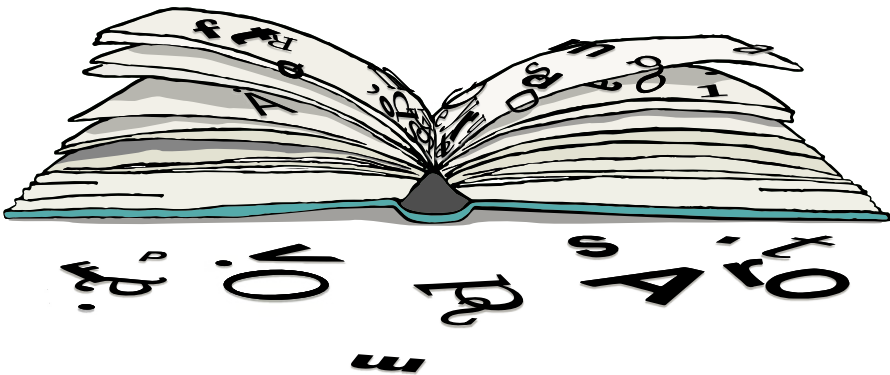


# Words don't come easy

Decoding and reading comprehension difficulties  
in adolescents with intellectual disability



Karin Nilsson



# Words Don't Come Easy

Decoding and Reading Comprehension Difficulties in  
Adolescents with Intellectual Disability

Karin Nilsson



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**To Leon**

**You are the sunshine of my life**

# Abstract

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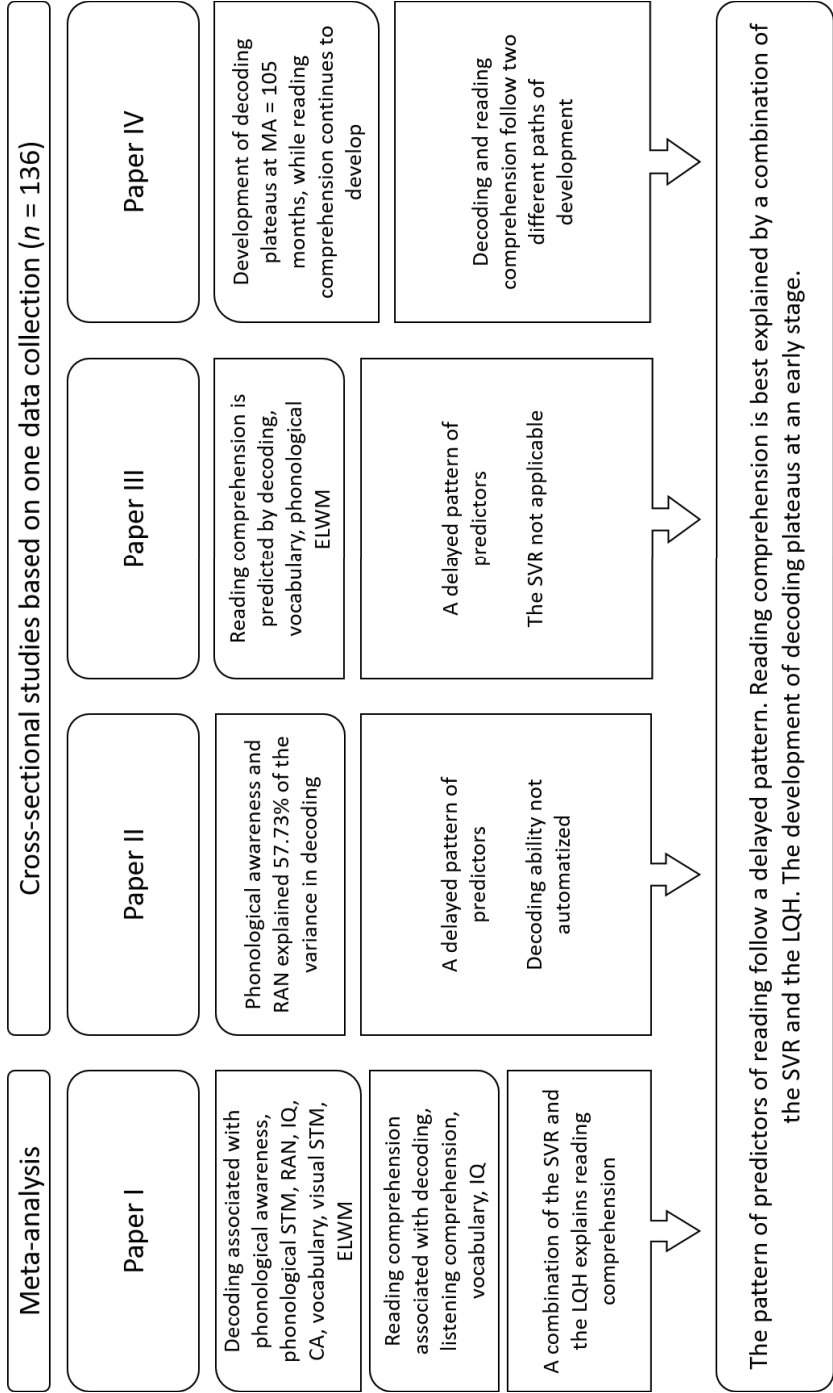
Individuals with intellectual disabilities (ID) have difficulties with decoding and reading comprehension. However, studies focussing on why these difficulties occur are very sparse, and the existing literature has found conflicting results. This thesis investigated the development of reading abilities and the concurrent cognitive, linguistic, and environmental predictors of decoding and reading comprehension in Swedish adolescents with non-specific ID. In addition, this thesis evaluated the applicability of one of the most commonly used theoretical frameworks of reading comprehension: the Simple View of Reading (SVR). The results showed that the development of reading abilities in adolescents with ID is in line with the model of developmental delay. This means that the development of reading abilities is not qualitatively different from typical reading development, but the rate is slower. Further, it means that the pattern of concurrent predictors is similar to the pattern found in a younger typically developing population. In Swedish adolescents with ID, decoding is predicted by phonological awareness and rapid automatized naming (RAN), and reading comprehension is predicted by decoding, vocabulary, and phonological executive-loaded working memory (ELWM). This thesis also found that the developmental trajectory of decoding plateaus at a mental age of 8:9 years, while it is expected in typically developing children that decoding ability continues to increase until early adolescence. The explanation for this early plateau could be either cognitive or educational, but most likely a combination of both. Lastly, the results from this thesis also suggest that the SVR is not sufficient for explaining reading comprehension in adolescents with ID. Instead, a combination of the SVR and the Lexical Quality Hypothesis (LQH) is suggested as a successful way of explaining the variance in reading comprehension. Taken together, the results from this thesis imply that reading instruction and interventions originally developed for typically developing children are likely to be effective for individuals with ID.

# Sammanfattning

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Personer med intellektuell funktionsnedsättning (IF) uppvisar svårigheter med avkodning och läsförståelse, men studier som fokuserar på varför dessa svårigheter uppstår är få till antalet och litteraturen har visat motstridiga resultat. Den här avhandlingen undersökte utvecklingen av läsförmågan samt de kognitiva, språkliga och miljörelaterade prediktorerna av avkodning och läsförståelse hos svenska ungdomar med IF av okänd etiologi. Vidare applicerades the Simple View of Reading (SVR) som teoretiskt ramverk för att förklara variationer i läsförståelse. Resultaten visade att utvecklingen av läsförmågan hos ungdomar med IF är i linje med the model of developmental delay. Detta innebär att utvecklingen inte skiljer sig kvalitativt från den typiska läsutvecklingen, men att den går i en långsammare takt. Det innebär även att mönstret av prediktorer liknar det mönster som återfinns i den yngre typiskt utvecklade populationen. Hos svenska ungdomar med IF prediceras avkodning av fonologisk medvetenhet och snabb benämning, medan läsförståelse prediceras av avkodning, vokabulär och fonologiskt arbetsminne. Avhandlingen visade även att utvecklingen av avkodning verkar plana ut vid en mental ålder av 8:9 år, vilket går stick i stäv med forskning på typiskt utvecklade barn som visar att avkodningen fortsätter att utvecklas upp i tonåren. Orsaken till att avkodningsförmågan planar ut belyses utifrån både kognitiva och utvecklingsrelaterade förklaringsmodeller. Slutligen visade avhandlingen att SVR inte är tillräckligt för att förklara läsförståelse hos svenska ungdomar med IF. Istället föreslås en kombination av SVR och the Lexical Quality Hypothesis (LQH) som ett framgångsrikt sätt att förklara variationen i läsförståelseförmåga. I och med att utvecklingen av läsförmågan följer ett försenat, snarare än ett kvalitativt annorlunda, mönster bör läsundervisning och läsinterventioner som utvecklats för typiskt utvecklade barn potentiellt ha god effekt även för personer med IF.

# Reading ability in adolescents with intellectual disabilities





# List of Papers

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

- I. Nilsson, K., Elwér, Å., Messer, D., & Danielsson, H. Variables Associated with Reading Ability in Individuals with Intellectual Disabilities - a Systematic Review and Meta-Analysis.
- II. Nilsson, K., Danielsson, H., Elwér, Å., Messer, D., Henry, L., & Samuelsson, S. (2021). Decoding Abilities in Adolescents with Intellectual Disabilities: The Contribution of Cognition, Language, and Home Literacy. *Journal of Cognition*, 4(1), 58. DOI: <http://doi.org/10.5334/joc.191>  
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- III. Nilsson, K., Danielsson, H., Elwér, Å., Messer, D., Henry, L., & Samuelsson, S. (2021). Investigating Reading Comprehension in Adolescents with Intellectual Disabilities: Evaluating the Simple View of Reading. *Journal of Cognition*, 4(1), 56. DOI: <http://doi.org/10.5334/joc.188>  
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- IV. Nilsson, K., Elwér, Å., Messer, D., Henry, L., & Danielsson, H. Developmental trajectories of reading ability in adolescents with intellectual disability.

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# Abbreviations

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ADHD	Attention Deficit Hyperactivity Disorder
ASD	Autism Spectrum Disorder
DS	Down Syndrome
ELWM	Executive-Loaded Working Memory
Gc	Crystallized knowledge
Gf	Fluid reasoning
ID	Intellectual Disability
LQH	Lexical Quality Hypothesis
MA	Mental Age
RAN	Rapid Automatized Naming
STM	Short-Term Memory
SVR	Simple View of Reading
WS	Williams Syndrome



# Introduction

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Individuals with intellectual disability (ID) exhibit difficulties with reading, both with decoding and reading comprehension (Lemons et al., 2013; Ratz & Lenhard, 2013; Wei, Blackorby, & Schiller, 2011). Despite evidence that these difficulties exist, research addressing reading abilities in populations with ID is sparse. The overarching aim of this thesis was to identify factors that could influence reading abilities in Swedish adolescents with ID and thereby contribute to our understanding of why these difficulties arise.

Today, being able to read is a prerequisite to participating in society, and since July 2019 the Swedish education act guarantees early interventions and support in compulsory schools to those students who are at risk of falling behind in reading, writing, or math (Skollag, 2010). No such guarantee currently exists for students enrolled in compulsory schools for pupils with learning disabilities, but during the writing of this thesis, a Government bill containing a proposal that the guarantee should also include students in compulsory schools for pupils with learning disabilities was submitted (Utbildningsdepartementet, 2021). The bill was passed by the Swedish Government in June 2021, and this change of legislation will take an effect in July 2024.

