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Specific language impairment
in pre-adolescence, adolescence, and adulthood

with special emphasis on health-related quality of life

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ACADEMIC DISSERTATION

To be publicly discussed, with the permission of the Faculty of Medicine of the University of Helsinki, in the Niilo Hallman Auditorium of the Hospital for Children and Adolescents, Stenbäckinkatu 11, Helsinki University Central Hospital, on December 11th 2009, at 12 noon.

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To my family

Abstract

This clinical study focused on effects of childhood specific language impairment (SLI) on daily functioning in late life. SLI manifests as poor language production or comprehension or both in a child with age-level non-verbal intelligence and no other known cause for deficient language development. Problems in language production are more easily detected, whereas comprehension deficiencies may go unrecognized, especially in cases where speech appears nearly normal. Earlier studies have indicated that receptive language (comprehension) problems are associated with more negative long-term effects than expressive language problems. Most research has, however, focused on measuring language or other performance at follow-up, not self-perception of daily functioning and participation, which are considered important in the International Classification of Functioning, Disability, and Health (ICF), the international standard for measuring health and disability. Therefore, the aim here was to evaluate, using self-administered questionnaires, the effect of receptive SLI on functioning and abilities at different time-points of life, and to identify, if possible, childhood factors affecting outcome.

To investigate the self-perceived aspects of everyday functioning in individuals with childhood receptive language disorder compared with age- and gender-matched control populations, the 15D, 16D, and 17D health-related quality of life (HRQoL) questionnaires were applied. These generic questionnaires include 15, 16, and 17 dimensions, respectively, and give both a single index score and a profile with values on each dimension. Information on different life domains (rehabilitation, education, employment etc.) from each age-group was collected with separate questionnaires. The study groups comprised adults, adolescents (12-15 years), and pre-adolescents (8-11 years) who had received a diagnosis of receptive SLI and had been examined, usually before school age, at the Department of Phoniatics of Helsinki University Central Hospital, where children with language deficits caused by various etiologies are examined and treated by a multidisciplinary team. The psychologists' examination records received special attention.

The adult respondents included 33 subjects with a mean age of 34 years. They showed a discrepancy between verbal and nonverbal performance in the childhood examination records. The HRQoL was measured by applying the 15D questionnaire. The subjects perceived their HRQoL to be nearly as good as that of controls, but on the dimensions of speech, usual activities, mental functioning, and distress they were significantly worse off. They significantly more often lived with their parents (19%) or were pensioned (26%) than the adult Finnish population on average; being pensioned was related to low levels of usual activities and mental functioning. Only 16% had not received any extra educational support at school. Adults with self-perceived problems in finding words and in remembering instructions, manifestations of persistent language impairment, had much lower total HRQoL scores than other participants and the controls.

Of the adolescents and pre-adolescents, 48 and 51, respectively, responded. All participants had at some point received a diagnosis of receptive SLI. The majority in both groups had received special education or extra educational support at school. They all had attended speech therapy at some point; at the time of the study only one adolescent, but every third pre-adolescent still received speech therapy. The 16D score of the adolescent group did not differ from that of controls, but the 16D profiles differed on some dimensions; subjects were significantly worse off than controls on the dimension of

mental functioning (thinking clearly and logically), but better off on the dimension of vitality. The 17D score was no different in pre-adolescents with SLI than in controls, although the 17D profiles differed. The study group was significantly worse off on the dimension of speech, whereas the control group reported significantly more problems in sleeping.

Of the childhood performance measures investigated, low verbal intelligence quotient (VIQ), which is often considered to reflect receptive language impairment, was significantly associated with some of the self-perceived problems, such as problems in usual activities and mental functioning, in adults.

The 15D, 16D, and 17D questionnaires served well in measuring self-perceived HRQoL. Such standardized measures with population values are especially important in confirming with the ICF guidelines. The results obtained agree with previous studies concerning both the heterogeneity of the study groups and the wide range of outcomes. In the future these questionnaires could perhaps be used on a more individual level in follow-up of children in clinics, and even in special schools and classes, to detect those children at greatest risk of negative long-term effects and perhaps diminished well-being regarding daily functioning and participation.

Tiivistelmä

Tämän tutkimuksen lähtökohtana oli kiinnostus kielenkehityksen erityisvaikeuden eli kielihäiriön (specific language impairment, SLI) vaikutuksista yksilön myöhempään elämään ja jokapäiväiseen toimintaan. Kielihäiriöisellä lapsella on ongelmia puheen tuotossa ja/tai ymmärtämisessä, vaikka hän on ei-kielellisesti normaaliälyinen eikä hänellä ole todettavissa muuta tunnettua syytä kielellisiin vaikeuksiin. Puheen tuoton ongelmat ovat helpommin havaittavissa kuin puheen ymmärtämisen ongelmat, jotka voivat jäädä huomiotta etenkin, jos puhe on päällisin puolin normaalia. Aiemmat tutkimukset ovat osoittaneet, että puheen ymmärtämisen ongelmat aiheuttavat kuitenkin enemmän kielteisiä pitkäaikaisvaikutuksia. Suurin osa seurantatutkimuksista on keskittynyt suoriutumisen mittaamiseen kielellisillä ja muilla kykytesteillä, ei niinkään yksilön omiin arvioihin mahdollisuuksistaan osallistua päivittäisiin toimintoihin, vaikka kansainvälinen toimintakykyluokitus (International classification of functioning, disability and health, ICF) tätä suosittelee. Tämän tutkimuksen tavoitteeksi tuli siksi kyselytutkimuksella selvittää erityisesti puheen ymmärtämisen vaikeuteen painottuvan kielihäiriön vaikutusta päivittäiseen toimintakykyyn eri ikävaiheissa ja tunnistaa mahdollisuuksien mukaan niitä lapsuusiän suoriutumiseen liittyviä tekijöitä, joilla on yhteyttä myöhempään pärjäämiseen.

Päivittäistä toimintakykyä kuvaamaan käytettiin terveyteen liittyvän elämänlaadun mittareita (HRQoL, health-related quality of life) 15D, 16D ja 17D, joihin on saatavissa myös tavallisen väestön vertailuarvot. Näissä geneerisissä (yleisissä) mittareissa on 15, 16 tai 17 ulottuvuutta, ja ne tuottavat tuloksen sekä yhtenä indeksilukuna että eri ulottuvuuksia kuvaavana profiilina. Erillisillä kyselylomakkeilla selvitettiin muita tietoja, kuten koulumuotoa, saatua kuntoutusta tai työllisyystilannetta. Tutkimuksessa oli aikuisia, nuoria (12-15-vuotiaita) ja varhaisnuoria (8-11-vuotiaita), joilla oli diagnosoitu, pääosin ennen kouluikää, puheen ymmärtämiseen painottuva kielihäiriö ja jotka olivat olleet tutkimuksissa Helsingin yliopistollisen keskussairaalan audioniatrisella osastolla. Osastolla moniammatillinen työryhmä tutkii ja hoitaa lapsia, joilla on eri syistä häiriöitä kielellisessä kehityksessä.

