated global self-esteem in young children to a differentiated model of self-esteem as outlined above (Harter, 1993). More recent studies have emphasized the importance of looking at differences in self-esteem in different domains (Riddick *et al.*, 1999), applying the multidimensional model of self-concept. In the study by Frederickson and Jacobs (2001) and that by Pakzad and Rogé (2005), dyslexic children were found to have significantly lower perceived scholastic competence than their normally achieving peers, but their global self-worth was not significantly lower. Marsh, Craven and Debus (1999) argued that as the children matured, the relationship between academic attainment and self-esteem both lessened and became more subject specific.

Montgomery (1994) also found that children with LD reported lower academic and competence self-concepts than did non-disabled children, but did not differ from non-disabled and high achieving children in their social, family, affect, or physical self-concepts. Ridsdale (2004) maintains that dyslexia influences academic, rather than global self-esteem. The reading-disabled children in the study of Casey *et al.* (1992) revealed more emotional problems and considered themselves to be less competent scholastically than their peers, but they did not rate themselves as less physically or socially competent.

Considering behaviour and conduct problems associated with dyslexia, Fergusson and Lynskey (1997) and Jorm, Share, Matthews and Maclean (1986) found that, when the associations between reading difficulties and conduct problems were adjusted for confounding factors, there were no statistically significant associations between reading difficulties and conduct problems. Early conduct problems was such a confounding factor. Willcutt and Pennington (2000)

found no relationship between reading disability and aggression, delinquency or conduct disorder, when controlling for the significant relation between reading disability and ADHD. Gellert and Elbro (1999) outlined the research on behaviour problems associated with reading disabilities and concluded that the co-occurrence is not sufficient to imply a simple causal relationship. They suggested that a common underlying factor, early language difficulties, was the cause of both behaviour problems and reading difficulties. Moreover, the high prevalence of reading and writing disabilities that were found in the study of juvenile delinquents by Svensson, Lundberg and Jacobson (2001) seemed primarily to be related to social and cultural factors, home backgrounds, limited school attendance and poor self-esteem rather than to constitutional problems of a dyslexic nature.

As to poor peer relations associated with dyslexia, Westling-Allodi (2002) showed that good peer relations could serve as compensation for academic shortcomings. She suggested that one way to deal with difficulties at school is to 'turn on' peer relations, i.e. actively choose to invest in relationships rather than scholastic achievements.

To sum up the research on low self-esteem, social and emotional problems in children and youth with dyslexia:

- There is an association between reading difficulties and poor self-esteem, social, emotional and conduct problems.
- Co-occurrence is not sufficient to imply a simple causal relationship.
- The effects on peer relations are unclear.
- Reading and writing difficulties are more associated with low global self-esteem in younger than in older children.
- When children are old enough to differentiate between different domains of the self, global self-esteem improves in many cases, while it is common that academic self-esteem stays low.
- Research results on LD children might not be applicable to dyslexic children.

## **The Process of Acceptance of the Disability**

There are some common features involved in coping with a disability, irrespective of its nature, but every disability calls for specific adaptation tasks (Coyne & Racioppo, 2000). The life situation of the individual living with a disability is so

profoundly characterized by the condition-related stressors that the most effective coping strategies are those that explicitly relate to the condition (Elfström, Kreuter, Persson & Sullivan, 2005; Higgins, Raskind, Goldberg & Herman, 2002). For children whose reading and writing acquisition is slow, or even absent, the enterprise is quite different to what young individuals with, for example physical disabilities have to deal with.

In describing the process of acceptance I have adopted the model proposed by Higgins *et al.* (2002).

### **1. Awareness of difference**

In the beginning, the child who does not learn to read and write like others will feel frustrated and confused. There is an uncertainty about what is the matter. The child feels different and 'stupid' (Burden, 2005; Reiff, Gerber & Ginsberg, 1997). The child senses that something is very wrong, but is bewildered at what it is (McNulty, 2003). The same usually goes for parents, unless one or both parents are dyslexic themselves. In many cases, this state of mind can last for years, until it is established that the problem is dyslexia. Thus the child has to face his or her shortcomings not knowing what the problem is or, if it is possible to do anything about it. The demands of school involve not only reading and writing, but also the ability to gain knowledge in several other domains, such as mathematics, history, geography, etc. The child has to find means to learn all the subjects despite having reading difficulties. Cosden *et al.* (2002) found that the development of self-understanding was associated with lower self-esteem, i.e. when the child begins to realize the difference, its self-esteem decreases.

### **2. The labelling event**

There is a link between adjustment and identification of the difficulties. Most dyslexia researchers agree that early diagnosis improves adjustment, because early identification makes early interventions possible and low self-esteem need not become permanent (Hellendoorn & Ruijsenaars, 2000; Høien & Lundberg, 1999; Johnson, Peer & Lee, 2001; Lyon *et al.*, 2001; Reiff *et al.*, 1997; Rogan & Hartman, 1990). It is considered to be a relief for the child to understand what the matter is, together with the realization that the problems have nothing to do with being unintelligent.

However, Riddick (1996) and Zetterqvist-Nelson (2003) have pointed to the complexity of reactions to being labelled as dyslexic, the multiple purposes that the diagnosis can serve, and the significance of the personal meaning that the child assigns to the diagnosis. Labels of a disability are used to describe or explain an individual's functioning at the biological, psychological or sociological

levels. A disability is however not only a matter of definition; it is a personal one of how each person with an impairment defines him- or herself.

Many of the children in Zetterqvist-Nelson's study experienced the diagnosis as a threat to their self-esteem; they did not want to stand out as a person who needed help. Zetterqvist-Nelson also stressed the risk that the label may form the child's identity. Nevertheless, the children also experienced the label as a moral relief, meaning that they were not responsible for their shortcomings. In the Riddick research, all but one of the children found the dyslexia label helpful at a personal level, as a relief and explanation of their difficulties. However, half of them did not find the label helpful at a public level, being afraid of teasing, which was the case in the study of Singer (2005) as well. Zetterqvist-Nelson concluded that the influence of the dyslexia label is dependent on which meaning the child attaches to it. McNulty (2003) stressed the manner in which labelling is conducted, implying that the child needs help to understand the diagnosis.

### **3. Understanding/negotiation of the disability**

A feature common with other disabilities is that positive adaptation involves understanding what the disability is, and what its consequences are, now and in the future (Cosden *et al.*, 2002). Self-understanding allows people to utilize their strengths and advocate for their needs (Spekman, Goldberg & Herman, 1992). Cosden *et al.* suggest that there is a developmental shift that occurs during adolescence, where self-understanding begins to lead to self-acceptance. With time, young people become more knowledgeable about their disability which increases self-acceptance. Cosden *et al.* maintain that the availability of significant others with whom to discuss their disability is particularly important for the acceptance of the difficulties. Davenport (1991) found that those in her study who revealed a high acceptance of the diagnosis were more likely to receive help from adults, to attempt to master difficult material and to emphasize the value of social support.

### **4. Compartmentalization**

Related to understanding is the capacity to compartmentalize the disability. This means that the individual regards the disability as only one aspect of the self. Compartmentalization of a disability has been shown to be a positive adjustment factor. (Reiff *et al.*, 1997; Petersson, Ekensteen & Rydén, 2006). A person *has* a disability, he *is not* his disability.

Cosden *et al.* (2002) suggest that a certain level of cognitive development is necessary for compartmentalization: 'As the child's cognitive complexity increases, including their metacognitive abilities, they are more able to see

themselves from multiple perspectives. That is, they are able to hold on to a self-perception that includes strengths and weaknesses without denying their disability, exaggerating their skills, or becoming overwhelmed by the academic problems' (p. 44). Compartmentalization also involves the acknowledgement of strengths and talents, i.e. the realization that one has capacities in other domains unrelated to reading and writing, e.g. in sports and in the social domain (McNulty, 2003; Alves-Martins, Peixoto, Gouveia-Pereira, Amaral & Pedro, 2002). In the study by Goldberg, Higgins, Raskind & Herman (2003), successful informants demonstrated an ability to compartmentalize their LD, which allowed them to acknowledge strengths as well as weaknesses and to make use of the social support available to them. Starting in adolescence, they prevailed not because they had remediated their LD, but because they had capitalized on a particular ability or interest to help them achieve self-esteem. Success was broadly defined, and included parameters such as employment, education, independence, family relations, social relationships, crime/substance abuse, life satisfaction and psychological health.

## **5. Transformation**

The process of transformation involves the acknowledgement of the positive sides of the disability and the possibilities in life despite the difficulties. Higgins *et al.* (2002) concluded that not all of their informants had reached this stage, but that passage through all stages of acceptance correlated highly with success.

Reiff *et al.* (1997) refer to a reframing process, by which they denote a reinterpreting of the experience of disabilities from something dysfunctional to something functional. By this they mean the realization that it is not the disability itself that is the obstacle but instead the ability to defy the various challenges involved in living with the disability. This finding agrees with Maughan (1995), who found that the best adjusted of the adults with dyslexia in his study were those who had made choices consistent with their assets and weaknesses. 'It is our premise that awareness, understanding, and acceptance of one's disability are critical elements to the development of positive self-regard' (Cosden *et al.*, 2002, p. 33).

## **Resilience Research**

Research has traditionally focused on the negative effects of dyslexia, but recently there has been a shift in perspective. Margalit (2003) and Meltzer (2004) have stressed the need for research that focuses on learning disabled sub-groups who

view themselves positively and who display resilient attitudes that help them succeed despite their difficulties. *Resilience* refers to a child's development of competence even under conditions of pervasive or severe adversity (Egeland, Carlson & Sroufe, 1993), a concept approaching the significance of 'salutogenesis', described above.

Regarding earlier research along this line, Reiff *et al.* (1997) found one overriding positive factor in their interview study of highly successful learning disabled adults, namely the quest to gain control over their lives. In the study by Reiff *et al.* as well as that by Fink (2000), internal factors such as persistence and determination were the most important. Persistence, along with family support, was emphasized as important for a positive outcome in the studies of Rawson (1977), Scott *et al.* (1992) and Werner (1993).

In the study of Goldberg *et al.* (2003), successful informants demonstrated an ability to compartmentalize their learning disability, which allowed them to acknowledge strengths as well as weaknesses and to make use of the social support available to them. Starting in adolescence, they prevailed not because they had remediated their learning disability, but because they had capitalized on a particular ability or interest to help them achieve self-sufficiency.

McNulty (2003) also established that a compensatory niche, like arts and social activities, or a special interest, like history, had helped improve self-esteem. In the Davenport study (1991), acceptance of the diagnosis was shown to be associated with healthy adaptation to a learning disability.

Hellendoorn & Ruijsenaars (2000) identified seven factors that increase the chance of a favourable socio-emotional outcome, based on their own study as well as those by Finucci, Gottfredson and Childs (1985), Gerber and Reiff (1991), Morrison and Cosden (1997), Rogan and Hartman (1990) and Spekman *et al.* (1992):

- Temperamental and personal characteristics that help the person to make good use of his or her own abilities, to elicit positive responses of parents, teachers, and other adults and to make realistic educational and vocational plans.
- Care giving styles of parents that foster self-esteem in their child.
- A family background that values education and provides the means to enlist special educational and psychological services (usually associated with high socioeconomic status).
- A cooperative relationship between family and school.
- Recognition of the learning disability at a relatively early age.