The introduction provides an overview of the population, models in disability research, typical reading development and theories of reading, and a summary of the research field focussing on reading and ID.

## Intellectual Disability

ID is a neurodevelopmental disorder with an onset during the developmental period and it includes both intellectual and adaptive difficulties (American Psychiatric Association, 2013). To be diagnosed with ID, an individual must fulfil three criteria: 1) deficits in intellectual functioning, such as problem-solving, planning, and reasoning; 2) deficits in adaptive functioning in at least one domain (conceptual, social, and/or practical) that affects activities of daily life such as communication, social participation, and

independent living; and 3) onset during the developmental period. There are four different degrees of ID, namely mild, moderate, severe, and profound. The focus of this thesis is on individuals with mild to moderate ID. Having an ID in the mild to moderate range entails learning difficulties that affect academic abilities such as reading, writing, and math. For example, the conceptual understanding of abstract phenomena such as time and money is limited. Furthermore, difficulties with the perception and interpretation of social signals are common and an individual with ID might need help with daily activities such as grocery shopping, taking care of a home, and handling money (American Psychiatric Association, 2013). ID has no single cause, and it is present in a range of different conditions. It could be part of a syndrome, such as Down syndrome (DS) or Williams syndrome (WS) but the aetiology can also be unknown. The latter is often referred to as non-specific ID or ID with unknown aetiology, since no biological cause has been identified. This group is the population of interest in this thesis, and the term non-specific ID will be used.

The prevalence of ID is estimated to be somewhere around 1% (Maulik, Mascarenhas, Mathers, Dua, & Saxena, 2011; McKenzie, Milton, Smith, & Ouellette-Kuntz, 2016). However, there are differences between low- and middle-income countries and high-income countries. In a meta-analysis by Maulik et al. (2011), it was found that low- and middle-income countries had a prevalence of around 1.5%, while the prevalence in high-income countries fell slightly below 1%. This difference can be explained by several factors, for example, the lack of adequate screening methods for genetic conditions (Dave, Shetty, & Mehta, 2005), and that inadequate maternal and child care could increase the risk of birth-related infections and injuries.

Research focussing on the cognitive abilities of individuals with ID has shown that both children and adults with ID exhibit difficulties with executive functions, such as shifting, inhibition, planning, and working memory (Danielsson, Henry, Messer, & Rönnerberg, 2012; Danielsson, Henry, Rönnerberg, & Nilsson, 2010; Henry & MacLean, 2002; Palmqvist, Danielsson, Jönsson, & Rönnerberg, 2020; Schuchardt, Maehler, & Hasselhorn, 2011). In addition, individuals with ID exhibit language difficulties of varying degrees. For example, studies have found deficits in language comprehension (Witecy & Penke, 2017), narrative ability (Barton-Hulsey, Sevcik, & Ronski, 2017; Hessling & Brimo, 2019), and vocabulary (Roberts, Price, & Malkin, 2007; Van der Schuit, Segers, van Balkom, & Verhoeven, 2011). Moreover, adolescents with ID appear to have a less structured semantic network compared to typically developing children which could be an important underlying factor for language difficulties in ID (Nilsson et al., 2021).

In Sweden, ID is diagnosed by a psychologist after a thorough evaluation. Individuals that are not expected to reach the goals of the compulsory school curriculum due to ID are offered a place in a compulsory school for pupils with learning disabilities or upper secondary school for pupils with learning disabilities. These provide a different form of schooling with a specialised curriculum (Skolverket, 2013, 2022b). According to the Swedish education act, a student with ID has the right to choose to be enrolled in compulsory school for pupils with learning disabilities where all students follow the same curriculum or choose an inclusive setting where the other students follow the curriculum for the general compulsory school. The Swedish education act does not support the right to choose school setting for students with ID in upper secondary school (Skollag, 2010),



but the Swedish National Agency for Education emphasises that it would be beneficial with a collaboration between the two forms of schooling, especially when it comes to subjects of a more practical nature.

## Disability Research

When conducting research on populations with disabilities it is important to use broader theoretical perspectives to be able to understand and explain the underlying mechanisms adequately. Two models, or frameworks, have influenced this thesis and they are described below.

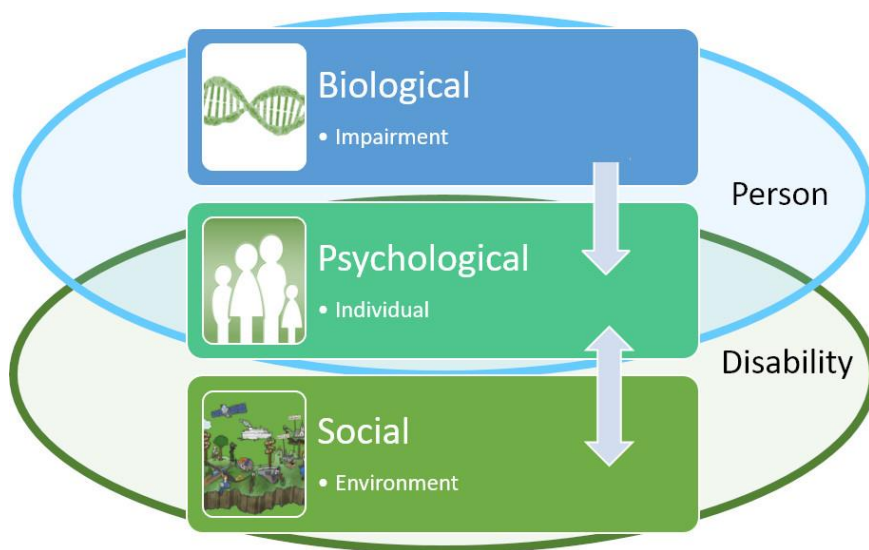
### The Biopsychosocial Model

For a long time, the biomedical model of disease dominated health care and research with a narrow focus on biology as the only source of impairments. The consequence of this was that the entire focus was placed on measurable somatic variables, neglecting psychosocial factors (Engel, 1977). As a reaction to the biomedical model, the social model emerged from the British disability movement (Shakespeare & Watson, 2001). This model emphasised the role of the environment and the society (that was initially described as oppressive), and in this way moved the focus away from the body. The social model also suggests that the term impairment refers to the actual impairment in the body, while disability refers to the social barriers put up by society. An individual is not considered as disabled until the environment creates a barrier that the individual cannot overcome. Hence, disability is viewed as a social construction and not as something present on the individual level (Shakespeare & Watson, 2001). The problem with using the biomedical model or the social model is that they are both reductionist. In the biomedical model, all explanations are reduced to the body and thus, only focus on impairment. In the social model, all explanations are reduced to the environment and thus, only focus on disability.

Engel (1977) proposed the biopsychosocial model as a new framework for both research and clinical work. Engel argued that it is crucial to take both the individual and the social context around the individual into consideration to fully understand a condition. Furthermore, Engel gave a clear example as to why a biopsychosocial model is necessary for both research and health care. The biomedical markers for a specific disease are usually the information used for diagnosis, but this information does not provide any prognosis for how the individual will cope with the disease. Hence, biomedical markers only provide information about the potential manifestation of the disease. How each individual experiences the disease, and their level of impairment, will depend on other factors (Engel, 1977). This model has gained a lot of support in the literature, but there are concerns about the biomedical model still being in a dominant position (Fava & Sonino, 2007). An illustration of the biopsychosocial model and how it can be used in explaining disability is provided in Figure 1.

This model provides a broader perspective on disabilities in general. The biopsychosocial model applied to this thesis, namely research on reading abilities in adolescents with non-specific ID, implies that the explanation for the existing difficulties can be found on either

a biological, psychological, or social level – but most likely on several of these levels. The impairment will always be present on the biological level, but how the disability manifests itself will also depend on individual factors on the psychological level and the surrounding environment on the social level. In this thesis, the biopsychosocial model has influenced both study design and discussions on potential processes explaining the results.



*Figure 1.* Visualization of the biopsychosocial model explaining disability. Created by Josefine Andin and Emil Holmer (2022; unpublished).

## The Developmental Delay and Difference Models

The investigation of ID has been pursued in different ways. One theoretical framework has had an indisputable effect on the modern way of conducting research with this population – namely the “two-group approach to mental retardation” formulated by Zigler (1967). This framework was developed as a response to the quest of finding the core deficit of ID, which was pursued by a majority of researchers during that time. Research on ID was defect oriented, and the goal of most investigations was to find the biological cause of that defect. However, Zigler stressed that a large proportion of individuals with ID did not display any biological manifestations. Instead, this group often came from families with lower IQs and lower socioeconomic status, and Zigler referred to this type of ID as “familial” or “cultural-familial”. Zigler (1967) suggested that individuals with familial ID composed the lower end of the normal distribution of intelligence, and hence the development differed from a typically developing individual only with respect to the rate of development and the end point of development. The group with familial ID was contrasted against the ID group with a biological cause, referred to as “organic” ID, that was expected to exhibit qualitatively different patterns of development compared to typically developing individuals (Burack et al., 2012).

The two-group approach resulted in two models, namely the developmental delay model and the difference model. In the beginning, these models distinguished between the familial and organic ID but the developmental delay model was later expanded to include ID of all aetiologies (Burack et al., 2021). Furthermore, Zigler (1967) stressed that the performance level of individuals with ID could not be attributed solely to cognitive functioning. Instead, he argued for a holistic approach (“whole child”) and placed a focus on social-personality characteristics that had been largely absent in the existing literature on ID (Hodapp, 2021). This line of reasoning fits well with the aforementioned biopsychosocial model that was proposed a decade later (Engel, 1977).

Today, the terminology has changed and organic ID is often referred to by different conditions (e.g. Down syndrome, Williams syndrome), and familial ID is referred to as non-specific ID. The developmental delay model and the difference model have been used throughout this thesis when posing research questions and hypotheses, in an attempt to find out whether the participants with ID follow a pattern of reading development that is delayed or qualitatively different from that of typically developing children.

## Reading Development

To read is to successfully convert a written message into sounds, words, and sentences, to retrieve the words from a mental lexicon, to understand the syntactical relation between the words, to connect the words to your prior knowledge about the world, and to finally grasp the full meaning of the message. Ergo, reading is a difficult task that requires both cognitive and linguistic abilities.

## Reading Comprehension

Reading comprehension is a complex combination of processes that requires the reader to interpret information on word, sentence, and discourse levels while simultaneously connecting that information to prior knowledge about the world (Cain, 2010). The successful development of reading comprehension depends on many factors. For a child to comprehend text rather than spoken language, a child needs to be able to decode the words (Gough & Tunmer, 1986). Successful development of reading comprehension is also dependent on vocabulary knowledge (de Jong & van der Leij, 2002) and syntactic awareness (Muter, Hulme, Snowling, & Stevenson, 2004). Apart from comprehending words and sentences in a text, a reader also needs to develop skills on the discourse level, such as inference skills, comprehension monitoring, and knowledge of story structure (Cain, Oakhill, & Bryant, 2004). Making inferences means to go beyond what is written in the text, to read between the lines, and this requires knowledge about the world and also the possibility to access this knowledge during reading. Comprehension monitoring means the ability of the reader to evaluate whether or not the story makes sense and also to realise when comprehension fails, and to do something about it. Lastly, knowledge about story structure means that a child reading, for example, a narrative text is able to identify an individual character’s goals, and also to interpret the actions carried out by that character in relation to the goal. This skill is commonly developed through being read stories (Cain, 2010).