Aikuisia kyselyyn vastanneita oli 33 ja heidän keski-ikänsä oli 34 vuotta. Lapsena tehdyissä psykologin tutkimuksissa heidän kielellinen suoriutumisensa jäi ikäodotuksista, mutta ei-kielellinen suoriutuminen oli ikätasoista. Terveyteen liittyvän elämänlaadun mittarina käytettiin 15D-mittaria. Tutkimusryhmän aikuisten terveyteen liittyvä elämänlaatu oli indeksilukuna keskimäärin lähes verrokkien tasolla, mutta yksittäisistä ulottuvuuksista puheen tuottamisen, tavanomaisten toimintojen, ajattelun selkeyden ja ahdistuneisuuden osalta tutkimusryhmän tulokset olivat merkittävästi verrokkeja heikommat. Tutkimusryhmäläisistä 19 % asui vielä vanhempiansa kanssa ja 26 % oli eläkkeellä: nämä luvut ovat merkittävästi suuremmat kuin väestössä keskimäärin. Vain 16 % ei ollut saanut minkäänlaista lisätukea oppimiseen kouluaikanaan. Ne tutkimusryhmäläiset, jotka raportoivat aikuisina sellaisia kielihäiriön ilmentymiä kuten ongelmia sanojen löytämisessä ja ohjeiden ymmärtämisessä, saivat selvästi alemmat 15D indeksiluvut kuin muut tutkimusryhmäläiset tai verrokkit.

Nuoria kyselyihin vastanneita oli 48 ja varhaisnuoria 51. Heillä kaikilla oli jossain vaiheessa ollut diagnoosina puheen ymmärtämiseen painottuva kielihäiriö. Enemmistö molemmista tutkimusryhmistä oli erityisluokilla tai sai muuta tukea koulunkäynnilleen. Kaikki olivat saaneet puheterapiaa ennen kouluikää. Tutkimushetkellä nuorista enää yksi, mutta varhaisnuorista vielä joka kolmas sai puheterapiakuntoutusta. Nuorten

tutkimusryhmäläisten elämänlaatumittari 16D:n indeksiluku ei eronnut verrokeiden luvusta, mutta tutkimusryhmäläiset kokivat ulottuvuuden ”ajattelun selkeys” merkittävästi heikommaksi kuin verrokkit, kun taas ulottuvuudessa ”elinvoimaisuus” tilanne oli päinvastainen. Varhaisnuoret eivät eronneet verrokeista terveyteen liittyvän elämänlaadun suhteen 17D-mittarin indeksiluvun perusteella. Yksittäisistä 17D-ulottuvuuksista merkittävät erot havaittiin puheen tuotossa, jossa tutkimusryhmäläiset kokivat merkittävästi enemmän ongelmia, ja nukkumisessa, jossa taas verrokeilla oli merkittävästi enemmän ongelmia.

Niistä lapsuuden tutkimustuloksista, joita tähän tutkimukseen kerättiin, matala kielellinen älykkyydosamäärä, jonka voidaan ajatella heijastavan osaltaan kielellisiä ymmärtämisen vaikeuksia, oli etenkin aikuisilla yhteydessä myöhempään toimintakykyyn, erityisesti tavanomaisiin toimintoihin ja ajattelun selkeyteen.

Terveyteen liittyvän elämänlaadun kyselyt 15D, 16D ja 17D olivat toimivia mittareita jokapäiväisen toimintakyvyn arvioinnissa ja pyrittäessä vastaamaan ICF:n ohjeistukseen toimintakykyarviointiin liittyen. Saadut tulokset vastaavat aiempien tutkimusten tuloksia sekä liittyen tutkimusryhmien heterogeenisyyteen että pitkäaikaisvaikutusten moninaisuuteen. Tulevaisuudessa näitä kyselyitä voisi käyttää kielihäiriöisten lasten seurannassa yksilöllisemmällä tasolla sekä klinikoissa että erityisluokilla ja pyrkiä siten löytämään ne lapset, joilla on suurin riski kielteisiin pitkäaikaisvaikutuksiin liittyen päivittäiseen toimintakykyyn ja osallistumiseen.

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List of original publications

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

- I Arkkila E, Räsänen P, Roine RP, Sintonen H, Vilkmán E. Health-related quality of life of adults with childhood diagnosis of specific language impairment. *Folia Phoniátrica et Logopédica* 60: 233-240, 2008.

- II Arkkila E, Räsänen P, Roine RP, Vilkmán E. Specific language impairment in childhood is associated with impaired mental and social well-being in adulthood. *Logopedics Phoniátrics Vocology* 2: 1-11, 2008.

- III Arkkila E, Räsänen P, Roine RP, Sintonen H, Saar V, Vilkmán E. Health-related quality of life of adolescents with diagnosis of specific language impairment. *International Journal of Pediatric Otorhinolaryngology* 73: 1288-1296, 2009.

- IV Arkkila E, Räsänen P, Roine RP, Sintonen H, Saar V, Vilkmán E. Health-related quality of life of children with specific language impairment aged 8 to 11. Accepted.

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Abbreviations

ADHD	attention-deficit hyperactivity disorder
ATP	auditory temporal processing
DLD	developmental language disorder
EEG	electroencephalogram
ERP	event-related potential
HRQoL	health-related quality of life
ICD-10	International Classification of Diseases, 10 th edition
ICF	International Classification of Function, Disability and Health
IQ	intelligence quotient
LD	language disorder
LI	language impairment
MMN	mismatch negativity
PIQ	performance intelligence quotient
PLI	primary language impairment
RAP	rapid auditory cues
SD	standard deviation
SES	socioeconomic status
SI	sensory integration
SLI	specific language impairment
SPECT	single-photon emission computed tomography
STM	short-term memory
SWB	subjective well-being
VIQ	verbal intelligence quotient
WHO	World Health Organization

1 Introduction

A child's language development is sometimes slower than expected, the first words and sentences being delayed, awakening the concerns of parents or other caretakers regarding causes and long-term effects. As the prevalence of late speech can be up to 10% (Dale et al., 2003), in Finland, where the annual birth rate is close to 60 000, concerns about a child's language development affect thousands of families. In cases of mere developmental delay, both the short- and long-term prognosis is reasonably good. But, what appears to be a developmental delay at first glance can actually be a specific deficit in language development or a wider range of developmental deficits. This being the case, short-term progress is often limited and long-term effects probable.

Delayed speech can be an early sign of specific language impairment (SLI), but while a speech delay was frequent in children with later SLI-diagnosis, not all of them were late-talkers (Asikainen, 2005). Of 6-year-olds with persistent speech delay, 11-15% had SLI (Shriberg et al., 1999). The distinction between delayed development and a developmental deficit is not always clear-cut, requiring expertise in child language development and knowledge of risk factors predisposing to specific developmental problems, comorbidity, and associated problems. Therefore, multidisciplinary team-work is necessary in SLI diagnostics and follow-up to ensure early identification, proper diagnosis, and sufficient supportive actions (Rutter, 2008). Following the guidelines of the International Classification of Diseases and Related Symptoms, 10th edition (ICD-10) of the World Health Organization (WHO) (www.who.int/classifications/apps/icd/icd10online/), which in Finland is the basis for clinical diagnostics, for a diagnosis of SLI any known disease, such as a hearing impairment or a genetic syndrome, or environmental factor affecting language development must first be excluded and substantial impairment in age-level language performance, despite normal nonverbal intelligence, observed. When it comes to determining sufficiently poor performance, the diagnostic criteria are far from unambiguous and the criteria applied vary in research and in clinical work (Asikainen, 2005). In Finland, diagnostic examinations mainly take place in specialist healthcare, which is also responsible for planning medical rehabilitation (e.g. speech therapy or occupational therapy) and follow-up.

SLI is a common developmental disorder, affecting around 7% of preschool children (Tomblin et al., 1997), comprising the largest disability group in preschool children. The prevalence of attention-deficit hyperactivity disorder (ADHD) is estimated to be about the same (3-6%) (Goldman et al., 1998), but the prevalence of, for instance, autistic spectrum disorders is much lower, ranging from less than 0.1% to around 1% (Newschaffer et al., 2007). SLI is a disorder of neurobiological origin (Webster and Shevell, 2004) and strong genetic predisposition (Bishop, 2006). Based on several follow-up studies, it is clear that in the majority of cases SLI persists through adolescence and into adulthood, and often cause problems in academic and occupational attainment, in emotional and mental health, and in social functioning (Clegg, 2005). In addition, there is substantial comorbidity with other developmental disorders (Hill, 2001). However studies that investigate self-perception of the condition are scarce (Records et al., 1992; Conti-Ramsden and Botting, 2008; Tomblin, 2008).