- Intensive, effective intervention during the early school years.
- Proactive acceptance of and openness about the disability.

In conclusion, several characteristics appear important for a positive adjustment in dyslexic individuals, most frequently personal characteristics such as amiability, persistence, acceptance of the diagnosis and the ability to compartmentalize the disability. Essential external factors include compensation in the form of a niche or special interest, and support from significant others.

# **The Empirical Studies**

## **General Aim**

The general purpose was to take advantage of the unique opportunity of conducting a study of the hundreds of young people who had passed through the dyslexia clinic in Lund, Sweden, where the author was employed as a psychologist. There were several questions about Swedish children with developmental dyslexia that might find an answer through a repeated contact with the young people who had been assessed several years earlier. In all, the hopeful expectation was that the results of the study would provide useful implications for parents, teachers, psychologists and others who come into contact with dyslexic children, in order to prevent or diminish the negative consequences of the disability.

## **Specific Aims**

### **Study I**

Clinical observations formed the background of the study. Many school psychologists and teachers hold the opinion that students with different kinds of LD, including dyslexia, tend to gradually lag behind their peers, with respect to cognitive abilities. However, on a closer examination of the research on dyslexia specifically, as distinguished from the more vaguely defined LD group, scientific studies turned out to be scarce, and extremely limited in Scandinavia. References are given in the section about intelligence stability above. Besides, the results were contradictory.

The specific aim of Study I was to answer the following questions: Is there a setback in cognitive development, as measured with current intelligence tests, in young people with developmental dyslexia as compared to normal subjects? If so, is this setback general or specific to some areas of intelligence, for example the verbal domain? If there is a setback, what are the conceivable reasons?

### **Studies II and III**

The theoretical background of Study II and Study III was that dyslexia has been shown internationally, to be accompanied by emotional distress, deviant behaviour and low self-esteem, especially in the academic domain, in children and teenagers. References are given in the section about social and emotional problems and dyslexia above. The clinical background was the author's experi-

ence of many children who had bad experiences of school. These children might not be representative of all dyslexic children, though.

The purpose of **Study II** was to ask young dyslexic people about their experiences of school and how they felt that the disability had influenced their well-being, accomplishments, peer relations and belief in the future. Contemporary research on the psychosocial consequences of dyslexia in Sweden is scarce. In addition, the international studies referred to are frequently based on parent and teacher ratings and rarely on accounts by dyslexic young people themselves. This study focuses on the subjects' own memories and feelings and how they experience their current situation.

The specific aim of **Study III** was a search for factors that generate resilience to a continuous feeling of low self-worth. International research indicates that even if emotional secondary effects are common, they are far from being general, as outlined in the introduction of this thesis. In several cases the self-esteem of young people with dyslexia improves remarkably when they grow older. Moreover, many adults have been very successful in spite of persisting dyslexic difficulties. Consequently, the concern was to uncover the underlying mechanisms of a positive emotional adjustment. The study focused on identifying the subjects who showed a good adjustment in order to find out what characterized them. The concepts used in this context were 'global self-worth' and 'sense of coherence', the latter being the essence of the salutogenic approach. These concepts were dealt with in the introduction of this thesis.

The study was the first in Scandinavia. European and American research had earlier identified several characteristics important for a positive adjustment in individuals with dyslexia or LD, the most frequent being internal features such as amiability, persistence, acceptance of the diagnosis and the ability to compartmentalize the disability. Essential external factors were compensation, in the form of a niche or special interest and support from significant others. For a detailed outline of previous research findings, see the section above on resilience research.

## Methods

The collection of data was carried out between 2003 and 2004, by the author exclusively. The purposes and methods used in the three studies of this thesis were different, Study I being a quantitative study and Study II and III quantitative as well as qualitative studies. Consequently, methods are not generally shared and will be treated separately below.

Study II and III both use interviews, but for different purposes, and in Study I some questions from interviews were used to highlight possible relationships to the setback in verbal ability. Also, information about the participants' IQ, collected in Study I, was used in Study III.

Participants in the three studies were essentially the same and will be described below, along with a description of the selection process. The subjects were tested and interviewed at the same occasion. Tests were completed in the morning and the interview took place after lunch, a total of three to five hours.

## **Participants**

### **Selection of subjects**

To start out, the aim was to include all children who had been diagnosed with dyslexia in the clinic during the years 1994–1999. The clinic opened in 1994 and the year 1999 was chosen as the far end to ensure a follow-up time of at least three years. All test protocols from this time interval, which amounted to several hundreds, were examined. Planning Study I, it became obvious that raw values from the WISC-III tests might be needed for comparison, since two different versions had been used during this period. From the middle of 1994 to 1998 a Swedish standardization version of WISC-III, the WISC-III<sup>s</sup>, was in use. Consequently, all children were excluded from the study that had been tested by a psychologist outside the clinic because raw values were not available. There was also a smaller group tested before mid-1994 with yet another, earlier version of WISC, the WISC-R, and was therefore excluded. There remained 174 subjects. Going through the medical records of these 174 persons, 71 were excluded, either because they had not been diagnosed as dyslexic, or because they had an additional diagnosis such as ADD (Attention Deficit Disorder), ADHD (Attention Deficit Hyperactivity Disorder) or DAMP (Dysfunction of Attention, Motor and Perception). The referral practice described above had resulted in a random group, whereby thus more than one-third did not meet the diagnostic criteria. In the cases of children with ADD, ADHD and DAMP, it was considered that their additional difficulties might interfere with cognitive development and emotional adjustment, and it would be hard to rule out their influence, and they were thus excluded.

In addition, two persons had died, and one was severely ill. Finally, 100 individuals remained.

### **Drop-out rate**

There were 35 persons who could not or did not want to be tested, however ten of these agreed to be interviewed by telephone. Of the remaining dropout group of 25 (25%), two were individuals who could not be located. Ten persons declared that they did not have time, and that they had no remaining problems with reading or writing. Thirteen did not want to participate, without explaining why.

Regarding age and sex, the mean age in the dropout group was 18 years, i.e. one year younger on the average than the participating subjects, and there was a majority of male subjects in the dropout group of 25 individuals—21 men and four women.

A comparison of IQ levels at first test, documented in test protocols, was made between the 65 subjects being tested at follow-up and the 35 who were not. It was reasonable to think that if the IQ level at first test were the same for the participating group as for the drop-out group, it would be likely that the participating group would be representative for the whole group. The mean VIQ for the participating subjects was 101.5 and for the drop-out group 100.0. The corresponding mean PIQ was 95.6 and 94.5, respectively. An independent samples t-test showed no difference between the groups. It was concluded that the participating subjects were representative of the group as a whole.

A comparison between the ten subjects who were not tested, but only interviewed, and the 65 subjects that were tested showed a difference in age. The ten who were only interviewed were two years older on the average, reflecting the fact that several of them had moved away from the county and therefore could not come to the clinic. There were seven male and three female subjects in this group. There was no significant difference with respect to VIQ or PIQ at first test compared to the 65 other subjects.

### **Participating subjects**

Mean age at the time of diagnosis had been 12 years (range 7 to 16, SD = 2.6) and at follow-up it was 19 years (range 14–25, SD = 2.1). The mean interval between diagnosis and follow-up was 6½ years (range 3½–10, SD = 2.6). Two-thirds (48) were male, and one-third (27) were female. This corresponds with a general male predominance of dyslexia (Høien & Lundberg, 1999). At the time of test and interview two-thirds were still in some kind of education and one-third had finished school (See Table 1).

As can be seen, of those who had finished the regular upper secondary school (39 subjects), only five, or 13%, had gone to university. This is to be compared to 43% in the general population (SCB, 2005). Of the university students, four were female and one male.

Table 1. *Participants' occupation at the time of interview.*

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In education (all levels) (n=47)	
Secondary school	9
Upper secondary school	27
Adult secondary school*	6
University	5
Not in education (n=28)	
Unemployed	4
Military service	2
Temporary employment	7
Permanent employment	15

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\* Swedish 'KomVux' or 'Folkhögskola'

All subjects had received special education at one or more levels in school, but nobody had attended a special class or school for dyslexic children. It has been shown by Thomson (2003) that dyslexic children can be cognitively favoured by being put in a school specialized for them.

### Parents

The proportion of the subjects who had grown up with only one parent was 38% (in all but two cases with the mother), which compares closely to 37% in the Swedish population (SCB, personal communication with K. Lundström, 12 Dec., 2004). On account of this, the educational level of the mothers only was recorded, and was found to be evenly distributed, irrespective of marital status; 35% had attended secondary school only, 30% had passed upper secondary school and had received vocational training, and 35% had a university degree.

Interviews with parents were carried out in order to validate the interviews with subjects. It was the author's apprehension that some of the young people in the studied group might feel uneasy and not willing to admit difficulties, since keeping up a positive self-image often involves making light of or denying problems. The so-called self-serving bias is a well known psychological strategy for protecting or enhancing one's self-concept (Blaine & Crocker, 1993; Campbell & Sedikides, 1999; Mezulis, Abrahamson, Hyde & Hankin, 2004). Moreover, the participants might have rather dim memories of the first years of school. For these reasons, it seemed adequate to interview one of their parents too. The author asked the subjects for permission to interview one of their parents. They were requested to choose the parent most familiar with their dyslexic problems and

school history. In all cases but one, it turned out to be the mother. The parent was then interviewed by telephone or in person, depending on their preference. It turned out to be very difficult to contact all the mothers—they did not answer the telephone and did not call back after repeated messages on the answering machine, and finally only 50 parents of the 75 subjects were interviewed. A comparison between the subjects whose parents were interviewed and those, whose parents were not interviewed, did not yield any significant differences with respect to age, sex or FSIQ. The parents who did participate were also proportionally distributed in the three ‘adjustment’ categories that were subsequently identified in Study III.

## **Instruments**

### **Study I. Test instruments**

A comparison was made between test results at the time of diagnosis, between 1994 and 1999, and the time of follow-up, 2003–2004. The difference between the first and second test was calculated on FSIQ, VIQ, PIQ, and on subtest scaled scores. Also, the relationship between VIQ and PIQ was calculated at initial test and at follow-up.

The test instruments used were the WISC-III and the WAIS-III (Wechsler Adult Intelligence Scale, 3<sup>rd</sup> ed.).

Comparisons were complicated by two circumstances. The first was that two different versions of the WISC-III had been used at the time of diagnosis, depending on when the tests were given. Between 1994 and mid-1998 a Swedish standardization of the British-American WISC-III was carried out in order to collect Swedish scaling for scores. Around mid-1998 the Swedish scaling was available and the version used thereafter was the WISC-III. The standardization version was labelled the WISC-III<sup>s</sup>. The norms used in the WISC-III<sup>s</sup> were the British WISC-III norms (Wechsler, 1992; Psykologiförlaget, 1994). There was no difference between the WISC-III and the WISC-III<sup>s</sup> in the Performance subtests and these were also identical with the British-American version. All verbal subtests of both the WISC-III and the WISC-III<sup>s</sup> differed from the British-American version except Digit Span. The WISC-III and the WISC-III<sup>s</sup> were exactly the same in Similarities and Arithmetic, but differed in Information, Vocabulary and Comprehension, in the way that in the final version (WISC-III), over-items that did not contribute to the reliability were excluded (Psykologiförlaget, 1999). The agreement on Vocabulary was very good and also on VIQ, PIQ and FSIQ. The VIQ split-half reliability coefficient was .92, and for the Vocabulary subtest it was .82 (Psykologiförlaget, 1999).