## **The Simple View of Reading**

The Simple View of Reading (SVR) states that reading comprehension is the product of decoding and comprehension (Gough & Tunmer, 1986; Hoover & Gough, 1990), where comprehension refers to linguistic comprehension – the process of understanding the meaning of spoken words. It is important to stress that reading is the product of these two processes, since if any of the components are equal to zero then reading is equal to zero (Gough & Tunmer, 1986). It is possible to decode words and sentences in a foreign language (especially a language with a transparent orthography), but this is not considered reading because comprehension equals zero. Conversely, a preschool child may be able to comprehend a spoken sentence, but if the child is not able to decode the relevant letters this will not be considered reading. The SVR has been evaluated in many studies over the years, and the framework has received considerable support in the literature. The SVR has been found to successfully predict reading ability in typical monolingual readers (Cain & Chiu, 2018; Lervåg, Hulme, & Melby-Lervåg, 2017; Torppa et al., 2016), as well as in second language readers (Mancilla-Martinez, Kieffer, Biancarosa, Christodoulou, & Snow, 2011; Verhoeven & van Leeuwe, 2012).

The SVR framework has also proven to be beneficial when classifying reading disabilities (Cain, 2010). This classification describes the underlying reason why reading comprehension fails, which could be due to impaired decoding, impaired listening comprehension, or both (Gough & Tunmer, 1986). The core symptom of dyslexia is difficulties with decoding, while listening comprehension abilities often constitute an area of strength (Snowling, 2000). The opposite relation is true for poor comprehenders, where decoding abilities often remain largely intact while listening comprehension and other linguistic abilities are affected (Cain & Oakhill, 2006; Elwér, Keenan, Olson, Byrne, & Samuelsson, 2013). A third group of poor readers exhibit difficulties both with decoding and listening comprehension, and could for example include individuals with ID. The SVR is not only applicable in research but also in clinical practice when explaining relationships between language and reading in children referred for speech-language evaluation (Ebert & Scott, 2016).

Furthermore, there is evidence that the relative contribution of the components in the SVR shift over time (Juel, Griffith, & Gough, 1986; Lervåg et al., 2017). During the early stages of reading development, decoding ability has a strong impact on reading comprehension. This is because the ability to decode is still developing. However, once decoding is mastered by the student it decreases in importance for reading comprehension, and listening comprehension increases in importance.

## **Lexical Quality Hypothesis**

The Lexical Quality Hypothesis (LQH) states that the variation in the size of the vocabulary and quality of the representations of words known by a reader will have consequences for word reading and subsequently reading comprehension (Perfetti, 2007). Skilled readers will show higher-quality representations of a larger proportion of words compared to less skilled readers. Perfetti (2007) describes lexical quality as knowledge about a word's form and meaning, but also knowledge about how words are used. The vocabulary of a given reader will include words with a wide variation in lexical quality, and individual readers will differ in their average lexical quality. Lexical quality is

considered to have many different aspects. One quality aspect is to know that *though* and *tough* are not the same. Another quality aspect is to know that *dissertation* and *an essay written by a candidate for the degree of Doctor of Philosophy* are the same. Yet another quality aspect is to know how to pronounce the word *bow* in the following two sentences: “Put the *bow* in your hair” and “You need to *bow* in the presence of a royal person”.

There are studies supporting the role of lexical quality in relation to both reading comprehension and decoding. For example, Ouellette (2006) found that depth of vocabulary knowledge added unique variance in reading comprehension even after accounting for age, nonverbal IQ, decoding, and vocabulary breadth. Braze, Tabor, Shankweiler, and Mencl (2007) found that a composite variable of vocabulary breadth and vocabulary depth added unique variance in reading comprehension. Furthermore, vocabulary depth has been found to add unique variance in irregular word reading (Ouellette & Beers, 2010).

### **Predictor of reading comprehension**

The SVR and the LQH emphasize the importance of decoding, listening comprehension, and vocabulary as predictors of reading comprehension. However, there are multiple studies suggesting that other variables might be of importance in explaining the variance in reading comprehension both concurrently and longitudinally, such as working memory (Cain et al., 2004; Christopher et al., 2012; Seigneuric & Ehrlich, 2005; Swanson & Howell, 2001), IQ (Hulslander, Olson, Willcutt, & Wadsworth, 2010; Tiu, Thompson, & Lewis, 2003), and grammatical skills (Muter et al., 2004; Silva & Cain, 2015).

## **Decoding**

Decoding is the aspect of reading where letters are converted into sounds and subsequently blended to form words and sentences. The development of decoding is often described as going through several stages. However, the literature differs in how many stages it takes to develop an automatized decoding ability (Ehri, 2005; Frith, 1985). In the beginning, children do not use the correspondence between letters and sounds, instead, they use visual cues. This stage is referred to as the “logographic” stage (Frith, 1985) or the “pre-alphabetic” stage (Ehri, 2005). During this stage, children are able to recognize words as pictures, for instance, famous logotypes. However, children tend to not react to letters being changed within the word as long as the logotype keeps its colours and shape. The next step in development is that the child learns to use letter-sound correspondence. Frith (1985) refers to this stage as the alphabetic stage, while Ehri (2005) divides this stage into two phases: the partial alphabetic phase and the full alphabetic phase. Here, the child learns that letters correspond to sounds that comprise spoken language and thereby learns to decode novel words. Once a child has reached this alphabetic insight, all words can be read. However, for decoding to be automatized and efficient the child needs to transit into the next stage. The final stage of decoding development is referred to as the orthographic stage (Frith, 1985), or the consolidated alphabetic stage (Ehri, 2005). Here, a child learns to recognize words by sight without having to sound out the word. Cues such as letter sequences and spelling patterns are used (Kamhi & Catts, 2012). Stage theories of decoding development have been criticised. On the one hand, a child can be in more than one stage at the same time since mastery of a

stage is not a prerequisite to moving on to the next. The majority of words might be decoded in an orthographic manner, while the child still needs to use the alphabetic strategy of sounding out words from time to time. On the other hand, in transparent orthographies, such as Swedish, the alphabetical stages might not even be distinguishable since word reading development is driven by fluency rather than phonology, compared to opaque orthographies such as English (Furnes & Samuelsson, 2010). Decoding development in English has been found to progress more slowly and less efficiently compared to more transparent orthographies (see for example; Patel, Snowling, & de Jong, 2004), and since many of the theories on decoding development stem from research on English speaking children these theories need to be applied cautiously within research on transparent orthographies.

### **Predictors of Decoding**

The most common predictors, both longitudinal and concurrent, of decoding ability found in research on typically developing children are phonological awareness, RAN, and letter-sound knowledge (Hulme & Snowling, 2013; Landerl & Wimmer, 2008; Scarborough, 1998; Schatschneider, Fletcher, Francis, Carlson, & Foorman, 2004). The relative contribution of phonological awareness and RAN shifts over time, especially in a transparent orthography where phonological awareness makes a less important contribution than reading speed. In the early school years when the ability to decode is developing, phonological awareness is a strong predictor of decoding performance. However, as decoding ability develops the impact of phonological awareness diminishes while RAN persists as a predictor (Furnes & Samuelsson, 2010; Landerl & Wimmer, 2008).

In addition to the most commonly reported predictors, vocabulary has been found to predict decoding ability (Ouellette, 2006; Ouellette & Beers, 2010). Furthermore, there are studies, mainly focussing on individuals with reading disabilities, suggesting that other abilities could be of importance for decoding, such as verbal fluency (Cohen, Morgan, Vaughn, Riccio, & Hall, 1999; Reiter, Tucha, & Lange, 2005; Smith-Spark, Henry, Messer, & Ziecik, 2017), and visual memory (Kibby et al., 2015). Environmental factors such as the educational level of parents and socioeconomic background have also been found to relate to the development of decoding in typically developing children (Noble, Farah, & McCandliss, 2006; Segers, Damhuis, van de Sande, & Verhoeven, 2016; Wang, Ma, Li, Huang, & Wang, 2022).

### **Measuring decoding**

The ability to decode could be measured in different ways. It is often of interest to investigate whether an individual has the ability to read both alphabetically and orthographically. The sounding-out strategy used in the alphabetic stage is often referred to as phonological decoding, phonological recoding, or sometimes only decoding, and this ability is tested by letting the participant read lists of nonwords. The strategy used in the orthographic stage is referred to as word recognition, sight word reading, or orthographic reading, and this ability is tested by letting the participant read lists of real words. Many studies make a distinction between these two strategies. However, these two forms of decoding are highly related (Aaron et al., 1999) and so in this thesis, a composite

variable of both phonological decoding and word recognition was used. Hence, this ability will be referred to as decoding throughout this thesis.

## **Reading Ability and Intellectual Disability**

### **Reading Comprehension**

Studies investigating reading comprehension abilities in individuals with ID have found that they perform on a level much lower than expected from their chronological age (Jones, Long, & Finlay, 2006), but also that they perform low in relation to other disability groups (Wei et al., 2011). Further, these studies have found a range of different concurrent and longitudinal predictors. Some studies show that decoding and listening comprehension plays a crucial role in explaining reading comprehension abilities (van Wingerden, Segers, van Balkom, & Verhoeven, 2017, 2018; Verhoeven & Vermeer, 2006), lending support to the SVR. In these studies, non-verbal IQ also emerged as a significant predictor alongside the components of the SVR. One study looked at two types of reading comprehension, lower-level reading comprehension (explicit content) and higher-level reading comprehension (implicit content), and found that decoding and listening comprehension was sufficient when explaining lower-level reading comprehension, but not higher-level reading comprehension (van Wingerden, Segers, van Balkom, & Verhoeven, 2014). Instead, non-verbal reasoning was the only significant predictor of higher-level reading comprehension, indicating that the cognitive demands of this task were high for the participants. All the predictors mentioned above correspond to a delayed model of development since they could also be found in research on typically developing children. However, there are studies where early literacy skills, i.e. phonological awareness and letter-sound knowledge, have been found to predict growth in reading comprehension directly (Sermier Dessemontet & de Chambrier, 2015; van Wingerden et al., 2018), which is in line with a difference model of development. In the longitudinal study by van Wingerden et al. (2018), reading comprehension measured in Wave 3 was directly predicted by early literacy skills measured in Wave 1, over and above the impact of decoding, listening comprehension, and prior reading comprehension skills measured in Wave 2. This direct impact of early literacy skills is rarely seen in research on typically developing children because the impact is often mediated via decoding. The authors argue that this direct impact could be an effect of the cognitive demands associated with the phonological awareness tasks (van Wingerden et al., 2018), meaning that the tests may reflect other abilities such as verbal working memory rather than phonological awareness.