In developmental medicine, the difference between normal and abnormal performance is not always clear-cut; two children with almost identical impairment profiles may have diverging chances to participate because of differences in intellectual strength,

environmental support, and personal temperament. Thus, determining the level of activity and participation should play an important role in clinical assessments. The International Classification of Functioning, Disability, and Health (ICF) encourages clinicians to take into account the social aspects of a disability along with the medical aspects (www.who.int/classifications/icd). Measures with “normal values” from population controls and with self-perception, such as health-related quality of life (HRQoL) instruments, could serve as tools for measuring the effects of SLI on everyday functioning.

HRQoL measurements have been increasing in the field of medicine because of growing interests in quality of care, clinical effectiveness, and cost-effectiveness (Guyatt et al., 1993). The originally Finnish HRQoL instrument, the 15D, was developed to correspond to the definition of health comprising physical, mental, and social well-being (Sintonen, 2001). Today the 15D is a widely applied generic measurement tool available in 24 languages. Based on the 15D, versions have been developed for 12- to 15-year-old adolescents (16D) and for 8- to 11-year-old pre-adolescents (17D) (www.15d-instrument.net/15d).

The audiophoniatric ward in Helsinki University Central Hospital has since 1961 attended to numerous children with language impairments throughout Finland, although, in the last two to three decades, the children have mainly come from the greater Helsinki area. The ward has a multidisciplinary team to ensure comprehensive examinations. Such a broad perspective on treating children with language impairments is quite uncommon, and the archives comprise massive data. The basis for this study arose from clinical interests regarding the long-term effects of SLI on the lives of children treated in the ward. Medical research concerning SLI has been rare in Finland; recently, a thesis on diagnosing SLI was published (Asikainen, 2005). In a continuation of that valuable effort, this study attempts to gain knowledge and awareness regarding SLI and its long-term effects on life.

2 Review of the literature

2.1 Specific language impairment

The emphasis of the review is mainly on receptive SLI.

2.1.1 Definition and diagnosis

Specific language impairment refers to disproportionate difficulties in language development in relation to other aspects of development. The International Classification of Disease (ICD-10) defines specific developmental disorders of speech and language as follows: “Disorders in which normal patterns of language acquisition are disturbed from the early stages of development. The conditions are not directly attributable to neurological or speech mechanism abnormalities, sensory impairments, mental retardation, or environmental factors. Specific developmental disorders of speech and language are often followed by associated problems, such as difficulties in reading and spelling, abnormalities in interpersonal relationships, and emotional and behavioural disorders.” A receptive language disorder (ICD-10; F80.2) is “a specific developmental disorder in which the child's understanding of language is below the appropriate level for its mental age. In virtually all cases expressive language will also be markedly affected and abnormalities in word-sound production are common”. (www.who.int/classifications/apps/icd/icd10online)

By definition, the basis of the diagnosis of SLI is a discrepancy between the verbal and the nonverbal performance, confirmed with behavioural tests, use of language in a natural context, and exclusion of other known causes. However, the criteria used regarding cut-off points on behavioral tests vary in studies on SLI (for review, see Asikainen, 2005), and presumably even more so in clinical work. It is argued that the behavioral tests may not reveal all aspects of language problems, especially with increasing age (Asikainen, 2005), and that the specificity and sensitivity of the tests used must be critically attended to whenever they are applied for diagnostic purposes (Spaulding et al., 2006). Clinical “cut-off” for SLI seemed to be around 1.25 standard deviations (SD) below the mean (Tomblin et al., 1996). Leonard (1998) suggested that for the diagnosis of SLI the performance should be 1.5 SD below the mean on at least two standardized language tests and the nonverbal intelligence quotient (IQ) above 85 points.

2.1.2 Terminology

The term SLI for developmental disabilities concerning language acquisition and use is widely applied especially in research literature. Among the first articles regarding the “specifically language-impaired” was that of Fey and Leonard (1984). Bishop (1997) was in favor of the term because of its neutral approach to the underlying cause; specific refers to seeing the impairment in otherwise normal development, and impaired to diminished quality and quantity. Some debate on the term has taken place especially concerning the

specificity of the language impairment in SLI (Plante, 1998; Hill, 2001; Ullman and Pierpont, 2005). Other commonly used terminologies include developmental language disorder or deficit (DLD), primary language impairment (PLI), language disorder (LD), and developmental dysphasia.

2.1.3 Etiology

Genes play a major role in the pathogenesis of SLI. Twin studies show heritability estimates ranging from around 50% to 75% for school-aged children, and environmental factors are relatively unimportant (Bishop, 2002). In her twin study, Hayiou-Thomas (2008) discovered, however, a distinction between speech and general language abilities; although closely related etiologically, the dominant influences on speech seem to be genetic, and on language more from children's shared environment. The model of inheritance of SLI is different from known dominant or recessive patterns, resembling complex genetic disorders, like asthma and diabetes (Bishop, 2006). Observed characteristics of SLI vary individually and in relation to age, which makes determination of phenotypes difficult (Bishop, 2006).

In their review article, Prathanee and colleagues (2007) state that along with the genetic component also maternal (young mothers, low socioeconomic status (SES), low education level) and birth (2nd or later child) conditions increase the risk of SLI. The maternal factors associated with an increased risk can, however, result from the mother's own deficits in language and literature, leading to lower education level and lower SES.

Structural neuroimaging studies suggest cortical dysplasia, abnormalities in white-matter, and atypical asymmetry of the language cortex in the brains of children with SLI (for a review, see Webster and Shevell, 2004). A single-photon emission computed tomography (SPECT) study of children with SLI supports the hypothesis of anomalous neurodevelopment in the etiology of SLI, and, furthermore, suggests the involvement of subcortical regions in addition to cortical structures (Ors et al., 2005). Electrophysiological studies using auditory event-related potentials (ERPs) and a mismatch negativity (MMN) component have yielded inconsistent findings regarding poor auditory temporal processing (ATP), which is often described in SLI. In her review article, Bishop (2006), however, concludes that tentative support for ATP being impaired in language and literacy disorders is available from MMN studies. In a Finnish MMN study of children with reading disabilities, subjects processed rise time and pitch change differently than control children, which provides further evidence for rapid auditory processing deficits (Hämäläinen et al., 2008). Electroencephalogram (EEG) findings indicate disturbances in the neuron migration process in children with SLI (Picard et al., 1998).

Pre-, peri-, and postnatal risk factors, such as infections, trauma, or hypoxia, that can affect brain development are seldomly related to SLI (Bishop et al., 2003). Less than three months' breastfeeding increased the risk of SLI and a longer duration of breast-feeding lowered the risk for persistent SLI (Tomblin et al., 1997). A recent study points out that low language input in small children who are raised in a severely deprived environment is followed by limited language skills (Windsor et al., 2007). After placement in an environmentally richer context, their language skills grow closer to the skills of community peers, but even after 12 months after placement they do not catch up with peers. A longer follow-up will reveal the incidence of SLI in this group of children with language delay.