The second complication was that, at the time of follow-up, the subjects were between 14 and 25 years of age, and therefore both the WISC-III and the WAIS-III must be used, the WAIS-III being applicable for subjects above 16 years of age. The norms of the Swedish version of the WAIS-III were the same as the British (and American) norms, since it has not been standardized in a Swedish population. This means that a comparison between WAIS-III and WISC-III<sup>s</sup> is a comparison using the same norms as in the U.K. Comparing the WISC-III and the WAIS-III, the correlation was between .78 and .88 (WAIS-III, Technical Manual. Wechsler, 1997). On subtest level, the highest correlation was in Vocabulary (.83) and Block Design (.80).

In conclusion, the agreement between the test versions used in the study was satisfactory. Tables displaying the comparisons between test versions can be seen in the appended article.

Interview questions about reading habits and about the amount and evaluation of special education received were also used in this study. The purpose was to find out if reading habits had any relationship to possible verbal changes and if the special education received was associated with possible changes in cognitive ability. Numerical values from 1 to 5 were assigned to the answers (see Appendix, interview questions 30, 25 and 25a).

### **Interviews in Study II and Study III**

(See Appendix for all questions and answer alternatives)

A semi-structured interview was carried out with 75 subjects. The interview was used instead of only questionnaires since the subjects had reading difficulties (the questionnaires used in Study III had to be read aloud to several of the participants). This also made it possible to check that the questions were fully understood. The interview questions were framed in order to cover a wide range of appropriate areas of interest. Earlier research results as well as the purpose of the study determined the choice of questions.

Areas of interest were background data, present occupation, school grades, school curricula chosen, family circumstances, parents' education and occupation, number of siblings and physical and mental health. Questions about the subject's and family reading habits were included as well as experiences of success or failure in school and feelings of well-being in school. The impact of dyslexia on school accomplishments, self-esteem, peer relations and on present situation was covered, as well as the subjects' belief in the future. Reactions to the diagnosis, acceptance of and openness about the disability were also treated, as well as feelings of being different on account of the dyslexia. Questions were also put about how much effort the subjects had put into their school work, the extent of

help from parents, teachers and others, and questions about parents' expectations of school accomplishments. Another area covered was how the subjects had experienced the relationship between school and their parents. The subjects' opinions of the importance of being good at school and at reading and writing were also treated. Hobbies, interests and sports were covered as well. In the last question subjects were asked to reflect on what they thought had been good for them in spite of the adversities that they might have encountered in school.

The interview was semi-structured; 14 questions were open-ended and 26 questions could be answered by choosing an alternative, which was described both verbally, e.g. from 'not at all' to 'very much', and with a numerical value. This was done partly in order to make it easier for the subjects to answer the questions and partly to facilitate a comparison between subjects, with the purpose of quantifying results.

All the interviews were performed by the author and were recorded and listened to twice. All answers were written down afterwards, categorized and assigned numerical values where applicable. Two-tailed non-parametric Spearman's correlations were computed using SPSS 13.0 (Statistical Package for the Social Sciences). Correlations around .30 were considered of medium size and correlations around .50 as large, in accordance with general practice in the behavioural sciences. As Cohen states: 'Thus, when an investigator anticipates a degree of correlation between two different variables "about as high as they come", this would by our definition be a large effect,  $r = .50$ ' (Cohen, 1988, p.81). The significance level for the correlations and t-tests was set to  $p \leq .05$ .

In the interviews with parents, exactly the same questions were used, but in a rephrased manner, such as: 'Do you think he feels different because of his dyslexic problems?'.

To determine the subjects' emotional adjustment and self-esteem, a special focus in the interviews was on subjects' and parents' answers to questions reflecting optimism or pessimism, the dyslexia's impact on peer relations and self-esteem, acceptance of and openness about the dyslexia, influence on current everyday life, feelings of being different and favourable factors for general well-being.

Self-esteem is not, as illustrated in the introduction of this thesis, an unambiguous concept, but in the interviews it was allowed to carry the meaning that the subjects and parents in the study attached to it.

### Questionnaires used in Study III

Two questionnaires, together with interview answers, were used with the purpose of identifying well adjusted subjects. The aim was to find out what characterized these subjects in comparison to subjects not so well adjusted.

#### *Jag tycker jag är ('I think I am', or ITIA) questionnaire*

In order to measure global self-worth, the ITIA questionnaire was used (Ouvinen-Birgerstam, 1999). The scale has been standardized on 1470 secondary school children, aged 14–16 years, the split-half reliability of the scale being .91–.93 and the one-year interval test-retest correlation .82. The validity of the scale has been examined and proven to be good (Friis, 1982; Ouvinen-Birgerstam, 1984, 1999). Eight items, referring to different school situations, were omitted, since the group studied comprised several subjects who had finished school; this left 64 items. Therefore there were no available norms, but comparisons of raw values were made between groups.

The 4-point response scale ranges from –2 to +2 with the alternatives; 'Exactly like me', 'Fairly like me', 'Not exactly like me', and 'Not at all like me' to statements concerning psychical well-being (16 items, range: –32 to +32), relationships with family and parents (13 items, range: –26 to +26), relationships with others (11 items, range: –22 to +22), skills, talents and abilities (12 items, range: –24 to +24), and physical appearance (11 items, range –22 to +22). High values designate a positive self-worth. The omitted items were dropped from the physical appearance scale (2), the skills, talents and abilities scale (2), the relationships to family and parents scale (1) and relationships with others scale (3). All 65 subjects who came to the clinic filled in the ITIA.

#### *Sense of Coherence scale questionnaire*

The *Sense of Coherence* (SOC) instrument measures a person's stress-resilience capacity (Antonovsky, 1993). Respondents are asked to select a response on a 7-point semantic differential scale, 4 being the middle value. A sentence example is: 'Do you feel that you are treated unjustly?' Alternatives from 1 ('very often') to 7 ('very seldom/never') are given. The higher the value on SOC, the stronger is the sense of coherence. The items are categorized in three groups, *Comprehensibility*, *Manageability* and *Meaningfulness*, described in the introduction of this thesis. The 13-item version was used because of the interviewees' reading difficulties, so that the statements had to be read aloud to most of the subjects. This version has been shown to correlate highly ( $r = .93$ ) with the standard 29-item version (Hansson & Olsson, 2001). The test-retest (6 months) reliability of the 13-item version is .77 (Coe, Romeis, Tang & Wolinsky, 1990).

SOC has mostly been used in clinical studies on adults, but in a cohort of normal Swedish secondary school children in the ninth grade, a mean score of 56 (girls) and 60 (boys) was calculated on the 13-item version (Hansson & Olsson, 2001). In the study of Margalit and Eysenck (1990), the mean score was 59 and there were no gender differences in a sample of 742 adolescents (12–16 years).

The SOC questionnaire was answered by 58 of the subjects. Seven of the subjects who came to the clinic did not fill in the questionnaire, either because of lack of time or because they did not comprehend the statements. Statements in the SOC are of a more complex nature than those of the ITIA questionnaire. The subjects who were interviewed by telephone were not given the questionnaires. The author's judgement was that it would take too long with subjects who had stated they did not have the time or motivation to come to the clinic.

## Results

### Study I

There was a significant 'loss' in mean VIQ between the first and second tests. The mean decrease was 7.4 IQ points, from 101.5 to 94.1 ( $p < .001$ ). As to PIQ, there was a significant 'gain' of 10.8 IQ points, from 95.6 to 106.4 ( $p < .001$ ). There was no significant change in FSIQ. The mutual relationship between VIQ and PIQ was altered between the two points of time. At first test there were 18 individuals whose VIQ was significantly ( $\geq 15$  points) higher than their PIQ, and only four individuals showed a significantly ( $\geq 15$  points) lower VIQ than PIQ. At second test the picture was the opposite; 27 individuals had a significantly ( $\geq 15$  points) lower VIQ than PIQ and only two individuals showed a significantly ( $\geq 15$  points) higher VIQ than PIQ.

VIQ decreased more the longer the test-retest interval, and it appeared as if the greatest change in VIQ took place after 18 years of age. As to PIQ the change was more continuous.

There were no significant sex differences either in VIQ or PIQ change.

On subtest level, the most dramatic and significant changes were in Vocabulary ( $-2.5$  on the scaled score) and Block Design ( $+2.3$  on the scaled score). The scaled score ranges from 1 to 19, with a mean of 10.

There was no correlation between interview answers on reading habits and verbal change. As to the amount of special education received, the answers were judged as not reliable. However, there was a correlation between the evaluation of special education and change in VIQ, in the direction that the more the subjects

valued the special education that they had received, the less was the VIQ decline ( $p < .01$ ).

### **Additional results**

After the manuscript of Study I was published, a non-parametric correlation between present reading habits and VIQ at second test was calculated. There turned out to be a significant correlation between present reading habits and VIQ at second test (correlation = .39,  $p < .01$ ), meaning that those who stated that they read 'quite a lot' or 'very much' scored a higher VIQ than those with little or no reading for pleasure.

## **Study II**

Of the 75 subjects, 40% felt that the dyslexia had influenced their self-esteem negatively 'quite a lot' or 'very much'. However, their self-esteem had improved when they grew older. The negative effects of dyslexia, in terms of feelings of distress and low achievement, were more profound in the first six years of schooling (ages 7–13). They had experienced feelings of being different, inferior and stupid. A majority felt they succeeded well in upper secondary school and their feelings of well-being in school improved substantially. The group who had left school, including the unemployed individuals, held a more optimistic belief in the future than those who were still in school or college. The subjects who were permanently employed were the most optimistic.

Most of the subjects (87%) had chosen a vocational programme in upper secondary school, or some special programme with a curriculum of a certain sport combined with other subjects. All the employed subjects had blue-collar jobs.

Regarding the impact of the dyslexia on present life situation, all subjects had problems with at least spelling and slow reading. The dyslexic difficulties had a profound impact on school and school achievements for 80% of the interviewees. However, two-thirds of the interviewees felt, that their difficulties did not affect them any more, other than in reading and writing activities, i.e. it did not affect their self-esteem. Academic self-esteem seemed low though, considering that only 13% of those who had left school had chosen to go to college, compared to 43% in the Swedish population.

Most subjects had not experienced poor peer relations because of their dyslexic problems, on the contrary, there were many who said that being with friends had been their only source of pleasure in elementary and middle school. There was a small group (17%) with bad experiences, who had been bullied and not felt good about school. They blamed their dyslexia, and thought that the dyslexia had

affected their self-esteem deficiently. There was a strong correlation between experiences of being bullied and feelings that the dyslexia had had a very negative impact on self-esteem ( $r = .48, p \leq .001$ ).

Concerning reactions to the diagnosis, more than one-third did not remember. Among the others, there was a variety of reactions from feeling relief to pain and embarrassment. Quite a few had not understood the significance of the diagnosis. The younger the subjects were, the less open they were about their difficulties, indicating that the younger subjects were more embarrassed at their dyslexic difficulties.

### **Additional results**

Results from the interviews that were not included in the appended manuscript were answers to questions about teachers and special education (questions 21, 25 and 25a). All of the subjects had received some kind of special education. The answers were however not accurate enough to use as judgement on the amount of special education received.