### **Decoding**

Studies on decoding ability in individuals with ID have shown, similar to studies on reading comprehension, that they perform lower than expected in relation to their chronological age. Lemons et al. (2013) showed that only 13.9% of students with ID in Grade 11 met the benchmark for Grade 3. Another study found that a third of the participants with ID decoded words letter by letter (Ratz & Lenhard, 2013), which corresponds to the alphabetical stage in typical reading development. Research on the

predictors of decoding ability in individuals with ID has identified predictors in line with a delayed model of development, namely phonological awareness (Barker, Sevcik, Morris, & Ronski, 2014; Channell, Loveall, & Conners, 2013; Saunders & DeFulio, 2007; Sermier Dessemontet & de Chambrier, 2015; Soltani & Roslan, 2013; van Wingerden et al., 2018), letter-sound knowledge (Sermier Dessemontet & de Chambrier, 2015; van Tilborg, Segers, van Balkom, & Verhoeven, 2014; van Wingerden et al., 2018), and RAN (Barker et al., 2014; Saunders & DeFulio, 2007; Soltani & Roslan, 2013; van Wingerden et al., 2017). In addition, phonological memory has been found to influence decoding (Channell et al., 2013; Conners, Atwell, Rosenquist, & Sligh, 2001). However, there are studies that have identified predictors that correspond to a difference model of development. For example, some studies suggest that IQ might be of greater importance for decoding ability in ID groups, compared to the typically developing groups. One study by van Tilborg et al. (2014) investigated the predictors of decoding ability in two groups of children in the early stages of literacy acquisition, one group with ID and one group with normal language acquisition (NLA). The results showed that decoding in the NLA group was predicted by nonverbal IQ, phonological awareness, and letter knowledge while decoding in the ID group was only predicted by nonverbal IQ. Another study by the same authors showed similar results, but in the final model for the NLA group, nonverbal IQ did not exhibit a direct impact on word decoding, while this was the case for the ID group (van Tilborg, Segers, van Balkom, & Verhoeven, 2018). So, in the early stages of decoding development IQ seems to play a substantial role for children with ID. In addition, the impact of IQ has been established in adolescent participants. One study investigated the predictors of decoding in participants with DS and participants with non-specific ID, and the results showed that the correlations with common predictors such as phonological awareness and RAN diminished when IQ was controlled for (Levy, 2011).

## Summary

Individuals with ID exhibit difficulties with reading comprehension and decoding. However, trying to disentangle the mechanisms behind these difficulties has resulted in inconclusive results and only a few studies have evaluated theoretical frameworks of reading in relation to the ID group. Hence, as of today, there is no clear evidence in favour of either the developmental model of delay or the developmental model of difference. In addition, studies investigating reading ability in individuals with ID often base their results on small sample sizes and insufficient power. Consequently, there is a need for large-scale studies investigating reading ability in individuals with ID to enhance our understanding of the underlying mechanism of reading difficulties in this group.

## General Aim and Study Rationale

The overall aim of this thesis was to investigate the development and the concurrent predictors of reading ability in adolescents with ID to gain a further understanding of why individuals with ID exhibit poor reading skills. Paper I provided an overview of the existing research within this field and pointed out the lack of studies, specifically the lack of large-scale studies with sufficient power. Paper II and III investigated the concurrent predictors of decoding and reading comprehension and compared the set of predictors to



earlier research on typically developing children and theories of typical reading development. Finally, Paper IV provided an explorative investigation of the developmental trajectories of decoding ability in an attempt to deepen the understanding of decoding difficulties in individuals with ID.



# General Method

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This thesis is largely based on one large collection of data. Papers II, III, and IV are based on these data. Paper I is a meta-analysis and therefore has no empirical data.

## Paper I

The meta-analysis in Paper I was based on three separate literature searches conducted in August 2017, March 2021, and August 2022. Several searches were carried out for the data to be up to date.

## Inclusion and Exclusion Criteria

The inclusion criteria for the title, abstract, and full-text screening were the presence of measures of decoding and/or reading comprehension; correlational data; mean IQ at or below 70, and a maximum individual IQ of 85; a minimum sample size of 10 participants; participants with either non-specific ID, Down syndrome, Williams syndrome, or mixed aetiology. In addition, only articles in English were included. Primary articles differed with regard to the measure of decoding and IQ that was used. Any study with a standardised assessment of decoding and IQ was included. Whenever multiple measurements were reported, the order of preference (i.e. which correlation was chosen) was the following for decoding: word recognition, composite measure, phonological decoding, and the following for IQ: non-verbal, full scale, verbal. Articles were excluded for the following reasons: if their focus was another syndrome or another form of disability, if the participants had comorbidity with autism, or if the article was a review.

## Search Strategy

All three searches were made in four different databases, namely PubMed, PsycInfo, Web of Science, and ERIC. The search strategy included a combination of keywords related to reading (reading, literacy, decoding, word recognition), intellectual disability (intellectual

disability, mental retardation, mental deficiency, intellectual developmental disorder, developmental disability), and relation (relation, relationship, prediction, correlation, regression, association). After the removal of duplicates and the screening of abstracts, the three searches yielded 166, 199, and 34 articles for full-text screening. Two authors screened the abstracts and full-texts independently. Inter-rater reliability was calculated using Cohen's  $\kappa$  and ranged from .56 to .70, which is considered fair to good agreement according to Fleiss, Levin, and Cho Paik (2003). The percentage agreement ranged from 91-96%.

To find additional records not discovered through the systematic search, several other methods were used. Inquiries for file drawer data were sent to the authors of the included articles from the systematic search, in those cases the authors' contact information was successfully obtained. Reference lists in the included articles were scanned, articles citing the already included articles were identified and screened, and a request for grey literature was made during a poster presentation at the Society for Scientific Studies of Reading (SSSR) conference in Toronto, 2019. In total, the systematic search and the additional searches yielded 26 studies. One of these studies reported two independent samples, one with DS and one with non-specific ID (Levy, 2011), and because the samples were reported separately in the primary study, they were treated as two separate studies in the meta-analysis. Hence, the final set consisted of 27 studies.

## Coding of Effect Sizes

This meta-analysis addressed the correlations between decoding and its predictors and between reading comprehension and its predictors, meaning that several effect sizes from each study were of interest. However, the primary studies differed with regard to the number of variables that were assessed and some of the correlations were reported in many studies while other correlations were reported in one or two studies. To minimize the risk of bias where the result is driven by one or two studies, the decision was made to only include correlations reported in five or more studies. As a result, the meta-analysis coded the correlations between decoding and the following variables: phonological awareness, RAN, phonological short-term memory (STM), visuospatial STM, executive-loaded working memory (ELWM), IQ, chronological age, vocabulary, and listening comprehension and between reading comprehension and the following variables: decoding, listening comprehension, IQ, and vocabulary. Correlations between decoding and the following variables were excluded: letter-sound knowledge and grammatical comprehension. Correlations with reading comprehension and the following variables were excluded: phonological awareness, letter-sound knowledge, grammatical comprehension, phonological and visuospatial STM, ELWM, RAN, and chronological age.

## Paper II-IV

In the data collected for Paper II-IV, 136 participants were recruited and tested. The goal was to include 150 participants, and that goal was reached in terms of recruitment and written consents. However, the last months of testing were cancelled due to the Covid-19 pandemic and related school restrictions.

## Participants

The initial inclusion criteria were: mild non-specific ID, age 12-19 years, a measurable level of decoding ability (i.e. a score above 0 on the decoding test), normal or corrected to normal hearing and vision, Swedish speaking home environment since birth, and no comorbidity with other developmental diagnoses. Because comorbidity with other diagnoses such as attention-deficit hyperactivity disorder (ADHD) and autism spectrum disorder (ASD) is very common within the ID population prior to recruitment it was decided that the last inclusion criterion would be dropped if recruitment proved too difficult. Only 17 participants were recruited after six months of testing which resulted in the last inclusion criterion being dropped. In the final sample, 51% of the participants had additional diagnoses according to parental reports.

Participants were recruited via schools in the southern parts of Sweden. After initial contact with the principal, teachers distributed study information and consent forms to students that fulfilled our inclusion criteria. A total of 330 schools were approached, and approximately 650 consent forms were sent out. All participants attended compulsory or upper secondary schools for pupils with learning disabilities. In Sweden, this means that they have been assessed and diagnosed as having ID and an IQ < 70 by a clinical psychologist. Participants did not receive any compensation for taking part in this project.

## Procedure

All participants were assessed in their school environment. Test sessions were booked with each participant's teacher in order to fit the testing into the school schedule and to accommodate the test sessions to each participant's needs. The total testing time per participant was approximately four hours, and this took place in four sessions. Depending on the needs of the participant, these sessions were completed during two or four different school days. The sessions followed a pre-planned test order, namely: word recognition, IQ, vision, phonological decoding, hearing, visual sequential memory, reading comprehension, verbal fluency, phonological awareness, RAN, listening span, vocabulary, listening comprehension, questionnaires, digit span, grammatical understanding, odd one out span, and the Corsi blocks test. However, order alterations were allowed, which in practice usually meant that sometimes time-consuming tests were moved to the next session.

## Materials

The participants were tested with a broad range of tests measuring hearing, vision, cognition, language, and home literacy environment. We chose not to include a test of letter-sound knowledge in this data collection because this measure is more appropriate as a longitudinal predictor when assessed before the participants have started their formal reading instruction. Each test will be described in detail below.

### Decoding

Decoding was measured with Läst (Elwér, Fridolfsson, Samuelsson, & Wiklund, 2016). This test includes measurements of word recognition and phonological decoding. The test consists of two forms, covering both types of decoding. One form was used to assess

timed decoding ability and the participants were instructed to read separate lists of words and nonwords as quickly as possible for 45 seconds. The other form was used to assess untimed decoding ability and the participants were instructed to read the whole list of words and nonwords as accurately as possible. Testing of untimed decoding ability was stopped following 10 consecutive errors. The raw scores were the total number of correct words that were read on each form. The four measures of decoding were entered into a principal component analysis (PCA) and the main decoding variable used was the PCA for a one-component solution.

### **Reading Comprehension**

Reading comprehension was measured with LÄSt (Elwér et al., 2016). This test consists of 17 passages of increasing length and complexity. The participant's comprehension of each passage was assessed using multiple-choice questions. The first three passages were mandatory. After finishing these passages, testing was stopped if the participant answered less than two questions correctly following a passage. This stopping criterion was chosen on the basis that two correct answers represent more than chance. The raw score was the total number of correct answers.

### **Listening Comprehension**

Listening comprehension was measured with a subtest from Clinical Evaluation of Language Fundamentals, CELF-4 (Semel, Wiig, & Secord, 2003). The test leader verbally presented three short stories and participants were asked five questions about each story. The questions are designed to measure both comprehension of clearly stated events that occurred in the story and the participant's ability to make inferences and draw conclusions from the provided information. The raw score was the total number of correct answers.

### **Vocabulary**

Receptive vocabulary was measured using the Peabody Picture Vocabulary Test Third Edition, PPVT-III (Dunn & Dunn, 1997). The participants were asked to match a verbally presented stimulus word to one of four drawings. The test is arranged in blocks of 12 items and has a total of 204 items. The blocks are arranged in order of increasing difficulty and testing was stopped following eight or more errors within one block. According to the manual, the level of difficulty of the initial testing should be related to the participant's age. However, in this project, it was decided to start from the first block with all participants as it can be difficult to ascertain where to start graded tests in individuals with ID. The raw score was the total number of correct answers.