2.1.4 Prevalence

The prevalence of SLI is dependent on the criteria used for diagnosis. A frequently quoted cross-sectional epidemiologic study from USA reported a prevalence of 7.4% in preschool children (Tomblin et al., 1997). Their cut-off point for diagnosis was 1.25 SD below the mean on two out of five language test scores, and normal nonverbal test performance. A more stringent criterion of 2 SD below normal, gives, following the Gaussian curve, a 2.5% prevalence of language impairments. An SLI prevalence of less than 1% in the age group 0-6 years and an increase in the prevalence of SLI and delayed language disorder during a 10-year period were observed in a primary healthcare study in one Finnish town (Hannus et al., 2009). Of 3- to 6-year-olds in one university hospital area in Finland, a prevalence of 0.5% was reported based on the number of children receiving an SLI-diagnosis in a specialist clinic (Helminen and Vilkman, 1989).

The male-female distribution of SLI usually shows a slight male preponderance; Tomblin with associates (1997) had 59% males in their prevalence study, and Beitchman and colleagues (1986) 63% males in their prevalence study. In a prevalence study from Finland, the male-female ratio was around 3:1 (Hannus et al., 2009). In studies based on a specialist referral, the proportion of males is often much higher. Among 7-year-olds attending special language units, 77% were male (Conti-Ramsden and Botting, 1999). In a clinical study of children with primary language impairment, 83% were male (Shevell et al., 2005), and in another clinical study of preschool children with SLI the corresponding proportion was 74% (Asikainen, 2005).

2.1.5 Clinical course

2.1.5.1 Early signs

Early identification of speech and language problems is important for diminishing the long-term negative effects of the language disorder. One detectable sign is the late onset of speech. Yet only some 40% of children who were late talkers at the age of 2 still met the criteria of persistent language problems at 3 and 4 years, and thus, predicting outcome from performance at age 2 was too inaccurate for clinical use (Dale et al., 2003). Of the 2-year-olds with delayed language, 50% “recovered” by the age of 3 years to language levels similar to normal language peers (Sachse et al., 2008). Hence, late onset of speech is a valuable early sign when trying to find children at risk of persistent problems and perhaps SLI, but the rate of “false positives” is high.

Signs of early receptive language problems seem to have more predictive power than just talking late. The predictive value of receptive language skills at 2.5-3.5 years to general language outcome 1.5 years later was strong among children referred to clinical services with concerns about language (Chiat and Roy, 2008). Late talkers with receptive language problems and a familial risk for literacy problems had the worst outcomes on all language measures at 5.5 years compared with late talkers with a familial risk but without receptive problems, and late talkers without a familial risk (Lyytinen et al., 2005). A positive family history of SLI strongly predicted low scores on measures of language comprehension and expression at the age of 3 (Choudhury and Benasich, 2003). Language

comprehension at 3 years was the best predictor of language and reading levels at age 7, and this was evident for both children with and without a family history of SLI (Flax et al., 2009). Still, a follow-up of late talkers with no receptive problems at intake showed that even they continued to have weaknesses, albeit mild, in language-related skills compared with typically developing peers (Rescorla, 2002; Rescorla, 2005).

As language measures are of use for children closer to 2 years of age and clinical evaluation usually takes place even later, research offers methods for earlier screening. For example, in an ERP study, children with persistent delays in language development and of literacy already as infants showed compromised speech processing and perception (Guttorm et al., 2005). In a test of nonverbal rapid auditory cues (RAP), a psychophysical threshold at 7.5 months of age was the best predictor of language outcome at 24 months; children with poor RAP thresholds had significantly poorer language outcomes (Benasich and Tallal, 2002). These methods are, however, not yet in clinical use, at least not in Finland.

2.1.5.2 Language

Children with SLI show impaired performance on all or most of the language domains of phonology, syntax, semantics, and pragmatics. Phonology and syntax particularly involve the form of language, semantics mostly its content, and pragmatics its use. All these domains are important in both comprehension and production of language. The majority of research is from English-speaking countries, and some differences across languages are probable. In her review article, Bishop (2006) presents a list of common language features of SLI: delay of starting to talk, immature or deviant production of speech sounds, use of simplified grammatical structures, restricted vocabulary (in both production and comprehension), weak verbal short-term memory (STM), and difficulties in understanding complex language. She also stresses that SLI shows substantial heterogeneity and that the features change with age.

In a clinical group of Finnish preschool children with SLI (mean age 5 years 9 months), the features of language most often detected were as follows: phonologically incomplete words, missing words in sentences, morphologically, syntactically, and semantically incomplete sentences, verbal dyspraxia, and deficient understanding (Asikainen, 2005). School-aged children with earlier diagnosis of SLI continued to show impaired language at the age of 7 years; only 10% had totally recovered (Webster et al., 2004). Conti-Ramsden and associates (2001a) reported in their follow-up of children attending language units that at 11 years 89% still showed some language problems and 63% demonstrated widespread difficulties on language measures. Children with poor comprehension at 5 years had more language deficits at 12 years than peers without early receptive language problems (Beitchman et al., 1996a). Problems in sentence repetition and non-word repetition (both involving STM) seem to persist and are identifiable at the age of 11, even though more apparent language difficulties may have resolved (Conti-Ramsden et al., 2001b).

Adolescent language outcomes of children with preschool histories of SLI are similar. Children with significant language difficulties at 5.5 years performed poorly in all aspects of language at 15, and even the ones with resolved difficulties at 5.5 years showed marked deficits on tasks involving verbal STM and phonological skills at the age of 15 (Stothard et al., 1998). Based solely on language performance, only 50% of 16-year-olds met the

criteria of SLI, although the remaining 50% had all met the criteria at some earlier time (Conti-Ramsden and Durkin, 2008).

Young adults with developmental receptive language disorder when aged 7 to 8 years, were assessed at around 24 years, and a substantial proportion showed problems in different aspects of communication; half had problems sustaining conversation, 40% difficulties in the spontaneous reporting of events, 25% rather immature syntax, and half some prosodic oddities (Mawhood et al., 2000). A lack of well-standardized language tests for adults exists. In the study by Mawhood et al. (2000), Wechsler Intelligence Scale for Adults revised (WAIS-R) was applied, and the mean VIQ score was 75.60.

Adults with a history of moderate phonology disorder performed in their early 30s significantly worse on measures of articulation, expressive language, and receptive language than controls (Felsenfeld et al., 1992). Males with severe receptive childhood developmental language disorder had poor language outcomes in their mid-30s; on average, the language level was equivalent to that of an 11-year-old (Clegg et al., 2005). At the age of 25, receptive vocabulary was significantly poorer in individuals with childhood language impairment than in those with childhood speech impairment or normal-language controls (Beitchman et al., 2008).

2.1.5.3 Literacy

Early language difficulties put children at risk of poor reading achievement (Snowling et al., 2000; Lyytinen et al., 2004; Flax et al., 2009), and literacy problems often persist (Stothard et al., 1998, Johnson et al., 1999, Snowling et al., 2000, Young et al., 2002, Clegg et al., 2005, Catts et al., 2008). For example, school-leavers with a preschool diagnosis of SLI performed worse on tests of reading, spelling, and reading comprehension than age-matched controls, and, furthermore, the rate of reading retardation had increased from early school years. However, more than 35% had reading skills within the normal limits and those with early expressive phonology impairments had a particularly good outcome (Snowling et al., 2000). In their study including 7179 twin pairs, Harlaar and colleagues (2008) examined the associations between early language and later reading and concluded that suggestive evidence exists for a direct causal influence of early syntactic-semantic skills on later reading performance. The influence of shared environmental factors is substantial, and genetic factors also play a significant role.

Sometimes difficulties in reading comprehension and underlying language deficits, even SLI, go unrecognized, especially when the child has good phonological ability and reads superficially fluently (Nation et al., 2004). Also Torppa and associates (2007) found a subgroup of readers with poor comprehension despite average word recognition, and Kelso and associates (2007) report a subgroup of children with SLI who have poor reading and oral comprehension, but normal decoding skills.