The question about subjects' evaluation of the special education received turned out to be more straightforward and easy to answer. Those who valued the special education highly, felt to a higher degree than the others that they had succeeded well in secondary school ( $r = .35, p \leq .01$ ) and upper secondary school ( $r = .29, p \leq .05$ ), but there was no such correlation with feelings of success in middle school. On the contrary, many expressed that they had felt uncomfortable when they were younger, having to leave the classroom for these lessons: 'They gave me a laptop computer but I felt too embarrassed to use it'; 'I refused to go to the special education teacher, which is something I regret now, but it was so embarrassing'. In conclusion, it seems as if extra educational support was more appreciated with age.

Almost all of the subjects were able to mention at least one teacher whom they had appreciated. It was often a special educational needs teacher. To the question about what characterized these teachers, the following answers were most frequent: 'She understood what was difficult for me, and what was not difficult', 'She helped me and recorded texts for me', 'She believed in me, that I could make it' and 'She was encouraging'.

### Study III

Interview answers revealed that two smaller groups of subjects stood out from the rest and these were labelled the '*resigned*' (11 individuals) and the '*relaxed*' (14 individuals). The subjects in these groups had not succeeded well at all in school, but their socioemotional adjustment differed greatly with respect to belief in the future, acceptance of the disability, feelings of being different, self-esteem, feelings of well-being in school, peer relations and important interests or hobbies, all in the negative direction concerning the *resigned* individuals in contrast to the *relaxed* group of subjects.

The remaining 50 subjects showed more variation in adjustment and achievements but had one feature in common, namely that they had not given up. They had gradually been more successful through hard work and they had used the help received from parents and had steadily adjusted better to school and life. They were labelled the '*strugglers*'.

After the three groups were identified, their scores on the questionnaires were computed (see Table 1 and 2). The difference between groups on the self-worth scales in the ITIA questionnaire was calculated with the non-parametric Mann-Whitney rank order method (see Table 1). The group identified as *resigned* revealed a significantly lower global self-esteem than the other two groups, the *relaxed* and the *strugglers*. There were significant differences on all subscales, except on 'skills, talents and abilities'. On this subscale there was no significant difference between the *relaxed* and the *resigned*, implying a lower opinion of their competence as was revealed in the interviews as well. The global self-esteem of the *relaxed* group was not different from the *strugglers*, except on 'skills, talents and abilities', where the *relaxed* group scored significantly lower.

The difference between groups on the SOC questionnaire was also compared as to rank order, but yielded only one significant difference between the categories, on Comprehensibility in the comparison between the *resigned* and the *relaxed* group (see Table 2).

*Table 1. Comparison between groups on ITIA questionnaire, mean scores.*

Group	N	PW total (-32 to 32)	RFP total (-26 to 26)	RO total (-22 to 22)	STA total (-24 to 24)	PA total (-22 to 22)	Total (range)
Resigned	9	1.2	7.7	3	-3.9	3.7	<b>11.7</b> (-27 to 64)
Relaxed	13	14	21	10.8	1.5	13.8	<b>61.1</b> (32 to 82)
Strugglers	43	16.4	18.5	12	5	10	<b>61.9</b> (15 to 97)
Diff. (rank order) (resigned/relaxed)		p ≤ .05	p ≤ .05	p ≤ .01	p ≤ .2 <b>n.s.</b>	p ≤ .01	
Diff. (rank order) (resigned/strugglers)		p ≤ .01	p ≤ .01	p ≤ .00	p ≤ .01	p ≤ .05	
Diff. (rank order) (relaxed/strugglers)		p ≤ .97 <b>n.s.</b>	p ≤ .97 <b>n.s.</b>	p ≤ .45 <b>n.s.</b>	p ≤ .05	p ≤ .23 <b>n.s.</b>	
10 best adjusted	10	22.8	22.6	14.1	8.2	15	<b>82.7</b> (68 to 97)
Total	65						

N= Number, PW= Psychical well-being, RFP= Relationship to family and parents, RO= Relationships to others, STA= Skills, talents and abilities, PA = Physical appearance.  
n.s.= no significant difference

Table 2. Comparison between groups on the 13 item Sense of Coherence questionnaire, mean scores.

Group	N	Comp. (Mean item score)	Manage. (Mean item score)	Meaning. (Mean item score)	Total 13 items (range)
Resigned	6	3.7	4.1	4.1	<b>47</b> (33–65)
Relaxed	13	4.6	4.4	4.6	<b>56</b> (38–64)
Strugglers	39	4.3	4.4	4.6	<b>56</b> (39–69)
Diff. (rank order) (resigned/relaxed)		p ≤ .05 <b>n.s.</b>	p ≤ .37 <b>n.s.</b>	p ≤ .25 <b>n.s.</b>	p ≤ .09 <b>n.s.</b>
Diff. (rank order) (resigned/strugglers)		p ≤ .06 <b>n.s.</b>	p ≤ .34 <b>n.s.</b>	p ≤ .17 <b>n.s.</b>	p ≤ .11 <b>n.s.</b>
Diff. (rank order) (relaxed/strugglers)		p ≤ .10 <b>n.s.</b>	p ≤ .74 <b>n.s.</b>	p ≤ .93 <b>n.s.</b>	p ≤ .47 <b>n.s.</b>
Total	58				
10 best adjusted	10	4.7	4.7	5.0	<b>61</b> (58–66)

N= Number, Comp= Comprehensibility, Manage= Manageability, Meaning= Meaningfulness. n.s. = no significant difference

Because the *strugglers* were not all the same in many respects, the ten individuals with the highest scores on the two questionnaires were examined more closely (see Tables 1 and 2). The purpose was to identify what characterized the individuals who expressed the greatest sense of coherence and global self-worth, those who seemed the ‘*best adjusted*’. Ten were chosen in order to ensure a group large enough to provide a great deal of information on these factors, and small enough to resemble each other with respect to a strong SOC and global self-worth.

The agreement between parent and subject interviews was very good. Examples are given in the appended article. The agreement between questionnaires, calculated on total scores for each individual was also good ( $r = .69, p < .001$ ).

The *relaxed* group comprised the individuals that did not value academic success highly, but revealed a high global self-worth and sense of coherence. All had good peer relations and several were active in sports. Mothers were affectionate and optimistic about their children. The *resigned* expressed low self-esteem and feelings of hopelessness in the interviews and scored comparatively very low on both questionnaires. The *strugglers* group was by far the largest (50 subjects). All of them thought that their dyslexic problems had affected school accomplishments a great deal and still affected their reading and writing ability considerably. Most of them thought however, that the negative impact on their self-esteem had decreased with time. This had however not been achieved without hard work on their part. A majority had worked very much with their reading, writing and home-work. Early on they had also struggled with feelings of inferiority, but they felt that they had gradually adjusted to their situation.

The ten *best adjusted* in the *strugglers* group had been very determined in their school work and had received extensive help from their parents. All had a special interest, sport or talent. Describing themselves, the subjects recurrently used the word 'persistent'. The inspiration to withstand was attributed to the support from families, above all from their mothers. The parents expressed very affectionate relations to their children and positive views about their children's potentials. A view shared by most of the *strugglers* (and their parents) was that their dyslexia still influenced their reading and writing but that this was just one of many parts of themselves, i.e. they showed evidence of compartmentalization.

Of the ten *best adjusted*, five were permanently employed, all in blue-collar jobs. Three were still in secondary school, one in a vocational programme, and one was doing his military service. One of the young men had dropped out of school, but was now permanently employed and married with a baby. Three subjects had attended secondary schools with sports programmes like golf and football. Two of the ten individuals had plans to go to college.

Mean FSIQ at the time of the diagnosis of dyslexia was 95 (SD = 18) in the *relaxed* group, 84 (SD = 9.9) in the *resigned* group and 103 (SD = 16.9) in the *strugglers* group. Mean IQ among the ten *best adjusted* was 100 (SD = 13). In the group as a whole (75 subjects) the mean IQ was 98 (SD = 16.9).

The educational level of the mothers was evenly distributed, except in the *relaxed* group where only one of the mothers was educated above vocational training. There was no correlation between mothers' educational level and the

amount of help and support they had given, meaning that their willingness to help their children with school work had nothing to do with their own educational level.

The salutogenic factors that emerged through the interviews with the subjects with a high SOC and global self-worth were; having a niche, such as sports, social activities or a special interest or talent where they did well and which made them view themselves positively. Support from family, particularly mothers, and having good friends were very important too. The internal factor of being persistent was a frequently mentioned characteristic. Also, it was obvious that many of them had succeeded in compartmentalizing their difficulties so that the problems involved in being dyslexic did not overshadow their self-image.

The difference between group means on the self-worth scales in the ITIA questionnaire was calculated with the non-parametric Mann-Whitney rank order method. The group identified as *resigned* revealed a significantly lower global self-esteem than the other two groups, the *relaxed* and the *strugglers*. There were significant differences on all subscales, except on 'skills, talents and abilities'. On this subscale there was no significant difference between the *relaxed* and the *resigned*. The global self-esteem of the *relaxed* group was not different from the *strugglers*, except on 'skills, talents and abilities', where the *relaxed* group scored significantly lower (see Table 1).

### **Sex differences**

The general impression was that the female subjects revealed a stronger 'struggling' attitude in the interviews, i.e. that they were more ambitious in their schoolwork and more inclined to try to overcome their reading and writing difficulties. This was also confirmed by the fact that girls were in a minority in the *relaxed* group. However, a comparison between girls and boys on the question of how much effort they had put into their schoolwork yielded no such difference.

### **Connection between Study I and Study III**

A comparison was made between the findings of Study I and III, in order to find out whether the changes in IQ found in Study I had any relationship to the adjustment styles in Study III. The Verbal IQ decrease and Performance IQ improvement were calculated on the three categories in Study III.

When clustered together, the *resigned* and the *relaxed* groups showed a larger verbal ability loss (-10.2 IQ points) than the *strugglers* (-6.2 IQ points). The difference was not significant though. As to non-verbal (Performance) IQ, the

*resigned* and the *relaxed* groups exhibited less improvement (+9.9 IQ points) than the *strugglers* (+11.3 IQ points), but the difference was not significant here either.

Comparing the *resigned* and the *relaxed* groups with the ten *best adjusted* yielded a significant difference in VIQ decrease. The mean decrease in the *resigned* and the *relaxed* groups together was –10.2 IQ points and in the group of ten *best adjusted* it was only –2.8 IQ points. In the ten *best adjusted* group, five individuals (50 %) stated that they never read anything for pleasure. The other five in this group read ‘some’, ‘quite a lot’ or ‘very much’.

The corresponding increase in PIQ was 9.9 IQ points for the *resigned* and the *relaxed* groups clustered together and 13.5 IQ points in the ten *best adjusted* group, but this difference was not statistically significant.

## **General Discussion**

The general discussion will firstly deal with the results from the three empirical studies, more specifically the cognitive and psychosocial effects of growing up with dyslexia and factors that seem important for a positive outcome. Secondly the methodological limitations are treated and conclusions are offered. Finally the theoretical and practical implications are outlined.

## **Cognitive Development**

The importance of a rich vocabulary for reading comprehension is quite obvious. If more than 5% of the words in a text are unknown, the resulting comprehension will probably be very modest. When the child has learnt how to read, one of the major sources for vocabulary acquisition is written texts in newspapers, magazines, textbooks, manuals, novels etc. If your vocabulary is not sufficient for comprehension, you tend to avoid texts – texts that might have given you a chance to learn new words. This vicious circle is certainly not easy to break.