### **Grammatical Comprehension**

Grammatical understanding was measured using the Test for Reception of Grammar Version 2, TROG-2 (Bishop, 2003). The participants were instructed to listen to verbally presented sentences, and then select the picture corresponding to that sentence from one of four pictures. Items are divided into blocks of four and each block tests the understanding of a specific type of contrast. The blocks are arranged in order of increasing difficulty. One block is considered correct when all four correct items are selected.

Testing was stopped following errors in five consecutive blocks. The raw score was the total number of correct blocks.

### **Phonological Awareness**

Phonological awareness was measured using three different tests. Two of them were subtests from the Comprehensive Test of Phonological Processing (CTOPP; Wagner, Torgesen, & Rashotte, 1999). The Blending Words subtest requires participants to blend sounds to say a word. There are 20 items and testing was stopped following three consecutive errors. The Elision subtest requires the participants to repeat a word after the examiner and then say the word again but leaving certain sounds out. There are 20 items and testing was stopped following three consecutive errors. The third test, called 46-items (Olson, Forsberg, Wise, & Rack, 1994), requires the participants to repeat nonwords presented orally by the examiner and then to say the word again but leaving certain sounds out. There are 46 items and testing was stopped following five consecutive errors. Raw scores on each test were the total number of correct answers. All measures of phonological awareness were combined (sum of z-transformed measures) to give one variable that was used in all analyses.

### **Rapid Automatized Naming**

Rapid automatized naming (RAN) measures how quickly individuals can name objects, colours, or symbols (Wagner et al., 1999). Participants were given two different RAN tests; they were asked to name six different letters and six different colours as quickly as possible. Letters and colours were presented in random order. Time in seconds was recorded. The raw score was the total number of seconds from both forms. Measures of both letters and colours were combined (sum of z-transformed measures) to one variable that was used in all analyses.

### **Verbal Fluency**

Verbal fluency was measured using the Delis-Kaplan Executive Function System subtest (Delis, Kaplan, & Kramer, 2001), which involves several letter and category fluency tasks. The participants were asked to verbalize as many words as possible starting with a specific letter (three different letters were used: F, A, and S), and from two specific semantic categories (animals and boys' names). Each task has a time limit of one minute. Words starting with a non-target letter, words that are not animals or boys' names, and repetitions were all counted as errors. The raw score was the total number of correctly generated words. Raw scores from both tasks were combined (sum of z-transformed measures) into one variable that was used in all analyses.

### **IQ**

Full-scale IQ was estimated with the Block design and Vocabulary subtests from Wechsler Intelligence Scale for Children-Fifth Edition, WISC-V (Wechsler, 2014). These subtests were chosen due to their high reliability and a high correlation with the full-scale IQ (Silverstein, 1990). Testing and scoring were carried out according to the manual. Block design is a subtest in which participants were asked to arrange several blocks according to a given pattern. Testing was stopped following two consecutive errors.

Vocabulary is a subtest where the participants were asked to name pictures and explain the meaning of words. Testing was stopped following three consecutive errors.

### **Short-term and Working Memory**

Two tests assessed verbal and visuospatial executive-loaded working memory (ELWM); and three tests assessed visual, spatial, and phonological short-term memory (STM) respectively. Listening span, odd one out span, digit span, and the Corsi blocks test are in the format of span tests which have three trials per list length, and the participants were allowed to continue to the next span level if two out of three trials were correct (both items and serial order). Item sequences start with one or two items but become longer until the participant's performance breaks down. The raw scores were the total number of trials correct.

Listening span and odd one out span are measures of verbal and visuospatial ELWM. Listening span requires participants to listen to a sentence spoken by the examiner, state whether it is true or false, and retain the last word of that sentence while subsequent sentences are presented and processed. Odd one out span requires participants to choose one out of three shapes that is different from the other two and shortly after retaining its spatial position while subsequent odd one out decisions are made (Henry, 2001).

Phonological STM was measured with forward digit span from the WISC-V (Wechsler, 2014) and it requires participants to repeat a list of digits immediately in the same serial order as they were orally presented by the examiner. In order to ensure the same number of trials for all span tests, we added one extra trial at each list length to the forward digit span task using digits from the backward digit span assessment in the WISC-V.

The Corsi blocks and visual sequential memory tests were used as measures of spatial and visual STM. The Corsi blocks test involves participants mimicking the examiner who taps a sequence of up to nine identical spatially separated blocks. Visual sequential memory, a subtest taken from Test of Visual Perception Skills Revised, TVPS-R (Gardner, 1996) requires the participants to remember a sequence of shapes, and then shortly afterward identify the correct sequence from a set of possibilities. The sequences are increased in length and testing is stopped following three consecutive errors. The raw score was the total number correct.

### **Home Literacy**

Home literacy was assessed using questionnaires for both parents and participants. Parents were asked about their first language and which language the family used in their home environment. This information was only used for inclusion decisions and to describe our group of participants. In addition, parents were asked about their completed educational level and reading habits. Completed educational level was scored on a four-point scale: grade 1-9 (1), grade 10-12 (2), university degrees (3), and Ph.D. education (4).

Assessment of reading habits involved questions about how often the parents read different forms of literature (i.e. books, newspapers, comics, blogs/e-mails) how often they read for their child and how often they used to read to their child between the ages of three and seven. Reading habits were scored on a four-point scale: never or almost



never (1), 2-3 times a month (2), 2-3 times a week (3), every day, or almost every day (4). The parents were asked to fill in the questionnaire at home and return it to the examiners.

The participants were asked about their reading habits and reading skills. Reading habits were measured with questions about how often the participants read different forms of literature (i.e. books, newspapers, comics, blogs/e-mails) and were scored on a four-point scale: never or almost never (1), 2-3 times a month (2), 2-3 times a week (3), every day or almost every day (4). In addition, they were asked how much they enjoy reading, measured on a four-point scale: not at all (1), a little (2), quite a lot (3), very much (4). The final question concerned how the participants rated their reading abilities, measured on a four-point scale: poor (1), quite poor (2), quite good (3), and good (4). The participants were asked all questions verbally during the assessment, and the questionnaire was filled in by the examiner. The raw score for home literacy was the total sum of scores from both parents and participants. For participants with only one parent answering the questionnaire, that parent's score was doubled. The maximum score was 72.

### **Vision and Hearing**

Vision was screened using two different LEA-tests (Hyvärinen, Näsänen, & Laurinen, 1980); a 15-line distance chart (10 feet distance) and a near vision card (16 inches distance) to establish if the participants had normal vision. Participants with glasses were allowed to use them during testing. LEA-tests use symbols instead of letters or numbers. Participants with a visual acuity of  $\geq 0.8$  were included in the study. Hearing was screened with pure tone audiometry using a GSI 68 audiometer and an SA 201-IV audiometer and both were calibrated. The participants were wearing AudioCups during testing, to minimize the impact of external noise. The participants were instructed to press a button every time they heard a tone. The screening process involved the following frequencies: 250, 500, 1000, 2000, 3000, 4000, 6000, and 8000Hz. The threshold was measured using a standard audiological procedure and the screening level was set to 20dB HL. Pure tone average (PTA) was calculated based on the following frequencies: 500, 1000, 2000, and 4000Hz. Participants with a PTA between 20-25dB HL were included in the study. For participants with hearing aids, pure tone audiometry is not applicable. However, these participants were included and coded as hearing aid users.

## **Data Treatment and Statistical Considerations**

All data analysis in this thesis was done using the software R (R Core Team, 2017), and all manuscripts were formatted using the package papaja (Aust & Barth, 2017). Information about the specific packages is provided in each manuscript.

The meta-analysis in Paper I targeted correlations between decoding and reading comprehension and their respective predictors. Each correlation was synthesized separately using a random effects meta-analysis. Some of the studies used multiple measures of the same variable, for example, subtests of phonological awareness such as blending, elision, etc. To deal with the dependencies created by multiple measures, a robust variance estimation was used for the correlations in question.

The data used in Papers II, III, and IV comes from the same dataset. The percentage of missing data was low for all variables (maximum 2.21% for all variables). Missing values were treated as random and values were imputed using the Multivariate Imputation by Chained Equations (MICE) approach (van Buuren & Groothuis-Oudshoorn, 2011). The decoding variable used in all three papers was a composite variable created from four separate measures. The composite variable was the PCA for a one-component solution with high loadings for all decoding measures (range 0.88 to 0.93) which explained 81.9% of the variance.

## Ethics

Participating in this project was voluntary, and all participants had to give both written and oral consent before participating. For participants under the age of 15, written consent was obtained from their caregivers. For participants aged 15 or older, written consent was obtained both from the participants and their caregivers. In addition, all participants were asked for oral consent before testing started. Participants were informed that they were allowed to opt out at any stage of testing. This project received ethical approval from the regional Research Ethics Committee in Linköping, Sweden (2017/139-31).

An important ethical consideration for this project concerned the testing procedure. Participation meant being assessed with a large number of tests. On top of that, there was a built-in expectation that the participants would not score very highly on these tests considering that the project aimed at investigating abilities that are known to be affected in individuals with ID (such as linguistic comprehension, memory, and IQ). This is a common problem in disability research since tests are often developed for individuals in the middle and top range of the normal distribution, while disability research often targets individuals that are in the lower range on the abilities of interest. To minimize the risk of the participants experiencing feelings of failure, several preventive measures were taken. Most of the tests that were used in this project were tests developed for younger typically developing children. Because individuals with ID are not expected to perform on a level comparable with their chronological age, the decision was made to use tests standardized for younger children which probably reduced the risk of participants experiencing feelings of failure. In addition, the testing was divided into four different sessions that were compliant with the school schedule, so the participants only did a few tests at the time. During testing, breaks were allowed whenever necessary. Furthermore, stopping criteria were added to all tests to ensure that the participants were not subjected to excessive testing and failure. These criteria are described in detail for each test under “Materials”.

There were three test leaders in this project, and all of them had previous experience in testing and working with individuals with different disabilities. Two test leaders were speech and language pathologists with clinical backgrounds (one of whom is the author of this thesis), and one test leader was a teacher with long experience working with individuals in need of special support. This experience with testing means that the test leaders were used to picking up signals of stress or fatigue from the person being tested.

## Registered Reports

In 2013, the journal *Cortex* suggested a new publication format, called Registered Reports, to diminish publication biases and encourage the publication of null results (Chambers, 2013). A Registered Report is peer-reviewed in different stages of the preparation of the manuscript; both prior to data collection and after the study is completed. In the first stage, a manuscript including an introduction, hypotheses, a detailed method description, power analysis, statistical analysis pipeline, and pilot data (optional) is submitted for peer-review. The first round of review focusses on the importance of the research questions, the rationale of the proposed hypotheses, the soundness of the methodology and analysis pipeline, and the transparency and replicability of the methodology (Journal of Cognition, 2020). If the manuscript fulfils these requirements, the authors will receive an in-principle acceptance (IPA). Following IPA, the authors proceed with conducting the study, adhering exactly to their reviewed procedures. After finalising the manuscript, it is resubmitted and re-reviewed, and the authors are required to share their raw data and a laboratory log on a public repository (e.g. Open Science Framework). If the authors have adhered to their proposed procedures and made sensible interpretations of their results, the manuscript is published – regardless of the results (Chambers, 2013). The Registered Report format is expected to prevent publication bias, and minimize the influence of selective reporting, post hoc hypothesising, and low statistical power; furthermore, the incentives for questionable research practices are diminished (Chambers, Dienes, McIntosh, Rotshtein, & Willmes, 2015).