2.1.5.4 Educational and occupational attainments

Educational attainments are often lower in SLI populations than in typically developing peers (Records et al., 1992; Felsenfeld et al., 1994; Stothard et al., 1998; Young et al., 2002; Clegg et al., 2005; Snowling et al., 2006). At the end of compulsory

education, 44% of young people with SLI received at least one of the expected qualifications, but almost 25% did not take part in any examinations, and concurrent and early literacy and language skills have significant influences on academic attainments (Conti-Ramsden et al., 2009). Around half of the children with SLI have extra tutoring or other educational support at school (Beitchman et al., 1996a). In a study of 15-year-olds with SLI, 30% received extra educational support and 20% attended special schools (Stothard et al., 1998). Of 16-year-olds with SLI, 37% had received some form of special education placement at school (Tomblin, 2008). Young adults (17-25 years) with childhood SLI more often did not receive post-secondary education than controls (41% vs. 29%) (Records et al., 1992).

Occupational results from a 28-year follow-up study of adults with histories of moderate phonological/language disorders indicated that they more often occupied jobs considered unskilled or semiskilled than controls or same-sex unafflicted siblings. Furthermore, the unskilled jobs were such that required minimal reading, writing, and speaking skills (Felsenfeld et al., 1994). Jobs amongst young adults (23-24 years) with a childhood diagnosis of receptive SLI were largely manual or unskilled, and over half had never had a permanent job or had experienced long periods of no employment (Howlin et al., 2000). In their mid-30s 17 of these men had occupations consisting mainly of unskilled and manual labor occupations and almost two-thirds had experienced prolonged (over two years) periods of unemployment (Clegg et al., 2005). Three had never been and three had continually been in paid employment.

2.1.5.5 Social and emotional aspects

Poor social competence and being targets of victimization at age 11 were much more common in children with SLI than in typically developing peers (Conti-Ramsden and Botting, 2004). Compared with normal language peers, children with SLI between the ages of 10 and 13 years perceived themselves more negatively in scholastic competence, social acceptance, and behavioral conduct, whereas in the younger age group (6-9 years) no difference emerged (Jerome et al., 2002). Wadman and colleagues (2008) report a risk of low self-esteem and shyness, but age-level sociability in adolescents with SLI. Anti-social personality was more prevalent in 19-year-old males with preschool language problems than with speech problems or normal language (Beitchman et al., 2001).

Self-reports of adolescents in their first year of post-16 education (after 16 years of age) showed that they all had at least one person with whom they could share their joys and concerns, and most were optimistic about the future (Palikara et al., 2009). More than half of the subjects with receptive SLI had some problems in their early 20s in reciprocal relationships and one-third had no particular friends (Howlin et al., 2000). In their mid-30s one-half still had a limited range of friendships and more than 40% were limited or awkward when making social contact (Clegg et al., 2005). Only 7 (41%) of the 17 men were living independently, 5 (29%) lived with parents, and the rest participated in supported living (Clegg et al., 2005). Females with childhood language impairment became mothers at an earlier age than peers without language problems, and were more likely to be single mothers at the age of 25 (Beitchman et al., 2008). Adolescents with SLI scored significantly lower than typically developing peers in measures of social participation, and, furthermore, males with SLI scored significantly lower than their female counterparts (Tomblin, 2008).

2.1.5.6 Comorbidity

Dyslexia or specific reading disability is a disorder where despite adequate intelligence and opportunity to learn, literacy skills are poor. As reviewed above, many children with SLI have poor literacy skills. Regarding the relationship between SLI and dyslexia, Snowling et al. (2000) suggest that one “consider the child with a history of language impairment to be at risk of literacy difficulties in terms of the cognitive processes required for learning to read”. As the texts become more demanding linguistically, the contribution of syntactic, semantic, and pragmatic language skills grows. In their review article, Bishop and Snowling (2004) encourage taking into account both phonological and nonphonological language impairments as causes of reading impairment. A restricted problem with literacy and with production and comprehension of spoken language is, in their opinion, helpful to attend to separately, although the disorders (dyslexia and SLI) do have close behavioral similarities.

Poor motor skills are common in children with SLI (Rintala et al., 1998; Hill, 2001; Asikainen, 2005; Webster et al., 2006). Of preschool children with language impairments, 56% were regarded as clumsy, whereas only 14% of the control group with normal language demonstrated clumsiness (Asikainen, 2005). A relation between severity of the language disorder and occurrence of poor motor skills has been found (Asikainen, 2005; Webster et al., 2006). Hill (2001) reviewed the literature of SLI and concomitant motor impairments and found substantial comorbidity. She concluded that SLI is not a specific disorder of language; children with SLI experience a broad range of difficulties, motor incoordination being one of them. Whatever the underlying causes, impaired motor skills in children with developmental language disorders tend to improve at follow-up. Compared with children with no intervention, most children who attended a specific training program for a 10-week period improved more (Rintala et al., 1998).

Deficits in concentration were common in preschool children with language impairment; 54% demonstrated some deficiency, but 28% had concentration problems only in verbal tasks (Asikainen, 2005). Children with comorbid speech sound disorder and SLI were at increased risk for ADHD (McGrath et al., 2008). In a follow-up study by Beitchman and associates (1996b), 12-year-olds with poor comprehension or low overall performance at age 5 had more symptoms of hyperactivity than those with high overall performance or merely expressive language problems at 5 years. Another follow-up study reported 15-year-olds with histories of specific expressive problems to have more attention difficulties than peers with histories of receptive problems or no language problems (Snowling et al., 2006).

Some children with SLI have problems in language and communication that resemble autistic features, like “semantic-pragmatic deficit syndrome” (Rapin and Allen, 1998). Adolescents with a history of SLI were at risk of autism (3.9% met the criteria), and 26% presented behaviors common in autistic spectrum disorders (Conti-Ramsden et al., 2006). However, Williams and colleagues (2008) reviewed the literature for evidence of behavioral, neurobiological, and etiological links between language impairment in autism and in SLI, and found little. Their recommendation was to focus on predominant language features in each disorder, instead of the relatively small areas of overlap.

Psychiatric outcome in a 14-year follow-up of children with speech and/or language impairments and controls showed significantly elevated anxiety disorder rates in the language-impaired group compared with children with normal language or children with mere speech impairments (Beitchman et al., 2001). Social phobia was especially common

(Voci et al., 2006). Conti-Ramsden and Botting (2008) reported that compared with normal language peers, adolescents with SLI had significantly more anxiety and depression, and even though these were not directly the result of poor language, an association existed between emotional health and receptive language.

Snowling et al. (2006) described low rates of psychiatric disorder and no group differences in 15-year-olds with or without histories of SLI. Two of 20 young adults with receptive SLI at the age of 7 had schizophrenic symptoms; one had been in a hospital ward twice for hallucinations and delusions, and the other had developed delusions and paranoid fears and lost his job (Howlin et al., 2000).

Comorbid language disorders are not always recognized. Children referred to psychiatric intervention had high rates of language disorders; 53% had language impairments and in almost half of the cases the language problems went undiagnosed. The previously undiagnosed children significantly more often had fewer expressive problems, less severe language problems, and more serious externalizing behavioral problems than those with earlier recognized SLI (Cohen et al., 1993).