(Ingvar Lundberg, 2006, p. 71)

Among prominent researchers in the field of dyslexia, there seems to be a consensus about the detrimental effects of the dysfunction on vocabulary growth. One of the most obvious consequences of dyslexia is lack of reading experience (Rack 1997). The result is a double handicap, not only is reading and writing arduous in itself, but a limited vocabulary will be a hindrance to a deep and wide knowledge in all subjects. Stanovich (1986) referred to this phenomenon as the ‘Matthew’ effect. He considered slow reading acquisition to have cognitive, behavioural and motivational consequences that in turn slow the development of other cognitive skills and inhibit performance on many academic tasks. Yet it has not been shown before that a secondary effect of dyslexia is a ‘lag’ in verbal development. The research results have so far been contradictory, as accounted for in the introduction of this thesis.

Study I reported a gradual decline in verbal development and a corresponding improvement in nonverbal development in the studied group of dyslexic young people. Three possible interpretations of the results were outlined, the first being that results were not reliable because different test versions were used at first and second test. These uncertainties are treated in the section of methodological

limitations below. It was concluded that the agreement between tests was satisfactory. The second interpretation was that test-retest variation is more common in exceptional subjects. There is abundant research on LD children reporting significant changes over long time periods, as accounted for in the introduction. In all these studies however, with the exception of one, the direction of change was the same as in the present study. This concordance indicates that a 'real' change has taken place, which was the third possible interpretation.

A plausible explanation of the relative VIQ decline is that individuals with dyslexia have less experience in reading and writing which may lead to a reduced vocabulary and verbal ability compared to normal subjects. Allington (1984) and Nagy and Anderson (1984) have shown that children with reading difficulties encounter only a fraction of the amount of words, which normal and skilled readers come across. On subtest level, the most substantial decrease was on Vocabulary, which implied that the dyslexic individuals in the study had not matured in word comprehension and expression in the same way as the normative sample.

There were 33 subjects (50%) who stated that they never read anything for pleasure and seven answered 'once in a while', which together amounts to almost two-thirds of the subjects studied. There was however no correlation between stated present pleasure-reading habits and VIQ decline. If the hypothesis that lack of reading experience would lead to a verbal decline were true, the individuals who stated that they read 'rather much' or 'a lot' for pleasure should not have shown the same VIQ decline, as those who did not read at all, but there was no such difference. On the other hand, present pleasure-reading habits say nothing about other kinds of reading or previous reading habits. Those who reported frequent pleasure-reading might not always have done so. Moreover, the ten *best adjusted* displayed a significantly lower decrease in VIQ compared to the *resigned* and the *relaxed* individuals, even though their mean intelligence was average and not different from the *relaxed* subjects at the time of diagnosis. These subjects, determined not to give up, had worked hard at school and probably had had more verbal practice orally as well as reading and writing. The consequence was that they did not lag behind in verbal development as much as the other subjects in the study. Their pleasure-reading habits were not impressive however, where five of the ten *best adjusted* never read anything for pleasure. It seems that the amount of pleasure-reading alone is not responsible for the development of vocabulary and other aspects of verbal ability, but hard work in school can have the same effect.

There was a significant correlation in the group as a whole between VIQ and present pleasure-reading habits, meaning that the subjects with the highest VIQs

were the ones who most frequently read for pleasure. This implies a close connection between reading intensity and VIQ, but says nothing of directionality. Just as language deficits may be both a cause and a consequence of reading disabilities (Share & Silva, 1987), high VIQ may be both a cause and a consequence of extensive reading habits.

The relative gain in non-verbal ability was interpreted as the result of possible compensatory processes. Young people with dyslexia might develop other cognitive abilities than the verbal ones. It may be that they utilize other modes to acquire knowledge and understanding of the world than through reading, and are perhaps forced to become more visual and intuitive. Nichols *et al.* (1988), with similar research results, concluded: 'It may be that because there is a deficit of verbal ability in such children, they come to rely more heavily on nonverbal ability. Such exercise of one kind of ability at the expense of the other may lead to its greater development and even to its overdevelopment' (p.508). Many individuals with dyslexia are more creative (Everatt, 1997; Everatt, Steffert & Smythe, 1999) and visually oriented than others (West, 1992; Wolff & Lundberg, 2002). Lowe (2003) explored the cognitive processes in a group of dyslexic subjects and found that they were inductive by nature and used creativity and intuition to interpret information. Guyer and Friedman (1975) found that LD children appeared to use a nonverbal information processing mode to deal with academic tasks. Galaburda (1985) and Geschwind (1982) have also proposed that the abnormal brain symmetry found in many individuals with dyslexia, indicating that the right planum temporale is just as large as the left, could explain why many dyslexic individuals show talents in areas such as the visual arts, architecture and engineering. Larsen, Høien, Lundberg and Ødegaard (1990) showed that the right-hemisphere planum was larger than normal in the dyslexic subjects, indicating that the visuospatial functions associated with the right side of the brain might be more developed.

However, these propositions say nothing about a growth of non-verbal ability at the expense of verbal development. Dyslexic individuals might be more right-hemisphere oriented from the start, or the brain symmetry might be an illustration of the plastic properties of the brain. Reports on dyslexia being associated with superior visuospatial and creative abilities are contradictory (Eckert & Leonard, 2003), and often of an anecdotal character. In conclusion, the interpretation of the non-verbal improvement is speculative and needs more research.

## Psychosocial Aspects of Dyslexia

Many children and young people leave school with little self-esteem and without confidence in their ability to read and write... It is one of the most important responsibilities of nurseries and schools to ensure that all children and young people, irrespective of social, cultural or other differences develop an image of themselves as able to write and with such good linguistic confidence that language becomes a force both in the learning processes in school and education as well as in their lives. This is a basic human, democratic right.  
(SOU 1997:108, p. 7, 15)

The interviews in Study II revealed that the subjects had experienced great discomfort in the first six years in school, ages 7–13, but showed a good adjustment as they grew older, in contrast to the survey conducted by Bender and Wall (1994) of studies outside Scandinavia, which demonstrated that social-emotional development may be seriously hampered with increasing age in subjects with LD. Many of the subjects in the present study felt much better and more successful in secondary school, which was also shown in a yet unpublished Swedish study (Jacobson, Svensson, Nordman & Sandell, 2006) and in the study by Taube (1988). Peer relations were good in a majority of cases and the overall picture turned out to be more encouraging than in other studies referred to.

The emergence of low self-esteem when dyslexic-to-be children start school was discussed in a developmental context in the Introduction section of this thesis. The age 7–11 is a period when children have started to evaluate themselves ‘through the eyes of others’ and are sensitive to being different. The subjects in the study had felt different, inferior and stupid. The question is whether this distress experienced the first years of school is inevitable. McNulty (2003) suggests that the emotional stories that he uncovered indicated that negative emotions are never totally avoidable, but parental and professional support can reduce the frequency and intensity of the negative experiences.

Despite the subjects’ inferiority feelings, most of the interviewees did not feel that their difficulties had influenced their relations and friendships. It rather seemed as if good peer relations had compensated for their difficulties. Westling-Allodi (2000) suggests that one way to deal with difficulties at school is to ‘turn on’ peer relations, i.e. actively choose to invest in relationships rather than scholastic achievements. A smaller number of subjects (17%) had experienced poor peer relations though, having been bullied and felt uncomfortable at school and they blamed their dyslexia. These young people felt that the dyslexia still

affected their self-esteem harmfully. The interaction of low academic and low social self-esteem will be treated below in the section on 'adjustment to dyslexia'.

One of the reasons for an improved adaptation with age in the present study might be to do with the identification and gradual acknowledgement of the dyslexic difficulties, which is one important aspect of the process of acceptance of a learning disability (Higgins *et al.*, 2002). The identification of their difficulties most probably turned out to be positive in the long run, even if at the time of diagnosis, several of the children had not understood what the diagnosis meant and some felt terrible about being labelled. The mean age was 12 years, and the diagnosis, as in the study by Zetterqvist-Nelson (2003), seemed to have evoked various positive and negative reactions at the time. However, before identification, the children did not know what was wrong with them, and thus might have been very sensitive to feeling inferior in school attainments. Reading disabled children remain puzzled as to why they cannot read unless they have had the difficulties explained to them (Palombo, 2001). Riddick (1996) found that mothers reported particularly low self-esteem in their children before their problems were identified and specific support was offered.

Several of the young men and women said they had suspected that they were not as 'smart' as their classmates. After diagnosis, even if being diagnosed as dyslexic had been painful or confusing for some, most of the subjects were likely to have received more help and understanding. Most probably, it is not the diagnosis in itself that is important, but the children's *identification* and gradual acknowledgement of their difficulties, i.e. that they realise they are normal in every other aspect, but have a specific difficulty with reading and writing. Compartmentalization of a learning disability is an essential characteristic of the stages of acceptance (Higgins *et al.*, 2002), as described in the introduction of this thesis.

Early identification of reading and writing difficulties is recommended to diminish the risk of a self-esteem drop. It is just as important that the child is given as much information as is needed for him or her to understand what it means, now and in the future, in order to know how to relate to the difficulty. In the present study, there were several subjects who stated that they had not understood what the diagnosis meant until later on. McNulty (2003) concluded that the self-esteem of the participants in his study improved after testing and diagnosis, when these were conducted in a relevant manner that lead to adaptation.

Age-related maturation may have contributed to the gradual adjustment. Seiffge-Krenke (Lazarus, 1999) considers the age of 15 to be a turning point in the use of coping strategies and social resources. She maintains, on the basis of a

large scale international investigation, that late adolescents, having reached a more mature social and cognitive level, select social support strictly in accordance with the problem at hand, consider current options more often and think about the future consequences of their actions. This implies that late adolescents are more oriented to problem-solving coping strategies than younger children. Theorists have emphasized the positive effects of problem-focused coping on psychological outcomes (Zeidner & Saklofske, 1996).

Another reason for a better adjustment with age might be that most of the girls and boys had chosen a vocational programme in upper secondary school and experienced that they could do themselves justice in a totally new way. Many of them felt good about themselves and successful for the first time at school. Those who chose not to continue studying after leaving school seemed to experience their difficulties as much less frustrating than those who continued in some kind of formal education. They were more optimistic, with regard to their future prospects. Many of the individuals who were employed now felt that school had been an extended torment, and they emphasised how much better off they were after having left school than they could ever have imagined. This finding matches that of Maughan (1995), who found that the best adjusted of the adults with dyslexia in his study were those who had made choices consistent with their assets and weaknesses. Riddick *et al.* (1999) concluded that once the subjects in their study had left high-literacy-demand situations, they no longer felt disadvantaged or forced to compare themselves unfavourably with others.

It was obvious that the subjects' academic self-esteem specifically was low, considering that so few of them (13%) had chosen to go to college in comparison to the population in general (43%). This finding is supported by Zeleke's (2004) review of over 40 studies on academic self-esteem in students with learning disabilities, and also by the study of dyslexic students by Olofsson (2002) and Riddick *et al.* (1999). As was summarized in the introduction of this thesis, it seems that low academic self-esteem is founded early, and is very stable and rather unaffected by later, more successful experiences. Even among the ten *best adjusted*, only two were considering college studies despite their good overall self-esteem and adjustment.