To new adopters, the Registered Report format might seem rigid. However, this format does allow exploratory analyses, as long as these are clearly stated (Chambers, 2013). This format is not aiming at preventing authors from exploring unexpected findings, which is a common misunderstanding. If exploratory analyses are conducted, these should be reported in a paragraph dedicated to these analyses alone, which makes it transparent that these analyses are not connected to the IPA hypotheses. More importantly, the hypotheses cannot be altered to fit the results of these exploratory analyses. To make this format work with the scientific procedures, every part of the study needs to be reported transparently.

Papers II and III were submitted as Registered Reports, and both manuscripts received an IPA in April 2018. An agreement was made with the journal to re-submit the manuscripts before December 2020, and the manuscripts were resubmitted in November of that year. In Paper II, two exploratory analyses were added under a separate heading to ensure that the results obtained from the preregistered analysis plan were reliable.



# Summary of the Papers

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## Paper I

Paper I investigated the variables associated with decoding and reading comprehension in populations with ID through a systematic review and a meta-analysis. Four major databases were searched on three occasions using a set of keywords related to reading, ID, and correlations. A total of 27 samples were included in the meta-analysis. The results showed that decoding was significantly associated with phonological awareness, phonological STM, RAN, IQ, chronological age, vocabulary, visual STM, and ELWM. Reading comprehension was found to be associated with decoding, listening comprehension, IQ, and vocabulary. The results for decoding are, to a large extent, in line with previous research on children with typical development. However, the current study found a moderate relation between decoding and IQ and decoding and ELWM, which contrasts with findings from typically developing children where the relationship between decoding and IQ sometimes is referred to as non-existent and where ELWM is mostly found to correlate with reading comprehension. Previous research on individuals with ID has not always produced consistent results regarding the relation between decoding and IQ, but this meta-analysis indicates that IQ could play an important part in the development of decoding ability in individuals with ID. Furthermore, the variables associated with reading comprehension suggest that a combined framework of the SVR and the LQH might be a successful way of explaining reading comprehension in individuals with ID.

## Paper II

Paper II investigated the concurrent predictors of decoding ability in a large sample of Swedish adolescents with non-specific ID and evaluated the results in relation to previous findings on typically developing children to establish whether the pattern of predictors followed a delayed or different profile. One hundred and thirty-six Swedish-speaking

adolescents were included in the study. The participants were tested on a range of linguistic, cognitive, and environmental measures that had been shown to correlate with decoding in previous research on individuals with typical development, ID, or reading difficulties. A LASSO regression analysis showed that decoding was predicted by phonological awareness and RAN. These predictors together explained 57.73 % of the variance in decoding. Phonological awareness and RAN are the two most common predictors of decoding ability in children with typical development, suggesting that the reading profile of adolescents with ID is delayed rather than different. This implies that interventions and reading instructions developed for children with typical development could potentially be beneficial for individuals with ID.

## Paper III

Paper III had two aims. First, the applicability of the Simple View of Reading framework was evaluated in a sample of 136 Swedish-speaking adolescents with non-specific ID. Second, the concurrent predictors of reading and listening comprehension were investigated and evaluated in relation to a delayed or different pattern of development. The participants were tested on a range of cognitive, linguistic, and environmental measures. Structural equation modelling showed that the Simple View of Reading was not applicable in this population and that the predictors of comprehension were vocabulary and phonological ELWM, with the addition of decoding as a predictor of reading comprehension. The impact of listening comprehension on reading comprehension decreased to almost zero when vocabulary and phonological ELWM was included in the model. The pattern of predictors found in this study indicates a delayed development of comprehension.

## Paper IV

Paper IV investigated the developmental trajectories of decoding and reading comprehension, and their respective predictors, in relation to mental age (MA) in a sample of 136 Swedish adolescents with non-specific ID. Decoding, phonological awareness, RAN, reading comprehension, vocabulary, and phonological ELWM were plotted against MA using a polynomial local regression (method = “loess”). A visual inspection showed that the growth of decoding, phonological awareness, RAN, and phonological ELWM decelerated, or almost came to a halt, after approximately an MA of 105 months. The sample was divided into two age groups, and a linear regression was performed. The results showed that after an MA of 105 months (8:9 years), only reading comprehension and vocabulary exhibited significant growth. Normative data from typical readers shows that decoding should continue to develop until a reading age of 13 years. Hence, the decoding ability of adolescents with ID plateaus at an early developmental stage, while reading comprehension continues to develop. This pattern of development could be explained by both cognitive and educational processes.

# General Discussion

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This thesis reports the concurrent predictors and the developmental trajectories of decoding and reading comprehension in Swedish adolescents with non-specific ID. The new insights gained from this research include that the pattern of predictors of reading ability for adolescents with ID is similar to those found in research about children with typical development. Decoding was predicted by phonological awareness and RAN, and reading comprehension was predicted by decoding, vocabulary, and phonological ELWM. Further, it appears that reading comprehension is best explained using a combination of the SVR and the LQH because none of these theoretical frameworks are sufficient in explaining reading comprehension alone. Lastly, the development of decoding appears to plateau at a fairly low MA while reading comprehension continues to develop. Possible explanations and implications of these results are discussed below.

## A Delayed Development of Reading

The results from this thesis are in line with the model of developmental delay (Zigler, 1967). This means that the development of reading abilities in individuals with ID follows the same pattern, rather than a qualitatively different pattern, as the development of these abilities in the typically developing population, but at a slower rate. The meta-analysis in Paper I showed that the majority of the variables associated with decoding and reading comprehension is well documented in research on typically developing children. In addition, the results from Papers II and III show that the set of concurrent predictors of decoding and reading comprehension in adolescents with ID is similar to the set of predictors found in research on younger typically developing children. These results imply that reading instruction and interventions developed for typically developing children, or children that struggle with reading, could potentially be beneficial for individuals with ID. A longitudinal randomized-controlled trial showed that a comprehensive reading instruction program developed for struggling readers was effective for students with mild to moderate ID (Allor, Mathes, Roberts, Cheatham, & Al

Otaiba, 2014). Their study also highlighted that the participants with mild ID required approximately three years of comprehensive reading instruction to move from reading 20 words per minute to reading 60 words per minute, while the participants with an IQ ranging from 70 to 80 required approximately one and a half years of instruction to reach the same goal. This result is also in line with the model of developmental delay since it is assumed that individuals with ID will develop at a slower rate compared to typically developing children, or children representing a part of the normal distribution closer to the mid-range. Further, the results from Paper IV showed that decoding ability plateaus in an early stage of mental development, while reading comprehension continues to develop. This could be regarded as a different pattern of development since the development of decoding in a typical reader is expected to continue until early adolescence. However, according to Zigler (1967), the model of developmental delay expects the development to differ from a typically developing individual with respect to the rate of development and the end point of development. Hence, the plateau in decoding ability is not necessarily to be regarded as a qualitatively different pattern.

## **A Combination of Frameworks for Understanding Reading Comprehension**

As noted in the introduction, the SVR is one of the most commonly used theoretical frameworks in reading research and it has widespread acceptance. However, studies evaluating the SVR in populations with ID are very rare. This was the starting point for Paper III since there was an obvious gap to be filled. In Paper III, it was concluded that the SVR is not applicable due to that vocabulary and phonological ELWM directly influenced reading comprehension. The meta-analysis in Paper I found that decoding, listening comprehension, and vocabulary were all strongly associated with reading comprehension. The results from Papers I and III points towards the possibility that a combination of the SVR and the LQH might be a successful way to explain the variance in reading comprehension in adolescents with ID. This has been suggested in research on typically developing children as well, for example, Verhoeven and van Leeuwe (2008) found in a longitudinal study of Dutch-speaking typically developing children that a combined structural model of the SVR and the LQH, with decoding, listening comprehension, and vocabulary as predictors showed a substantial impact on reading comprehension. Furthermore, Braze et al. (2007) found that vocabulary added unique variance in reading comprehension over and above the contribution of decoding and listening comprehension. The authors concluded that, in line with the LQH, word knowledge plays an important part in reading comprehension.

It should be noted that the contribution of vocabulary and phonological ELWM to reading comprehension are not nearly as compromising for the SVR as it would have been with variables not connected to language, such as visual memory abilities – but in relation to the operationalization used in this thesis, the SVR was not supported. However, there are different views on how to operationalize the language comprehension component in the SVR, and the implications of that are discussed below.



## Is the Simple View of Reading Simple?

There are different ways of operationalizing the language comprehension component of the SVR. The research reported in this thesis used listening comprehension, as exemplified in the original article (Gough & Tunmer, 1986). However, the authors state that the comprehension component consists of "...linguistic comprehension, that is, the process by which, given lexical (i.e., word) information, sentences and discourses are interpreted." (p.7). Hence, it is also possible to argue for the use of composite variables of vocabulary and grammatical comprehension, often referred to as oral language abilities, as appropriate indicators of language comprehension. These different views of what constitutes the language comprehension component inevitably lead to different conclusions when other linguistic variables such as vocabulary and working memory are directly related to reading comprehension, over and above decoding and comprehension. Because researchers differ in whether or not they make a distinction between listening comprehension and oral language, a study was conducted to determine whether or not listening comprehension and oral language (receptive and expressive vocabulary and syntax) were unique constructs (LARRC, 2017). The results showed that the model with two factors had a better fit, but the authors concluded that oral language and listening comprehension are part of the same construct due to a high correlation between the factors.

One assumption is often made when investigating the SVR, and it is that the two components (decoding and language comprehension) are independent (Hoover & Gough, 1990). In most studies, including Paper I and Paper III in this thesis, these constructs are found to correlate very weakly, and hence they could be regarded as two separate constructs. However, this assumption could be violated when the language comprehension component is operationalized as oral language because vocabulary has been found to predict decoding (Ouellette, 2006; Ouellette & Beers, 2010). In a study by Tunmer and Chapman (2012), the components of the SVR were latent constructs formed by several variables. The decoding construct consisted of two separate measures of word recognition and a measure of letter-sound knowledge, while the language comprehension construct consisted of listening comprehension and vocabulary. The results from the structural equation modelling showed that the language comprehension construct was directly related to reading comprehension, but also via the decoding construct. Another study found that the decoding and oral language constructs were strongly related in preschool, but this relation gradually faded with increasing age (Kendeou, van den Broek, White, & Lynch, 2009). The results from these studies suggest that using a composite variable that includes vocabulary might violate the assumption of independence in the analyses.

## The Plateau in Decoding Development

The results presented in this thesis indicate that decoding ability plateaus in an early stage of mental development in adolescents with ID. This conclusion is supported by several findings:

Paper II showed that phonological awareness was a stronger predictor of decoding ability compared to RAN. Interestingly, the opposite is often true for typical adolescent readers in a transparent orthography (Furnes & Samuelsson, 2011; Landerl & Wimmer, 2008). Phonological awareness usually predicts decoding ability in the early stages of reading development, but as the reader becomes more fluent in decoding there is a shift in the importance of the predictors, and RAN becomes the most important variable. However, the results in Paper II indicate that the adolescent readers in this sample have yet to undergo this developmental shift.