2.1.5.7 Nonverbal performance

The diagnosis of SLI is based on the discrepancy between verbal and nonverbal performance (see above). Bishop (1997) sums up research in this area, and points out that the discrepancy criterion is necessary, especially when doing studies on the causes and patterns of SLI, and most studies include performance IQ (PIQ) of at least 80. She continues that IQ has relatively little impact on response to therapy (at least with IQ>70). In follow-up studies of children with an initial diagnosis of SLI, many show a substantial drop in PIQ later on and some no longer fulfill the criteria for diagnosis (Johnson et al., 1999; Mawhood et al., 2000; Conti-Ramsden et al., 2001a). Interestingly though, a drop in PIQ between childhood and early adulthood proved to be temporary; in later adulthood PIQ returned to levels similar to those of childhood (Clegg et al., 2005). Tomblin (2008) compared academic competence at age 16 of children with SLI (PIQ on average 99.78) and general delay (PIQ on average 82.65) as preschoolers, and found no significant differences regarding reading skills, parent- and teacher-reported school performance, or mathematical problem-solving skills. A trend towards slightly better performance was observed for students with SLI, which he considered to result more from better language skills than from differences in PIQ. However, some evidence exists that high PIQ acts as a protective factor against single-word reading difficulties in adolescents with a preschool SLI diagnosis (Snowling et al., 2000).

2.1.6 Intervention

Individual speech and language therapy is usually the “treatment of choice” for children with speech and language difficulties. In a clinical group of Finnish preschool children (<7 years), 85% with language impairment had received therapy prior to the diagnostic examinations, and 42% had received therapy for at least 1.5 years. Of the children, 19% had received sensory integration (SI) therapy, a type of occupational therapy (Asikainen, 2005).

Law and colleagues (2003) examined, by a comprehensive search of the literature, the effectiveness of speech and language interventions for children with primary speech and language delay or disorder. Because of the heterogeneity of both the studies and the results, they suggest that further research is needed to evaluate interventions for receptive language difficulties, but for expressive difficulties (especially phonology and vocabulary) intervention seems effective. Group or individual intervention by a specialist or trained parents did not differ regarding effectiveness.

When comparing specialist early care for speech- and language-impaired children with mainstream nursery care, results indicate that specialist services had more positive effects on the children's language abilities (Law et al., 2004).

2.2 Health-related quality of life

2.2.1 Definition

Health-related quality of life (HRQoL) refers to the part of the quality of life relating to health. A fundamental description of health comes from World Health Organization (WHO), and was put forth in 1948: "Health is a state of complete physical, mental, and social well-being and not merely the absence of disease or infirmity." (www.who.int/about/definition/en/print.html). In this wide sense, many aspects of well-being are related to health, and, thus, to HRQoL. However, HRQoL and quality of life (QoL) should not be used interchangeably; health-related well-being is a strong determinant of global QoL, but is not the only one (Sajid et al., 2008). HRQoL focuses mainly on issues that can be affected by healthcare and health policies (Räsänen, 2007).

2.2.2 Measuring HRQoL

In medical research, measurement of HRQoL aims to gather patients' own perspectives on their health status to give the clinicians a better understanding of the impact of a disease and its treatment on patients' lives (Sajid et al., 2008). Interest in quality of care, clinical effectiveness, and cost-effectiveness are the main reasons for growing popularity in measuring HRQoL (Guyatt et al., 1993). Ideally, measurement tools should be acceptable to patients, feasible, reliable and reproducible, valid, interpretable, and useful (Sajid et al., 2008).

The HRQoL tools for measuring the dimensions of health are usually generic or disease-specific. The disease-specific tools or instruments gather information about the impact of a certain disease or its treatment on issues relevant to that disease and are, therefore, able to detect small changes in health status and are useful in assessing the effectiveness of treatment (Räsänen, 2007). In longitudinal studies, disease-specific instruments are more responsive to change than generic instruments (Sajid et al., 2008). However, comparison between various diseases is not possible with specific instruments and generic instruments are preferred, as also in cross-sectional studies (Sajid et al., 2008).

The methodological classification of generic instruments divides them into measures using profiles (a number of physical and emotional dimensions describe the state of health) and measures using single index scores (the score describes the state of health) (Räsänen, 2007). The results differ even in the same patient group depending on the preferences used and from whom they are obtained, and no consensus exists regarding the most reliable HRQoL instrument (Räsänen, 2007).

2.2.3 15D, 16D, and 17D

The 15D is a generic HRQoL instrument that can be used both as a profile and as an index score measure (Sintonen, 1994b; Sintonen, 1995). It was originally developed to subscribe to the WHO definition of health (Sintonen, 2001). The 15D health state descriptive system has 15 questions corresponding to the following 15 dimensions: breathing, mental function, speech, vision, mobility, usual activities, vitality, hearing, eating, elimination, sleeping, distress, discomfort and symptoms, sexual activities, and depression (www.15d-instrument.net/15d). The single index covering all dimensions is calculated using a set of utility or preference weights elicited from the general public through a 3-stage valuation procedure (Sintonen, 2001). The maximum score of 1 refers to no problems on any of the dimensions. The minimum score is 0. In comparison studies of generic HRQoL instruments, the 15D compares favorably with other measures (Stavem, 1999; Hawthorne et al., 2001). The 15D has shown good agreement with disease-specific measures of HRQoL (Kauppinen et al., 2000; Haapaniemi et al., 2004).

The 16D and the 17D instruments are based on the 15D, and developed for adolescents aged 12-15 years and pre-adolescents aged 8-11 years, respectively (www.15d-instrument.net/15d). The 16D questionnaire includes 16 dimensions (mobility, vision, hearing, breathing, sleeping, eating, speech, elimination, school and hobbies, mental function, discomfort and symptoms, depression, distress, vitality, appearance, and friends), and the 17D questionnaire includes 17 dimensions (mobility, vision, hearing, breathing, sleeping, eating, speech, elimination, school and hobbies, learning and memory, discomfort and symptoms, depression, distress, vitality, appearance, friends, and concentration). Both instruments can be used as profile or single index score measures, and the valuation systems are based on application of the multi-attribute utility theory as in the 15D (www.15d-instrument.net/15d; Apajasalo et al. 1996a; Apajasalo et al. 1996b). Some significant differences exist between adolescents' and their parents' views, and therefore, measurement of the HRQoL of adolescents with the 16D-instrument is preferably by self-administration (Apajasalo et al., 1996a).

2.2.4 HRQoL in developmental disorders

2.2.4.1 Language disorders

HRQoL studies are scarce and only a few apply self-administration. Records et al. (1992) had a quality of life questionnaire, developed for the study, to collect information on various life domains, personal happiness, and life satisfaction in 29 young adults with a

history of SLI and 29 controls. The groups did not differ on average in these domains, despite feelings of less control over their lives in the SLI group. Tomblin (2008) reports several aspects of well-being closely related to quality of life or HRQoL in 16-year-olds with SLI and their controls with general delay (GD) and controls with typical language in kindergarten. Satisfaction with life, measured on a Satisfaction with Life Scale, which includes 5 items, showed no differences between the groups. Mental competence, global self-esteem, and social appearance are components of self-worth, and a significant difference existed in mental competence between adolescents with SLI and those with typically developing language. In global self-esteem, both diagnostic groups had significantly lower ratings than the typically developing group. The affective state (depression) was clinically different across all three groups; the rate of depression was the highest in the GD group, the second highest in the SLI group, and the lowest in the typically developing group (Tomblin, 2008).

In one study, parents' and professionals' perception of quality of life of children with speech and language difficulty aged 2-9 years was assessed by focus group interviews. The aim was to provide novel data on the HRQoL of children with these difficulties, and the authors concluded that factors like well-being and participation should be taken into account in assessments and interventions (Markham and Dean, 2006). The HRQoL of 3-year-old children shows significantly lower scores on the communication scale and social functioning scale for children with language delay than for their controls, as measured by a parental questionnaire (van Agt et al., 2005).