If 'Walking tall after leaving school' (SOU 1997:108) implies that all students should leave school with an unaffected academic self-esteem and confidence in their ability to read and write, I must conclude from my findings that this goal has not been met. If, on the other hand, it means that schools should offer educational niches and alternatives suited to each student's aptitude, it seems that the educational system in Sweden has been somewhat more successful. Several of the

young people in this study had found a programme in upper secondary school that helped them cope and develop their own capacities and talents.

## **Adjustment to Dyslexia**

Success is the ability to go from failure to failure without losing your enthusiasm.

*Winston Churchill*

There were many constructs—self-esteem, self-worth, self-efficacy, locus of control and SOC—that were helpful in understanding the reactions of the subjects in this study, all of which point in the same direction, to the importance of a sense of agency: ‘We tend to value ourselves in terms of how competent we think we are, how confident we are in performing well when required to do so, how much in control of the outcomes we consider ourselves to be, the ways in which we react to disappointment and failure, the strategies that we have at our disposal and the amount of effort we are prepared to invest in order to succeed’ (Burden, 2005, p. 20).

Research has shown that many children and adolescents with dyslexia display lower self-esteem than non-dyslexic peers, as described in the introduction of this thesis. However, when differentiated self-esteem measures are used, usually with the four to six domains described in the literature (Burden, 2005; Harter, 1993), similar to those in the ITIA (Jag tycker jag är) questionnaire used in the present study, and children are old enough to differentiate between different domains (Harter, 1993), children with dyslexia report lower academic self-concepts than their normally achieving peers, but their global self-worth is not significantly lower (Frederickson & Jacobs, 2001; Renick & Harter, 1989; Casey *et al.*, 1992).

In the search for factors important for a positive adjustment to dyslexia, three main groups of subjects were identified. Two of the groups, the *relaxed* and the *strugglers* revealed more optimism, acceptance of the disability and a stronger sense of global self-worth and coherence in contrast to a third group, described as the *resigned*. The latter group displayed lower global self-esteem than the other two. There were significant differences on all self-esteem subscales, except on ‘skills, talents and abilities’ that showed no significant difference between the *relaxed* and the *resigned*. The subjects in both these groups felt they had done poorly in school. The global self-esteem of the *relaxed* group was however just as high as that of the *strugglers*. This indicates that for global self-esteem to be

continuously low in young people with dyslexia, it takes more than a low perceived academic self-esteem. Ridsdale (2004) also maintains that dyslexia influences academic, rather than global self-esteem.

The relatively high global self-worth in the *relaxed* group seems to be the result of a deprecation of school achievements, including reading and writing. This is in line with the two routes to self-esteem enhancement; either raise one's level of competence or deprecate the importance of such competence (Harter, 1993). The *relaxed* individuals appeared to consider academic competence less important and considered it more important to be sociable, good at sports or being good with your hands. These preferences were supported by their mothers who seemed warm and accepting of their children. They expressed confidence in their children's ability to do well in life, despite their failure in school. These subjects had managed to compartmentalize their disability into a smaller, rather unimportant, personal domain, similar to the low achieving students in the study by Alves-Martins *et al.* (2002), who attributed less importance to academic achievement. Palombo (2001) also maintains that in searching for self-coherence, some learning disabled children dismiss scholastic achievement as unimportant. In contrast to the *resigned*, the *relaxed* subjects had found a niche, such as sports, social activities or a special interest where they did well and which made them view themselves positively. Also, they revealed better peer and family relationships. Their mothers appeared more accepting and less worried than those in the *resigned* group.

It appears that dyslexic individuals with a special talent or interest and without a family emphasis on scholastic achievements gradually adjust well and do not suffer from a sense of low self-worth.

Intelligence did not at first seem to play an important role for adjustment, as has been suggested before (Cederblad, 2003; Garnezy, Masten & Tellegen, 1984; Werner & Smith, 1992). The subjects in the *strugglers* and *relaxed* groups scored average on intelligence tests. On the other hand, the *resigned* subjects scored lower than average as a group. This indicates that these subjects may have had additional problems in school, on top of the reading and writing difficulties, which might have made their adjustment difficult. Yet there were several individuals in the lower range of the intelligence score in the other two groups of *strugglers* and *relaxed*. Low intelligence alone does not seem to predict low global self-esteem or poor adjustment, but together with poor relationships this might be the case.

The *resigned* scored much lower than the other two groups on peer relations and relation to family. Both academic self-efficacy and social self-efficacy address important aspects of young people's lives (Bandura *et al.*, 1999). Masten

*et al.* (1999) showed that better intellectual functioning, together with good parenting resources were associated with good outcomes in the context of adversity. Harter (1987) too, found additive effects on self-worth when she combined high support from significant others and competence in domains judged as important. Perceived competence in school work and peer relations have also been shown to be predictive of global self-worth in normal middle school children (Fenzel, 2000). Moreover, Robinson (1995) demonstrated the importance of perceived approval from class-mates together with emotional and instrumental support from parents for adolescents' global self-worth.

The *resigned* group revealed lower levels of sense of coherence (SOC) than the other subjects. Gana's (2001) results demonstrated that the SOC buffers the effect of stressful experiences on psychological well-being. Adversity affected well-being only among weak SOC individuals. These persons seemed to be more vulnerable to stressful experiences than those who had a strong SOC. The Gana model serves as another interpretation of the *resigned* group's low levels of psychical well-being.

It was not possible to single out one specific factor responsible for the difficulties and low global self-esteem among the *resigned* subjects. Rather than looking for single linear relationships, the association between risk and protective factors and disorder ought to rely on compounding multiple factors (Rutter, 1979). A mixture of the dyslexic difficulties, a low sense of coherence, little or no support from parents and teachers, poor peer relations, lower intelligence and lack of interests, hobbies and sports seem to be likely contributory factors. In the Hellendoorn and Ruijsenaars (2000) study, several of the adults revealed social and emotional problems. Many experienced difficulties in intimate relationships and in social contacts and they felt different, frustrated, fearful of failures and uncertain. The interviewees in that study, as well as the *resigned* subjects in the present study, seem to have had the double burden of low perceived competence in both the academic and social domain.

In sum, the majority (85%) of subjects in this study did not seem to have significant emotional problems; nevertheless, the presence of dyslexia appears to place one at greater risk for low self-esteem and distress. Given the risk associated with negative peer relationships and lack of adult support, the consequences of dyslexia can be worrisome for some individuals.

Compared to the two other groups, the *strugglers* seemed to hold higher beliefs of self-efficacy in scholastic attainments. This does not mean that they were not affected by their dyslexia in their academic self-esteem and aspirations; on the contrary, it merely means that they gradually had come to feel that they exercised control over their school work. Most of them thought that the negative impact on

their self-esteem had decreased with time. This had however not been achieved without hard work on their part. A majority had worked a great deal with their reading, writing and home-work and received extensive help from parents, particularly their mothers. Early on they had also struggled with feelings of inferiority, but they felt that they had gradually adjusted to their situation. They had managed to regard the dyslexia as only one aspect of themselves.

The ten *best adjusted* among the *strugglers* were studied more closely. They referred to their own persistence when asked about the positive factors influencing their well-being and achievements. Persistence can be defined as a tendency to endure despite adversities. This inclination has a close relationship to the self-efficacy concept, introduced by Bandura (1977) and described above. Unless people believe they can produce desired effects by their actions, they have little incentive to act or to persevere in the face of difficulties (Bandura *et al.*, 1999).

The persistence that the subjects and their mothers identified as one of the roots of well-being indicates also an internal locus of control, i.e. the subjects felt it was their own responsibility to deal with their difficulties. It was also shown by Reiff *et al.* (1997), in their study of highly successful adults, that a quest to gain control over life was an important aspect of success. Their subjects exhibited an internal locus of control.

In contrast, the *resigned* subjects in the present study expressed a feeling that trying hard was pointless, indicating a more external locus of control. The help they had received was not good or sufficient and they seemed paralysed by their difficulties, sensing that they could not do anything about it. There is a relationship between internal locus of control and higher achievement and achievement motivation (Bosworth & Murray, 1983; Findley & Cooper, 1983). Livneh, Lott and Antonak (2004) examined the psychosocial adaptation in individuals with various physical, sensory, psychiatric, learning and cognitive disabilities and found that adaptive respondents demonstrated perceived personal control over health outcomes.

‘Persistence’ was also identified as a vital positive characteristic in other research on the psychosocial outcome of dyslexia, which is accounted for in the resilience research section in the introduction. No explanation is however given in the previous research as to how this trait emerges.

The mothers of the ten *best adjusted* had, with one exception, supported their children with reading, writing and home-work. It is likely that these parents conveyed the message that trying hard was worthwhile, which counteracted the inclination to give up. It is reasonable to suggest that the persistence that the *strugglers* displayed was the result of their mothers’ conviction that they would

succeed, if they only worked hard enough. It might also reflect a developmental process from external to internal control; in the beginning they worked hard at school because they wanted to please their mothers—one young man said he had not wanted to let his mother down, as she had put so much effort into supporting him. Gradually they experienced the joy of success and, realized that persistence was rewarding. This stands in contrast to the *resigned* subjects who perceived increased effort as pointless. Galbraith and Alexander (2005) suggest: ‘If children can see their own role in the educational process as significant they may be encouraged to persevere in the face of difficulty’ (p. 29). As to Sense of Coherence, the ten *best adjusted* scored highest on Meaningfulness on the SOC Scale. Meaningfulness is a motivational component that refers to the extent to which subjects feel that certain areas of life are worthy of time and effort, and to their degree of involvement in various domains of life.

Only two of the ten *best adjusted* subjects had plans to go to college. These two individuals were still in school. Three of the ten had plans for more vocational training, and the others were quite happy with the work they were doing. Although it reflects low academic self-esteem, it also supports the idea that they had passed all stages of acceptance and had acknowledged the possibilities in life despite their difficulties.

Eight of the ten subjects had been very successful in different sports when they were younger, and five were still active. One young woman was very artistic and one young man excelled in computer science.

The parents described good and loving relations with their children and positive views about their children’s potential. Several mothers also described a general family attitude that difficulties in life are there to be overcome.

## Salutogenic Factors

To study resilience, investigators must specify the threat to development, the criteria by which adaptation is judged to be successful, and the features of the individual or the environment that may help to explain resilient outcomes.

(Masten *et al.*, 1999, p. 144).

The threat to development in this context was a continuous low self-esteem, associated with emotional problems and distress as well as low self-efficacy beliefs, low achievements and learned helplessness, attributes often associated with dyslexia. The criteria by which adaptation was judged to be successful was

high global self-esteem measures, a high sense of coherence together with life satisfaction and optimistic beliefs revealed in the interviews.

The features of the individuals and their environment that helped to explain positive outcomes were persistence and the ability to compartmentalize, as treated above. An internal 'locus of control' characterized the best adjusted subjects. The internal 'locus of control' together with persistence was thought to develop from their families' support and belief in their capacity to succeed. Acceptance of the disability was a general positive factor.

The subjects' experience of parental support and belief in their capacity and good peer relations were other factors that most certainly were important for adjustment. A solid interest, like sports and scouting, or a niche such as arts and computers were other important salutogenic factors. Choices of school programmes and employment consistent with the subjects' strengths and talents were another essential positive aspect.