Paper III showed that decoding had the strongest association with reading comprehension, and the impact of the linguistic predictors was not as strong. This relative contribution of the components in the SVR is often shown in younger typical readers when decoding ability is still developing (Juel et al., 1986; Lervåg et al., 2017; Verhoeven & van Leeuwe, 2012). When the ability to decode is mastered, linguistic abilities become much more important for the development of reading comprehension. This indicates that the adolescents in this study have not developed a level of decoding ability that allows them to go through this shift.

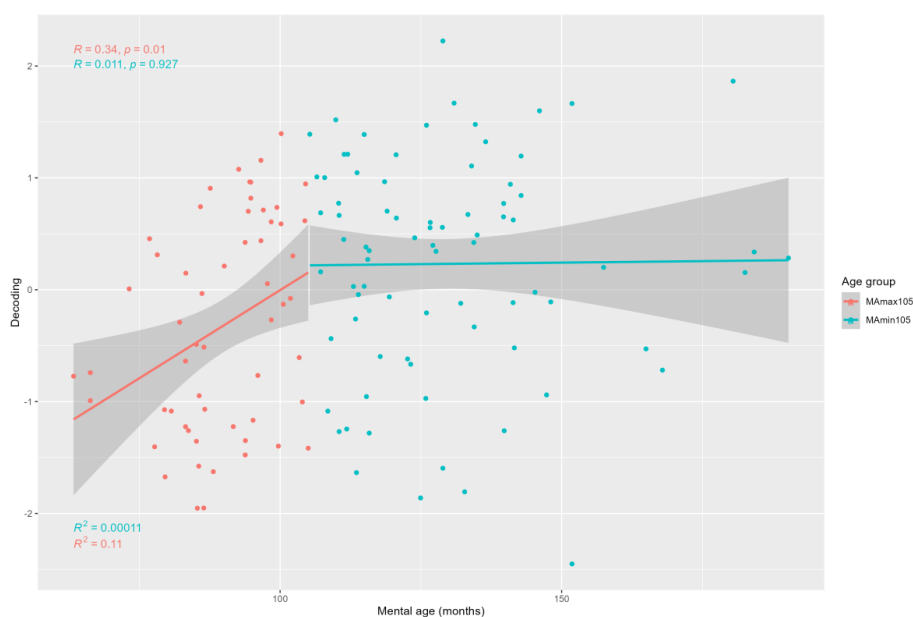


Figure 2. Plot from Paper IV showing the concurrent developmental trajectory of decoding

Paper IV showed that the concurrent developmental trajectory of decoding plateaus at a mental age of 8:9 years (see Figure 2) when decoding is expected to continue to develop until a reading age of at least 13 years. The reasons for this plateau are, however, not clear. The predictors of decoding, phonological awareness, and RAN, follow the same

pattern as decoding. However, it is impossible to tell whether the plateauing of the predictors is causing the plateau in decoding or vice versa. Since there is a reciprocal relationship between the predictor abilities and decoding, there is no way of telling the direction of the effect with the cross-sectional design used.

These results could be connected to the results from a large study by Ratz and Lenhard (2013), where the authors found that 29.8% of adolescents with ID still read at the alphabetic stage, meaning that words are decoded letter by letter and the decoding ability has not been automatized. Another study found that only 13.9% of individuals with ID in Grade 11 met the benchmark for word reading abilities for Grade 3, and the corresponding figure for passage fluency was 2.6% (Lemons et al., 2013). When combining evidence from earlier studies and the results found in this thesis, it appears that many adolescents with ID fail to reach the automatized stage of decoding.

It is reasonable to discuss two different sets of explanations for this plateau, emanating from different levels in the biopsychosocial model: explanations from cognitive processes and explanations from educational processes.

## Explanations from Cognitive Processes

Explanations from cognitive processes are connected to the cognitive deficits that constitute the ID diagnosis, and, therefore, stem from the biological and psychological level in the biopsychosocial model. Further, explanations on these levels assume that the results obtained in this thesis are caused by individual factors. Having an ID affects the development of academic abilities, even though a mild ID means that some degree of academic success can be reached (American Psychiatric Association, 2013). Therefore, it could be that deficits in cognitive functioning hinder further development in decoding abilities. It would be reasonable to assume that individuals with ID reach their full potential in an earlier stage of decoding development compared to typical readers. This is also in line with the developmental delay model, where individuals with familial ID are expected to develop at a slower rate and to a lower end point (Zigler, 1967).

This line of reasoning could also be connected to Cattell's Investment Theory (Cattell, 1963), which suggests that fluid intelligence (*Gf*; e.g. controlled mental operations to solve novel problems that cannot be performed automatically) is essential for the development of academic skills. This theory states that the greater the investment of *Gf*, the greater the acquisition of crystallized intelligence (*Gc*; acquired knowledge about for example language and the application of this knowledge). Studies are pointing towards the possibility that *Gf* is involved in the early stages of reading acquisition when decoding could be viewed as a form of problem-solving – a code that needs to be cracked (Cormier, McGrew, Bulut, & Funamoto, 2017; Ferrer, Shaywitz, Holahan, Marchione, & Shaywitz, 2010). One study used Cattell's investment theory together with Frith's stage model theory to investigate the relationship between *Gf*, *Gc*, phonological decoding, and word recognition in preschool children and adults. The results showed that *Gf* was strongly related to word recognition in preschool children, but not in adults. These group differences suggest that *Gf* plays a larger role during early reading development, and as the novelty of reading decreases so does the effect of *Gf* (Guerin, Sylvia, Yolton, & Mano, 2020). Applied to the results from this thesis, it might be the case that the lower levels of

intellectual functioning that is part of the ID diagnosis hinders early reading development. If we assume that a greater investment of *Gf* increases the acquisition of *Gc*, then the presence of intellectual deficits during reading development should create long term effects on the acquired levels of reading.

Another explanation could be related to the double-deficit hypothesis. This hypothesis was presented as an alternative conceptualisation of developmental dyslexia (Wolf & Bowers, 1999). The core deficit of reading disabilities was long considered to be impaired phonological processing skills, but this hypothesis claims that impaired naming speed (also referred to as rapid automatized naming; RAN) constitutes a second core deficit and that naming speed provides information of an individual's cognitive processing speed. Wolf and Bowers (1999) identified three different subtypes of poor readers: those with a phonological deficit, those with a naming speed deficit, and those with a double deficit. Readers with a phonological deficit would exhibit impaired accuracy, while readers with a naming speed deficit would exhibit impaired fluency. The authors further suggested that the double-deficit subtype would show pervasive and severe impairments in comparison to the other two subtypes because deficits in phonological awareness and RAN are assumed to have independent negative effects on reading (Wolf & Bowers, 1999). The results in this thesis show that phonological awareness and RAN are the most important concurrent predictors of decoding, and the double-deficit hypothesis could provide an explanation for the plateau in decoding development since it could be possible that an inherent deficit in cognitive processing of individuals with ID is responsible for the plateau. However, it should be noted that the evidence for the double-deficit hypothesis varies, especially when it has been tested in transparent orthographies. Some studies have found evidence in support of the hypothesis (Furnes, Elwér, Samuelsson, Olson, & Byrne, 2019; Torppa, Georgiou, Salmi, Eklund, & Lyytinen, 2012), and some question the applicability in a transparent orthography (Wimmer, Mayringer, & Landerl, 2000).

## Explanations from Educational Processes

Explanations from educational processes are connected to the school environment, and, therefore, emanate from the social level in the biopsychosocial model. An explanation on this level assumes that the results obtained in this thesis are a consequence of barriers set up by society and in this case the school environment.

In the Swedish school system, individuals with ID follow a different curriculum compared to general compulsory school and upper secondary school (Skolverket, 2013, 2022b), and students with ID could either be enrolled in an inclusive setting, where they are part of a mainstream classroom or be enrolled in a compulsory school/upper secondary school for pupils with learning disabilities. The curriculum for students with ID stresses reading instruction with a focus on phonics for Grades 1-6. However, this focus is shifted for Grades 7-9 and reading instruction instead targets the development of reading strategies, such as reading between the lines (Skolverket, 2022b). In the curriculum for upper secondary school, reading instruction is not targeted at all (Skolverket, 2013). This could explain the results in Paper IV, namely that the development of decoding stalls while reading comprehension continues to develop. Since it is known that individuals with ID develop at a slower rate, it would be reasonable to assume that these students would benefit from reading instruction that continues to focus on teaching phonics for a

longer period of time. There are multiple studies indicating that individuals with ID benefit from comprehensive reading instruction delivered over a long period of time (Allor et al., 2014; Sermier Dessemontet, de Chambrier, Martinet, Meuli, & Linder, 2021; Sermier Dessemontet, Martinet, de Chambrier, Martini-Willemin, & Audrin, 2019). It could also be argued that reading instruction in higher grades should focus on reading fluency training since the plateauing of decoding ability indicates that the ID group has difficulties with automatizing their decoding abilities. Another aspect of this explanation is connected to the teachers delivering reading instructions. A recent study from Switzerland revealed a substantial research-to-practice gap in the way reading instruction was provided in special education classrooms. Even though phonic instructions were applied in the majority of classrooms, only half of the teachers delivered the instructions with a systematic approach (Sermier Dessemontet, Linder, Martinet, & Martini-Willemin, 2022). In Sweden, teaching phonics is stressed in the national curriculum, but at the same time, barely 20% of teachers working in compulsory schools for pupils with learning disabilities have the correct credentials to do so (Skolverket, 2022a). This could potentially have the effect that reading instruction is delivered in an unsatisfactory manner due to a lack of proper education.

Further, it is possible that part of the explanation could lie in the type of school placement. The adolescent participants recruited for this thesis were all enrolled in compulsory schools for pupils with learning disabilities and upper secondary schools for pupils with learning disabilities. Earlier research has found that being fully included in a general education classroom predicts more progress in reading skills compared to being enrolled in a compulsory school for pupils with learning disabilities (Sermier Dessemontet, Bless, & Morin, 2012; Sermier Dessemontet & de Chambrier, 2015; Turner, Alborz, & Gayle, 2008). This was also found to be true for language and memory abilities (Laws, Byrne, & Buckley, 2000). These studies originate from the UK (Laws et al., 2000; Turner et al., 2008), where all schools are not obliged to follow the national curriculum, and Switzerland (Sermier Dessemontet et al., 2012; Sermier Dessemontet & de Chambrier, 2015), where the compulsory school for pupils with learning disabilities lacks an imposed curriculum. This means that it could be difficult to translate these findings to a Swedish setting, where the students follow the same curriculum regardless of the type of school placement. However, the difference between compulsory school/upper secondary school for pupils with learning disabilities and the inclusive setting might also be attributed to other environmental variables, such as the impact of being surrounded by students that do or do not exhibit the same cognitive difficulties. It might also be a bias involved, that the students applying to be enrolled in an inclusive setting may be diagnosed with a milder form of ID.