2.2.4.2 Other disorders

Parent-reported HRQoL of children and adolescents with ADHD is worse in its psychosocial aspects than that of a control group (Klassen et al., 2004). Preschool children (2-4 years) at risk or with developmental disabilities have significantly lower overall well-being and psychosocial health than their normally developing peers, as assessed by parent-reported HRQoL (Lau et al., 2006). A study by Sawyer and colleagues (2002) compared parental reports describing the HRQoL of children with mental (ADHD, major depressive disorder, conduct disorder) or physical disorders and those with no disorder in a large sample of children and adolescents (6-17 years). The results indicate that children with mental disorders have significantly worse HRQoL in several domains than children with no disorders and in many areas also worse HRQoL than children with physical disorders. They conclude "The results suggest that children with mental disorders and their families have problems in their day-to-day lives which extend beyond the symptoms which characterize their disorders" and continue "The findings also challenge the current distinction in the health care delivery system between physical and mental health care and support the importance of an integrated approach to health care delivery that does not codify the false dichotomy between physical and emotional health and well-being" (Sawyer et al., 2002).

Keilmann and colleagues (2007) investigated, among other things, the influence of language competence on psychological and physical well-being in 6- to 11-year-old hearing-impaired children. Compared with hearing-impaired children in mainstream education, children in special schools were less confident, and obtained worse scores in making friends, anxiety, and emotional mood. They concluded that deficits in speech

development and inability to understand speech in unfavorable conditions may have led to communication deficits and lower scores (Keilmann et al., 2007).

2.3 International classification of functioning, disability, and health (ICF)

The World Health Organization (WHO) endorsed the ICF framework in May 2001 for use as an international standard to describe and measure health and disability (www.who.int/classifications/icf/en/). It acknowledges that deterioration of health and some degree of disability can befall anyone, not only a minority, making it a universal experience. In this framework, the focus is shifted from cause to impact, placing all health conditions on an equal basis. A disability is not only a medical or biological dysfunction, but social aspects are also taken into account.

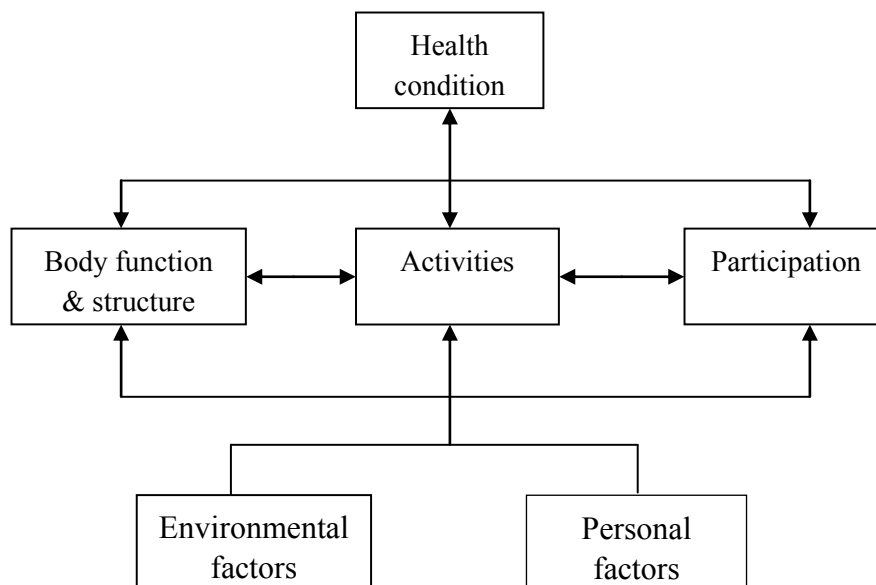


Figure 1 Interaction of concepts in ICF (2001).

Campbell and Sharakis-Doyle (2007) describe how the ICF can be used as a framework for school-aged children with SLI and emphasize the importance of a broader approach beyond language functioning. In their opinion, the known risks for academic and social difficulties seriously compromise the quality of life of children with SLI.

3 Aims of the study

The aims of this thesis were to explore

- by applying the generic 15D, 16D, and 17D HRQoL tools, the self-perceived daily functioning of adults, adolescents, and pre-adolescents with a childhood diagnosis of receptive SLI compared with that of their age- and gender-matched controls (I, III, IV)
- the long-term effects of SLI using self-reports collected from adults with histories of receptive SLI compared with general population data from public records and with self-perceived HRQoL measured with the generic 15D instrument (II)
- the type of schooling, extra tutoring, and rehabilitation received by adolescents and pre-adolescents with a diagnosis of receptive SLI, and the relations of these to self-perceived HRQoL measured with the generic instruments 16D and 17D (III, IV)
- how childhood performance explains self-perceptions of HRQoL in adults, adolescents, and pre-adolescents, and information received from adult self-reports and adolescent and pre-adolescent school and rehabilitation reports (I-IV)

4 Subjects and methods

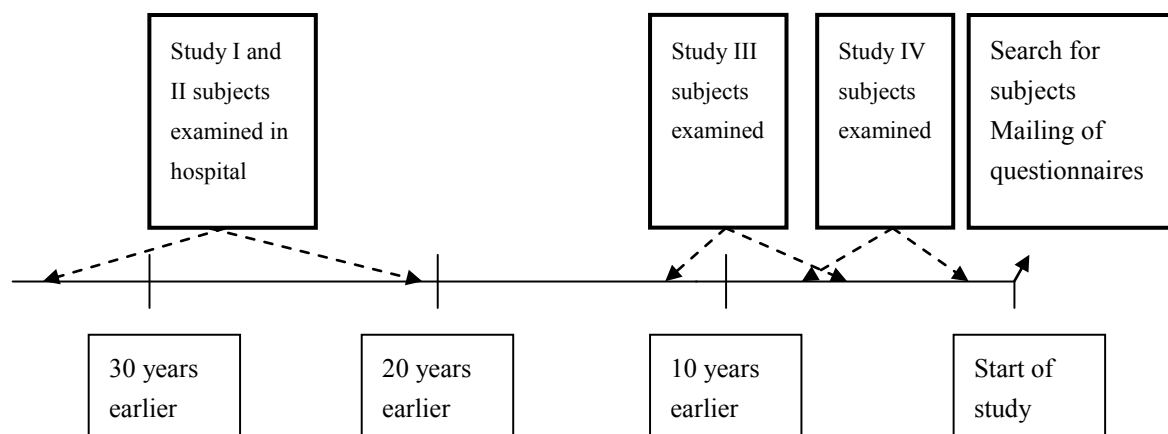


Figure 2 Timing of studies

4.1 Subjects

4.1.1 Adults (I, II)

The subjects were searched for from the records of psychological examinations performed in 1970-1986 in our department for language-impaired children with severe language disorders caused by various etiologies. Based on the Wechsler Intelligence Scale (WISC), we included individuals who fulfilled the criteria of normal performance (nonverbal) intelligence quotient (PIQ; ≥ 85 points) and subnormal verbal intelligence quotient (VIQ; < 85 points). Patients with gross neurological deficit or hearing impairment were excluded. Altogether 56 patients met the inclusion criteria. While sending the questionnaires, we found that one subject had died, one had moved abroad, and two had no registered address. The total number of adult subjects was therefore 52.

4.1.2 Adolescents (III)

Participants comprised children referred to and examined at the Department of Phoniatics, Helsinki University Central Hospital. All patients aged 12-16 years during fall 2003 who had received a diagnosis of receptive SLI at some point (ICD-10 F80.2; previously 3510A) were included. These children had been examined, usually before school age in a hospital ward for children with language difficulties due to different

etiologies. The multidisciplinary team in the ward comprised a medical doctor specialized in phoniatrics, a psychologist, a speech therapist, a specialized teacher for communication-impaired children, a nurse or child-carer, and in some cases, an occupational therapist and a social worker. The children had normal hearing, no gross neurological deficits, and no known metabolic or genetic syndromes. The subject group comprised 67 adolescents.