The salutogenic factors found in this study of Swedish dyslexic subjects are analogous to those of the international research presented in the section on resilience research above.

## Gender

There were no significant differences with respect to sex in verbal decline or performance improvement in the first study. In the interviews, the female subjects conveyed a more 'struggling' attitude, an impression which was supported by the fact that of the five subjects who were in college, four were female students. Also, there was a male predominance in the *relaxed* group, implying that this adjustment strategy is not typical for women. On the other hand, when comparing answers to the question on how much effort the subjects had put into their school-work, there were no sex differences. In sum, there were no obvious gender differences in either the cognitive or psychosocial impacts of dyslexia.

## Methodological Limitations

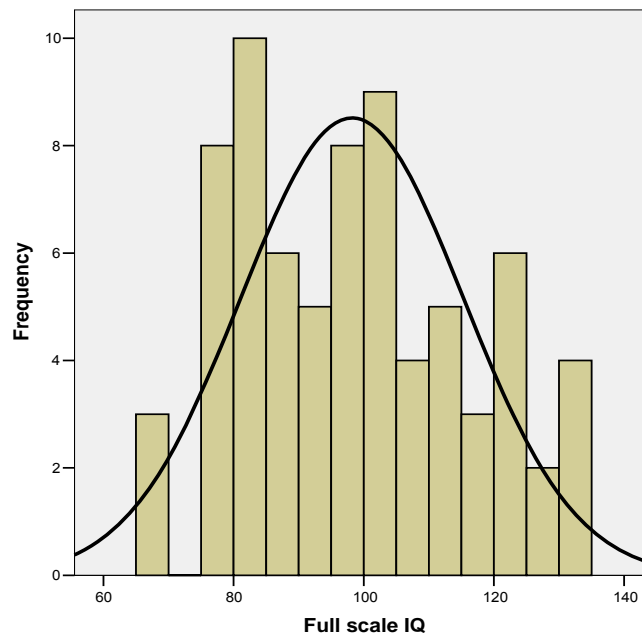
### Group representativity

#### Intelligence and sex

Was the studied group special in any way, or can conclusions drawn be generalized to other young people with dyslexia? Considering intelligence level, they were not special. Mean FSIQ for all 75 subjects was 98 IQ points (range 68–133, SD = 16.5) at the time of diagnosis and at follow-up 99 (range 62–127, SD = 13.7) for the 65 who were tested. Both figures were very close to the population mean, 100 IQ points (see Figure 1).

As to sex, there was a predominance of male subjects, which corresponds to earlier findings in dyslexic samples (Høien & Lundberg, 1999).

*Figure 1. Full Scale IQ at the time of diagnosis. N=75*



#### Comparison with drop-out group

Was the group studied different from the whole group, i.e. did the drop-out group of 25 persons (25%) differ from the studied group? Regarding intelligence, there was no difference. With respect to age, the dropouts were one year younger and

considering sex there was a major difference, with 21 male and only four female drop-outs. It is well known that women are more inclined to participate in all sorts of investigations. It is however impossible to know what the difference would have been if there had been no dropouts at all. Since the group of *relaxed* individuals was male-dominated, there might have been more subjects labelled as *relaxed*.

#### **More ‘concerned’ parents?**

It is possible that the parents of the studied group were more concerned than parents of dyslexic children in general. The fact that the subjects had been assessed in a clinic that specialized in dyslexia might imply that the parents had wanted their child to be examined by specialists. This may mean that the subjects had parents who were more engaged and concerned than average. The results indicating that many of the mothers had helped their children very much with their school work might therefore be biased, assuming that the more concerned parents are, the more help they give their children. Consequently, the positive outcome described in **Study II** and **Study III** might have been less encouraging with another sample, i.e. there might have been fewer *strugglers*. This does not, however, affect the comparisons made within the whole sample.

#### **Definition and severity of dyslexia**

As was discussed in the ‘Definitions of dyslexia’ section in the introduction, the studied group was diagnosed in a way which nowadays is called into question. The fact that all subjects had remaining problems several years after diagnosis, ranging from slow reading and poor spelling to almost complete illiteracy, indicates that they were dyslexic, although their possible phonological problems were not assessed.

As to the severity of the dyslexia at the time of second test and interviews, it was not measured. Although it is generally accepted that there are different degrees of severity, there are no commonly accepted methods to distinguish the ‘mild’ forms of dyslexia from the more ‘severe’. Degree of severity is likely to be important concerning feelings of being different, how much dyslexia affects every day life and the view of future prospects.

In the studied group, the dyslexic difficulties varied a great deal, even within the group of the ten *best adjusted* subjects. Therefore it seems plausible that the group as a whole was representative in this respect, but when it comes to individual differences it is not possible to know the impact of the reading and writing difficulties.

**Age at diagnosis and follow-up.**

There was a large age difference between the youngest and the oldest individual at the time of diagnosis, a range of 7–16 years, as well as a large time span between the time of diagnosis on the one hand and second test and interviews on the other (3½–10 years). The verbal and performance changes were calculated with respect to age at diagnosis, but there was no significant difference, probably because the time span between first and second test was comparatively large in all cases, allowing change to take place.

**Lack of control group**

In Study I, the test norms are based on large samples of normal children, and can therefore be considered a control group.

In Study II though, it would have been interesting to compare the subjects' experiences of school to a group of non-dyslexic controls, in order to see how children in general feel about school at different ages.

Moreover, it is not possible to know if these subjects had a lower global self-concept than their non-dyslexic peers, which would have been interesting. Since comparisons were made within the selected sample however, it was not the issue. The sense of coherence in the *relaxed* and *strugglers* groups were not lower than what has been found with normal teenagers (Hansson & Olsson, 2001; Margalit & Eysenck, 1990).

**Reliability of tests**

Three possible interpretations of the results of Study I were outlined, the first being that results were not reliable because different test versions were used at first and second test. However, in the Swedish standardization of the WISC-III, Swedish and British norms have shown a very good agreement, especially on the Performance scales. The British norms yielded a somewhat higher value on the verbal scales though, which probably means that if only the WISC-III<sup>s</sup> (British norms) had been used at initial test, the initial VIQs would have been somewhat higher on the whole, and the mean decrease even larger. Considering the use of different tests at follow-up, there is no information available concerning the agreement of the WAIS-III and the Swedish WISC-III, but the American comparison of the WAIS-III and the WISC-III yielded very high correlation coefficients (WAIS-III, Technical Manual, 1997). Since the British (in the WISC-III<sup>s</sup>) and British-American (in the WAIS-III) norms were used in most cases, there is good support for the assumption that the measured differences are sufficiently reliable. It might even have been an advantage that most of the subjects had been

assessed with the WISC-III<sup>s</sup> version using British-American norms, since comparisons were made in most cases using the same population as norm. As for the increase in PIQ, it is not likely to be an effect of test practice, since the follow-up interval was at least three and a half years and in most cases much longer.

Also, the subtests that showed the most dramatic changes, Vocabulary and Block Design, were the subtests that have the highest reliability coefficients in the verbal and performance scales, respectively.

### **Reliability of interviews**

One of the biggest criticisms of qualitative research is the absence of a set of techniques to judge the quality of data, such as probability statistics. The following is therefore a set of possible objections to the reliability of the interview results. There are several threats to the reliability, e.g. the choice of interview questions, the interviewer's influence on subjects' answers and the interviewer's interpretation of interview answers (McGrath & Johnson, 2003). An advantage was that I alone performed all interviews and that I had few preconceived opinions of the results; although the questions asked naturally reflect not only earlier research but also my own clinical experience.

Moreover, the interviewees' possible embellishment or exaggeration of problems in living with dyslexia must be taken into consideration. This problem was approached through interviews with parents as well, and there was a good agreement between subject and parent interviews and questionnaires and it was easy to differentiate between the three categories that emerged in Study III. In Study II, the method of assigning numerical values to answers and calculating correlations on the values, might also be questioned, even if all numerical answers also were associated to a verbal description. Yet another problem has to do with the concepts used. For instance, 'self-esteem' was allowed to carry the substance that the subjects put into it, but most certainly 'self-esteem' holds a variety of meanings in the whole group of subjects and parents.

## Conclusions

- The dyslexic individuals in the study had not matured in verbal ability in the same way as the normative sample. This was explained by the dyslexic students having less experience in reading and writing. The most substantial decrease was in vocabulary, implying a lag in word comprehension and expression.
- The amount of reading for pleasure does not seem to be solely responsible for the development of vocabulary and other aspects of verbal ability, but hard work in school can have the same effect. The best adjusted subjects who had worked hard in school did not display the same substantial verbal ability decrease.
- The relative gain in non-verbal ability that was demonstrated was interpreted as the result of possible compensatory processes, but the interpretation was judged as speculative. Reports on dyslexia being associated with superior visuospatial and creative abilities are contradictory, and often of an anecdotal character. The development of non-verbal intelligence needs more research.
- Many subjects (40%) had experienced great discomfort in the first six years in school, ages 7–13, but most of them (85 %) felt much better as they grew older.
- One of the reasons for an improved adaptation with age may have to do with the identification and gradual acknowledgement of the dyslexic difficulties.
- The subjects' academic self-esteem specifically seemed low, considering that so few of them (13%) had chosen to go to college in comparison to the population in general (43%).
- 'Walking tall after leaving school' (SOU 1997:108) implies that all pupils should leave school with an unaffected academic self-esteem and confidence in their ability to read and write. This goal does not seem to have been met.
- Most of the girls and boys (87%) had chosen a vocational programme in upper secondary school and then experienced more success and well-being.
- Among the ten best adjusted subjects, only two were considering further academic studies. Although it reflected a low academic self-esteem, at the same time it supported the idea that the ten best adjusted individuals had passed all stages of acceptance and had acknowledged the possibilities in life despite their difficulties.

- Dyslexic individuals with a special talent or interest and, who have grown up in a family where scholastic achievement is not considered important, seem to adjust well, gradually, and not suffer from a sense of low self-worth.
- For global self-esteem to be continuously low in young people with dyslexia, it seems to take more than a low perceived academic self-esteem. Marsh and Yeung (1998) point to the importance of separating academic from non-academic and general domains of self-concept. The results of the present study support this judgement.
- Peer relations were good in a majority of cases (83%). Good peer relations seem to have provided compensation for school failures.
- The majority of subjects (85%) in this study did not have any significant emotional problems. Nevertheless, the presence of dyslexia appears to place one at greater risk of low self-esteem and distress. Given the risk associated with lower intelligence, poor peer relations and lack of adult support, the consequences of dyslexia can be worrisome for some individuals.
- Low intelligence alone does not seem to predict low global self-esteem or poor adjustment in dyslexic subjects, but together with poor social relationships this might be the case.
- The persistence that the subjects and their mothers identified as one of the roots of well-being indicates an internal locus of control, i.e. the subjects felt it was their own responsibility to deal with their difficulties.
- The internal 'locus of control' together with persistence was thought to develop from their families' support especially their mothers' positive views about their children's potentials.
- Acceptance and compartmentalization of the disability was a general positive factor.
- The subjects' experience of parental support and mothers' belief in their capacity together with good peer relations were factors that most certainly were important for adjustment.
- There was no relationship between mothers' educational level and the amount of help and support that they had offered.
- A solid interest, like sports and scouting, or a niche such as arts and computers were other important salutogenic factors. Choices of school programmes and employment consistent with the subjects' strengths and talents were another essential positive aspect.