A third educational option to explore here is the Matthew Effect (Stanovich, 1986). This effect describes a gap between good and poor readers that continues to grow with increasing age. It states that the poor reader tends to avoid reading activities which leads to a lack of training and exposure to print. This will in turn lead to delays in the development of automaticity and speed in decoding (Stanovich, 1986). Further, this slow development in decoding will affect the development of both reading comprehension and vocabulary, leading to a downward spiral where the individual continues to avoid literacy activities. The results presented in this thesis indicate a delayed development of reading,

and that the participants with ID have not yet automatized their decoding ability. This could potentially lead to avoidance of reading activities and the subsequent effects described above. In addition, for the ID group, it could be the case that the lack of exposure to print is not only due to individuals avoiding reading activities due to feelings of failure, but also that the expectations from parents and teachers placed on this group are lower so that reading activities might not be offered and encouraged to the same extent as in typically developing children.

## **Methodological Challenges**

Being a researcher in disability research inevitably leads to several methodological problems and considerations. The more relevant ones are discussed below. In addition, benefits of using the Registered Reports format are considered.

### **Recruitment**

There is a fundamental problem in most disability research, and that is the difficulty of recruiting large samples that are representative of the targeted population. It is not possible to recruit via posters on campus for example. Data collection in a project focussing on disabilities requires a lot of work with reaching out to schools, clinics, patient organisations, etc to find the right population. On top of that, the populations are often extremely heterogeneous, and using narrow inclusion criteria might leave you with almost no participants at all. Another factor is the willingness to participate, which could be affected by the fact that individuals with some sort of disability often have several contacts with health care, rehabilitation services, and governmental agencies. If you are asked to participate in a study that might not have a direct benefit for you, it is understandable if that is given a low priority. This problem has resulted in a large number of underpowered studies with interesting results that usually cannot be generalized to a larger population. The field of disability research is in need of a funding model that is adapted to these specific conditions.

### **Issues of Assessing the Abilities of Individuals with ID**

Assessing abilities in individuals with ID could be challenging. Using standardized tests in research is desirable, but this might compromise the validity of the test since the targeted construct could change slightly. One example of this problem is from a study by van Wingerden, Segers, van Balkom, and Verhoeven (2018), where foundational literacy skills (a composite variable of phonological awareness and letter-sound knowledge) were found to directly influence reading comprehension, over and above decoding and listening comprehension. This relation is rarely found in research on typically developing children when decoding is part of the model. The authors argued that this could be because the tests of phonological awareness put a heavy cognitive demand on the participants with ID, and thus reflect more higher-order processes such as working memory and meta-cognition. Further, using standardized tests developed for the correct chronological age of the ID group could potentially generate floor effects. To deal with these pitfalls, the tests used in this thesis were developed for a younger typically

developing population. This prevented floor effects and also decreased the risk of the participants experiencing feelings of failure, which is an important ethical aspect.

## Heterogeneous Population

Another methodological challenge is how researchers treat the population with ID. Some research focus only on individuals with DS or WS, some studies (including this thesis) focus on ID without known aetiology, and some studies choose to only have ID as the inclusion criterion meaning that the participants have mixed aetiologies. It was pointed out decades ago that it is important to acknowledge that the cut-off point of  $IQ < 70$  is arbitrary, and not something that creates a group that is qualitatively different from individuals with an IQ above this threshold. Neither does it create a homogenous “subnormal” group (Zigler, 1967). This generates difficulties for researchers in disability research when deciding on inclusion criteria. It would be reasonable to assume that the explanation for why many studies of reading abilities in ID focus on specific syndromes is a false feeling of control over the biological level. However, even if the aetiology is the same, the population with that specific syndrome is still heterogeneous. The population targeted in this thesis is very heterogeneous, and this needs to be taken into consideration when interpreting the results. However, it could be argued, for this kind of educational research, that it makes sense to focus on a population that constitutes the majority of students enrolled in compulsory school for pupils with learning disabilities. The results obtained in this thesis should be regarded as generalizable to adolescents in this particular school setting in Sweden that have acquired some reading ability.

## Using Registered Reports as a Graduate Student

Having the opportunity to go through the Registered Report process as a graduate student has been equally challenging and exciting. Instead of immediately starting with preparations for my data collection, I spent the first 6 months planning and writing two Registered Reports. This was of course challenging, but also beneficial because I immediately had to review the literature. Using a pre-planned method and analysis protocol, which you are not allowed to deviate from, had both benefits and drawbacks. Because the analysis pipeline was already decided, we could start conducting the analyses directly after finishing the data collection. However, it became apparent that it is a difficult task to be transparent and detailed enough when describing an analysis pipeline, even when it is up to your future self to interpret the descriptions. In my case, we had stated two very clear hypotheses in each manuscript. This facilitated the interpretations of the results. The outcome of most analyses can be interpreted in numerous ways, but because our hypotheses were set and clearly stated we did not have the flexibility to cover all possible interpretations. This might sound like a drawback, but I want to frame this as one of the benefits of using this format. It is always possible to twist and turn the data, be it out of curiosity or as a means of finding novel results, but with this format, it all came down to one question: do we have support for any of our stated hypotheses? I would highly recommend graduate students to use this format. In many disciplines in Sweden, you need to have a certain number of published articles in order to defend your thesis. Many graduate students spend their last year waiting for journals to make decisions about their submitted articles, with the risk that they might be rejected based on the results or

based on some part of the method that the reviewers do not agree with. When using the Registered Report format the method is already peer-reviewed, meaning that any disagreements about tests or analyses have already been solved before data collection. Even if the Registered Report format does not guarantee publication, it makes the whole process more transparent and the graduate student can experience an increased sense of control over the publication process

## A Disability Research Perspective

The biopsychosocial model provides a broad perspective on disabilities (Engel, 1977), and it has enabled the field of disability research to leave a narrow focus on biology and move towards a focus on both individual and social factors to explain disability. Historically, individuals with ID have been labelled non-educable based on the fact that they have a cognitive deficit. The biological impairment led to an assumption about abilities, which in turn led to individuals with ID being institutionalised instead of educated. This view of individuals with ID is evident in the choice of terminology in the literature. Articles from the 1920s and 1930s referred to individuals with ID as “feeble-minded”, and for many decades the ID group was divided into “educable mentally retarded” and “non-educable mentally retarded”. Fortunately, our understanding of the abilities of individuals with ID has increased, and today researchers acknowledge that the biological impairment does not provide enough information about the individual potential.

In this thesis, the biopsychosocial model partly guided the study design with regard to the choice of predictor variables. The majority of variables provided information about the psychological level, such as measures of language and memory. One variable provided information about the social level, namely the home literacy variable which contained information about reading habits and the educational level of the parents. The biological cause of the ID was difficult to address in this thesis since the participants had non-specific ID, but IQ level could be regarded as an indication of deficits on the biological level. Furthermore, the biopsychosocial model enabled a variety of potential explanations of the plateau in decoding development found in this thesis. From a biological and psychological point of view, the plateau in decoding development can be attributed to individual factors such as deficits in cognitive functioning or cognitive processing. From a social point of view, the plateau in decoding could be a consequence of environmental factors such as lack of phonics instruction in higher grades, type of school placement, or the Matthew effect. The likely scenario is that the plateau in decoding development can be attributed to a combination of the aforementioned factors.

In addition to the biopsychosocial model, research on ID today is guided by the two group approach to mental retardation by Zigler (1967), meaning that focus is often placed on establishing whether a specific ability follows a delayed or different pattern of development compared to typically developing children. In this thesis, this approach was implemented by formulating hypotheses based on commonly used theoretical frameworks and earlier research on typically developing children. The results showed that reading comprehension and decoding ability in adolescents with ID follow a delayed pattern of development, which, according to Zigler, means that the development of



reading abilities in adolescents with ID only differs from typical development with respect to the rate of development and the endpoint of development (Zigler, 1967).

## Educational and Societal Implications

First, it needs to be acknowledged that there is a need for more research in order for the educational implications to be translated into action. There is a dire need for large-scale studies to further investigate reading development and possible interventions for individuals with ID. With that said, the results from this large research project show a delayed pattern of development for adolescents with ID which in turn indicates that reading instruction and intervention programs developed for typically developing children and children with reading difficulties could potentially be beneficial for individuals with ID.

In July 2024, a guarantee of interventions for students that lag behind with reading, writing, or math will be implemented in compulsory schools for pupils with learning disabilities (Utbildningsdepartementet, 2021). This is great news, but in order to increase the chance of fulfilling this guarantee the current curriculum needs to be evaluated and this should involve some important changes. Since we do know that individuals with ID benefit from comprehensive reading instruction for an extensive period of time (Allor et al., 2014; Sermier Dessemontet et al., 2021, 2019), it would be reasonable to focus on systematic phonics instruction in higher grades. Further, more pressure needs to be put on governmental agencies to act on the low percentage of teachers with the correct credentials in compulsory schools for pupils with learning disabilities. These implications are important to ensure that every student with ID receives the necessary support to develop reading abilities in accordance with their potential.

In Sweden today, society fails with including individuals with ID after they finish secondary school for pupils with learning disabilities. A doctoral thesis showed that 24 % of students with ID that finished secondary school between the years 2000 and 2011 were not engaged in work, education, or daily activities (Arvidsson, 2016). An interview study focussing on a sample of individuals from this group found that these individuals experienced difficulties with navigating and coordinating different systems of formal support (Luthra, Westberg, Högdin, & Tideman, 2020). There are, of course, multiple factors contributing to this outcome, but first and foremost the Swedish school system, and in this case, compulsory school/upper secondary school for pupils with learning disabilities needs to equip individuals with ID with tools that facilitate participation in society. Implementing systematic reading instruction in higher grades, and ensuring that students with ID are given the opportunity to develop in accordance with their potential, might be a successful way of achieving this.

## Future Directions

In order for the results of this thesis to increase their scientific standing, they need to be replicated. Future directions for this field are listed below.

The field of disability research, in general, and research focussing on ID, in particular, is in considerable need of large-scale studies with sufficient power, both cross-sectional studies and intervention studies. The number of cross-sectional studies with large sample sizes is increasing, but intervention studies still suffer from small sample sizes. In addition, more randomised controlled trials are needed to establish the effect of reading interventions focussing on both decoding and reading comprehension in individuals with ID.

In Sweden, there is a lack of studies comparing academic outcomes between students enrolled in compulsory school for pupils with learning disabilities and students enrolled in an inclusive setting. Studies from the Netherlands and the UK show that placement in an inclusive setting predicts more progress in reading skills (Sermier Dessemontet et al., 2012; Sermier Dessemontet & de Chambrier, 2015; Turner et al., 2008), but these results are difficult to apply to the Swedish setting due to differences regarding the curriculum. In addition, it would be of interest to perform observational studies in classrooms in compulsory schools for pupils with learning disabilities to gain a better understanding of how reading instruction is delivered to students with ID within the Swedish setting.

## Concluding Remarks

This thesis shows that the development of reading comprehension and decoding in adolescents with ID follows a delayed pattern, rather than a different one and that the development of decoding plateaus at an early stage. This plateau can be explained by cognitive factors, environmental factors, or both. Further, this thesis suggests that a combination of the Simple View of Reading and the Lexical Quality Hypothesis might be a successful way of explaining the variance in reading comprehension. Based on these results, this thesis argues that interventions developed for typical or struggling readers might be beneficial for students with ID if delivered for a longer period of time. With that in mind, the current curriculum in compulsory schools for pupils with learning disabilities needs to be evaluated since there is no emphasis on phonics instruction in higher grades.

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