- Sense of coherence seems to buffer the effect of stressful experiences on psychological well-being.
- The overall picture turned out to be more encouraging concerning dyslexic young people's global self-esteem and well-being than other studies referred to.
- Positive factors for a good adjustment in this study of Swedish dyslexic subjects are analogous to those of international research.
- There were no obvious gender differences in either the cognitive or psychosocial impacts of dyslexia.

## **Theoretical and Research Implications**

There is some research, outlined above, supporting the idea that dyslexic subjects are more talented in the visual domain, one being brain symmetry, or anomalous asymmetry, in the planum temporale (PT) region. These findings have been used as an explanation of a possible right hemispheric orientation in dyslexic subjects, i.e. in the visual, visuospatial and creative domains. The results of Study I were interpreted along this line, but it was concluded that this interpretation needs more research evidence than is available at the present. There is some, but very little, research supporting the idea that dyslexic subjects in general might be superior to non-dyslexic people in these areas (Everatt *et al.*, 1999; Wolff & Lundberg, 2002). Most of the other 'evidence' is of an anecdotal character. Moreover, as imaging and diagnostic methods have become more standardized, the evidence of an anomalous PT asymmetry in individuals with phonological dyslexia is inconsistent (Eckert & Leonard, 2003).

Thus, more research is needed to determine the relationship between dyslexia and anomalous PT asymmetry, and the connection between this anomaly and right hemispheric functioning. Furthermore, more research is needed to explore how non-verbal intelligence develops, and if compensatory processes are at all possible.

An obvious research implication concerns prevention and remediation of the primary problems, i.e. the reading and writing difficulties, so that the secondary effects of dyslexia treated in these three studies can be avoided. Remedial programmes that have been applied on school children have not as yet proven very successful. Typical school interventions for children with reading and writing difficulties can, according to Torgesen (2001), most accurately be described as stabilizing their degree of reading failure rather than remediating their reading skills. However, there is some promising recently published research on an exercise-based approach to dyslexia-related disorders, but the underlying reasons for the benefits reported are not altogether clear (Reynolds & Nicolson, 2006) and more research is needed.

The findings of Study II are to be regarded as trends and meant to provoke further study, possibly through prospective studies of young children at risk of dyslexia compared to a group of normal controls. Furthermore, the results of Studies II and III give rise to a need for empirical studies on diagnostic and school practices that can help dyslexic children early on in order to prevent, or at least alleviate, the secondary effects of dyslexia.

## **Practical Implications**

There remains much to be done about society's attitudes towards reading, writing and spelling problems. The secondary emotional distress that many dyslexics experience would be much less without the shameful undertone that the dysfunction carries. Schools should also offer alternative educational programmes suited to each student's aptitude, in order to give the dyslexic individual a chance to feel successful in school and in subsequent employment.

In school, it is recommended that special education training is carried out within the classroom in the early years of school so that dyslexic children, who seem to be very sensitive to being different in this age period, will not have to feel the embarrassment of having to leave the classroom for extra instruction. There were several of the subjects in the study who had refused special education early on because they did not want to stand out as someone who needed help.

One implication of this study is the importance of early identification, for which there is also good scientific support. If the student is allowed to fail or fall behind for a substantial period of time before they are identified as dyslexic, there is an obvious risk for possible secondary effects such as self-esteem drop. The mean age at diagnosis had been as high as 12 years in the studied group, and the self-esteem of many of the subjects had been affected in the early years of school.

It is quite possible to make a rather valid prediction early on of a child's risk of developing dyslexia. Høien and Lundberg (1999) have surveyed the research on the prediction of reading difficulties from phonological weaknesses in smaller children. Children at risk were those who showed phonological difficulties in kindergarten and had parents with reading problems, and the predictive value was around 80%. With an early identification of children at risk, the diagnostic procedure can take place in the first or second year of schooling if the child demonstrates difficulties in learning to read and write.

There are two obvious advantages of early identification, the first being that interventions have been shown to be more effective with younger children (Lundberg, Frost & Petersen, 1988; Torgesen, 2001). The second advantage is the possibility of preventing, or at least alleviating, the secondary problems in terms of a verbal lag and a sense of low self-esteem. It is vital that the child understands the meaning and consequences of the diagnosis in order to be able to gradually acknowledge and compartmentalize the disability. To receive a disability diagnosis can be the source of a psychological crisis and should be treated as such. In the present study, many of the subjects stated that they had not understood what dyslexia meant until long after diagnosis, something which most probably affected their self-image harmfully.

Furthermore, since it is likely that parental and professional support can reduce the frequency and intensity of the negative secondary effects, it is just as important that parents and teachers are well-informed about the diagnosis and what they can do to help. The results on salutogenic factors might be of help here. For children who have little support from parents, teachers have a very important task to fulfil.

A systematic and effective programme against bullying is another important implication.

A further suggestion is that students with dyslexia should be encouraged in areas such as sports, social activities or a special interest where they can do well and which makes them view themselves positively.

Another conclusion is that the documented relative changes in VIQ and PIQ imply that caution should be taken in drawing far-reaching conclusions from the results of a single intelligence test. The Wechsler scales are used all over the world in hundreds of thousands cases each year, and sometimes there are very important decisions made for individuals with different kinds of learning disabilities on the basis of test results. It is important to have in mind then that it is quite possible that a repeated test will give a significantly different result.

Dyslexic children need extensive verbal training, in school and elsewhere, as a preventive intervention of the possible verbal 'lag'. Since this is not done through reading and writing primarily, the training should take all sorts of oral forms; talking and listening. Computer programs such as synthetic speech, speech recognition and spelling programs are other effective aids in helping dyslexic children to keep up with their classmates.

This thesis has had an emphasis on different aspects of self-image and the importance of the child's own self-efficacy beliefs, internal locus of control, persistence and sense of coherence. It seems that what children with dyslexia need is not so much help, but 'empowering' support from significant others, i.e. adults who believe in the children's capacity to manage in school despite their difficulties and develop into individuals with a solid sense of self-worth.

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# Appendix

## Interview Questions.

1. *If you still are in school, which school do you attend now? Which grade? Which schools and where have you attended before?*

2. *Have you grown up with both your parents? If not, which one?*

3. *How has it been with books and reading when you grew up? Do your parents read anything for pleasure?*  
*Your mother?*

1 Not at all
2 A little, newspapers
3 Some
4 Very much, all the time

*Your father?*

1 Not at all
2 A little, newspapers
3 Some
4 Very much, all the time

4. *What are your parents' education and occupation?*

5. *Do you have any siblings? Do they read anything for pleasure?*

6. *Are you well now – and have you had any diseases when you grew up or felt sick, physically or emotionally?*

7. *Do you have any important hobby? Which kind?*

1 None
2 Have had, but quit
3 Yes, some
4 Yes, very important

8. *What were your grades when you finished 9<sup>th</sup> grade? Did you pass all courses? If not, which ones did you not pass? Which were your good subjects?*

9a *How do you feel you succeeded in elementary school?*  
9b. *in middle school?*  
9c. *in secondary school?*  
9d. *in upper secondary school?*

1 Very poorly
2 Poorly
3 Not so well
4 Well
5 Very well

10. *How do/did you feel in school on the whole, in terms of well-being?*  
10a. *In elementary school?*  
10b. *In middle school?*  
10c. *In secondary school?*  
10d. *In upper secondary school?*

1 Very poorly
2 Poorly
3 Not so good
4 Good
5 Very good

11. Do you or did you study a lot at home with assignments and other school work?

- ☐ Yes  
☐ No  
☐ Rather much

12. Which programme have you chosen in upper secondary school? Your first choice? Were you admitted?

13. What is your occupation today? If employed, is it permanent or temporary?

14. If you are in some kind of education, what and where is that?

15. How do you look upon the future?

- 1 Hopeless  
2 Negatively, I worry  
3 It will probably work out OK  
4 Positively  
5 Very positively

16. To which degree have your reading and writing difficulties influenced:

16a. School and school achievements?

- 1 Not much at all  
2 A little  
3 Some  
4 Quite a lot  
5 Very much

17. Peer relations in a negative way?

- 1 Not much at all  
2 A little  
3 Some  
4 Quite a lot  
5 Very much

18. Subsequent question: Have you been bullied because of your reading and writing difficulties?

- Yes ☐  
No ☐

19. Your self-esteem in a negative way?

- 1 Not much at all  
2 A little  
3 Some  
4 Quite a lot  
5 Very much

20. Have you had any other problems in school, apart from reading, writing and spelling?

- ☐ No  
☐ Yes  
What kind of problems?

21. Do you have or have you had a good teacher? If yes, in what way was he or she good?

22. Have you used any tricks in school to succeed better in spite of your difficulties?

23. Do you remember when they told you that you had dyslexia? ☐ No  
☐ Yes
24. If you remember, what did you think or feel then?  
1 Painful  
2 Embarrassed  
3 Nothing special  
4 Relief, acknowledged
25. Have you received extra help in school because of the dyslexia, i.e. special education?  
1 Not much at all  
2 A little  
3 Some  
4 Quite a lot  
5 Very much
- 25a. If yes, how did you like it?  
1 Worthless  
2 Bad  
3 Not so good  
4 Good  
5 Very valuable
26. How is or was the cooperation between your parents and school?  
1 Worthless  
2 Bad  
3 Not so good  
4 Good  
5 Very good
27. Do or did you receive any help at home with your school work? What kind of help?  
1 Not much at all  
2 A little  
3 Some  
4 Quite a lot  
5 Very much
- 27 a.  
From whom? ☐ Mother  
☐ Father  
☐ Both  
☐ Someone else
28. Have you received any help with school work outside school or family?
29. Did anyone read to you when you were little? Who? Did you enjoy it?
30. How are your present reading habits? Do you read anything for pleasure?  
1 Not at all  
2 A little  
3 Some  
4 Quite a lot  
5 Very much

31. *Do you have an interest or sport which means or has meant a lot for you?*
- 1 Not much at all  
2 A little  
3 Some  
4 Quite a lot  
5 Very much
32. *How important do you think it is/was for your parents that you succeed in school?*
- 1 Not much at all  
2 A little  
3 Some  
4 Quite a lot  
5 Very much
33. *How important do you think it is to read and write well?*
- 1 Not much at all  
2 A little  
3 Some  
4 Quite a lot  
5 Very much
34. *How important is/was it for you to do well in school?*
- 1 Not much at all  
2 A little  
3 Some  
4 Quite a lot  
5 Very important
35. *How do you do when there is something you cannot read or write? Do you ask for help, or do you have any strategies? Do you use any technical devices?*
36. *Do you usually tell people about your reading and writing difficulties?*
- ☐ Never  
☐ To people I know well  
☐ Most of the time
37. *How do you regard your dyslexia? Do you feel you have accepted it?*
- ☐ No  
☐ Partly  
☐ Yes, absolutely
38. *How much do you feel the dyslexia influences your every-day life at the present?*
- 1 Influences only reading and writing  
2 A little  
3 Some  
4 Quite a lot  
5 Overshadows everything
39. *Do you feel different because of your dyslexic problems?*
- 1 Not much at all  
2 A little  
3 Some  
4 Quite a lot  
5 Very important
40. *Could you reflect on what you think has been good for you? I'm thinking of such things that you think has made you feel happy, contented and valuable, in spite of the adversities that you might have encountered at school?*