4.1.3 Pre-adolescents (IV)

Participants comprised children with language difficulties referred to the Department of Phoniatrics, Helsinki University Central Hospital. All patients aged between 8 and 11 years during fall 2003, and who had, at some point, received a clinical diagnosis of receptive SLI (ICD-10 F80.2) were included. The children had normal hearing, no gross neurological deficits, and no known metabolic or genetic syndrome. The examinations had taken place usually before school age in the same hospital ward by a similar multidisciplinary team as described in Section 4.1.2. Altogether 64 children fulfilled the criteria of inclusion.

4.2 Population controls

4.2.1 Study I

The age- and gender-matched controls comprised 1915 persons of an initial nationwide sample of 10 000 individuals aged 18 years and over. This Health 2000 Health Examination Survey included the 15D questionnaire (Aromaa and Koskinen, 2004).

4.2.2 Study II

Relevant data on general adult population were gathered from information directly available in or derived from public registers (Statistics in Finland, 2005).

4.2.3 Study III

The controls comprised an age- and gender-matched population sample of 238 adolescents (91% response rate) from four elementary schools situated around the greater Helsinki area (Apajasalo et al., 1996a).

4.2.4 Study IV

The controls comprised 244 children aged 8-11 years from a population sample collected for an HRQoL study. They came from five elementary schools situated around the greater Helsinki area (Apajasalo et al., 1996b).

4.3 HRQoL measures

The HRQoL questionnaires in this study were in Finnish, which is also the original language applied in the 15D, 16D, and 17D. The English translations can be found in Appendices 1-3 and are also available at the 15D website (www.15d-instrument.net/15d).

4.3.1 Questionnaire for adults (I, II)

The HRQoL measurement tool is a generic questionnaire. The 15D (Appendix 1) covers 15 dimensions of physical, mental and social well-being with 15 questions (see also Section 2.2.3). The answers to the dimensions are divided into 5 levels, 1 being the best level and 5 the worst level. The tool is applicable both as a single index score, i.e. a summary of all dimensions, and as a profile, visualizing the dimensions in relation to each other or to other populations. The maximum 15D score is 1 (no problems on any dimension) and the minimum score 0.

4.3.2 Questionnaire for adolescents (III)

HRQoL was measured with the 16D questionnaire (Appendix 2). This questionnaire is based on the 15D questionnaire and is meant for children aged 12 to 15 years. The 16D has 16 dimensions that are divided into five levels (best level = 1, worst level = 5). Respondents chose the levels best describing their present health status. Proxy administration was also possible. The 16D serves both as a profile and as a single index score, where the maximum score is 1 (no problems on any dimension) and the minimum score 0.

4.3.3 Questionnaire for pre-adolescents (IV)

HRQoL was measured with the 17D questionnaire (Appendix 3), designed for children aged 8-11 years. This questionnaire is based on the 15D questionnaire. The 17D has 17 dimensions, each divided into 5 levels (best level = 1, worst level = 5). The 17D serves as a profile and a single index score measure, where the maximum score is 1 (no problems on any dimension) and the minimum score 0. The question on a dimension is accompanied by a simple drawing illustrating the topic. A structured interview is usually the mode of administration, but self-administration is also possible, and proxy administration when

necessary. The children were instructed to fill out the HRQoL questionnaire themselves and to ask for help if needed in reading and explaining the questions.

4.4 Study-related questionnaires

4.4.1 Questionnaire for adults (II)

The questionnaire contains 13 multiple-choice questions designed to elicit information about socioeconomic situation, education, own perception of skills regarding reading, writing, explaining things, and remembering instructions, family history of language or learning difficulties, and overall effect of childhood SLI on life (Appendix 4).

4.4.2 Questionnaire for adolescents (III)

The questionnaire designed for this study collected background information (Appendix 5). Five questions with multiple-choice answers dealt with type of schooling, special education, speech and language therapy and other interventions, and a question about self-estimated abilities in reading and writing.

4.4.3 Questionnaire for pre-adolescents (IV)

The study-specific questionnaire collected information about the type of schooling, additional special education/support, speech and language therapy, and other rehabilitation. The four questions had multiple-choice answers (Appendix 6).

4.5 Psychological examination records

All tests were administered in Finnish and had norms for Finnish children.

4.5.1 Adults (I, II)

The information obtained from the psychological examination records was as follows: age at time of examination, total verbal intelligence quotient (VIQ), verbal subtest scores, and performance intelligence quotient (PIQ). The test administered was the Wechsler Intelligence Scale for Children (WISC). Verbal subtests included the following: 1) information, containing questions of general knowledge, 2) similarities, measuring understanding of how two concepts are alike, 3) arithmetic, comprising arithmetic questions and concepts, 4) vocabulary, showing the ability to explain the meaning of

words, and 5) comprehension, measuring the ability to understand social situations and common concepts. The total VIQ was missing for two patients, but verbal performance, which had been tested earlier, was recorded as deteriorated. For Study I, any information on speech was also collected from psychologists' records and coded in the data as follows: 1 = phonological difficulties, 2 = articulation errors, and 3 = tendency for mutistic behavior. If naming difficulties were mentioned, this information was coded in the data as such.

4.5.2 Adolescents (III)

Psychologists' test results for subjects around school age (the year of the 7th birthday) were obtained. The tests used were the Wechsler Intelligence Scale for Children, revised and third edition (WISC-R, WISC-III), the Wechsler Preschool and Primary Scale of Intelligence and its revised edition (WPPSI, WPPSI-R), and neuropsychological verbal tests (NEPSU, an earlier version of NEPSY, neuropsychological test battery for children) (Korkman, 1988). The Wechsler tests varied depending on the age of the child and whether the revised versions were available.

4.5.3 Pre-adolescents (IV)

In the retrospective evaluation of patient records, if a child had been examined more than once, the testing date closest to school age was chosen, as with adolescents. The performance intelligence quotient (PIQ), the verbal intelligence quotient (VIQ), and the results from the verbal subtests were obtained. The tests used were the Wechsler Intelligence Scale for Children-Revised (WISC-R), the Wechsler Intelligence Scale for Children, third edition (WISC-III), or the Wechsler Preschool and Primary Scale of Intelligence-Revised (WPPSI-R). We also collected results from the Neuropsychological Test Battery for Children (NEPSY) (Korkman et al. 1997) when available.

4.6 Speech therapists' examination records

For adult subjects, the examination records were unavailable. For adolescents, the records were available only for some subjects, and therefore, are not included in the data.

4.6.1 Pre-adolescents (IV)

The speech therapists' reports were reviewed and available test results obtained. The tests most often used included auditory closure, auditory span, grammatical completion, and auditory reception subtests of the Illinois Test of Psycholinguistic Abilities (ITPA) (Kirk et al. 1968), those parts of the Reynell II (Reynell, 1987) test that measured receptive language, and the Boehm test of concepts (Boehm, 1986). The ITPA, Boehm,

and Reynell tests were entered in the data as being either at or below age-level. All of these tests have Finnish versions and norms for Finnish children.

4.7 Statistical analysis

In all studies (I-IV), data were analyzed using SPSS for Windows, version 12.0.1 (SPSS Inc., Chicago, IL, USA). Descriptive statistics were used to describe demographic characteristics. Comparative analysis of demographic characteristics between respondents and nonrespondents was performed using an independent samples t-test (two-tailed) and the Fisher's exact test for gender.

4.7.1 Study I

The Mann-Whitney U-test was used to compare the 15D score of patients and population controls. The independent samples t-test (two-tailed) and Wilcoxon's test were applied when comparing mean group scores between patients and population controls. The associations between respondent characteristics, the 15D score, and each dimension were measured using Spearman's rank correlation coefficients. Significance was set at $p < 0.05$.

4.7.2 Study II

The relationship between respondent characteristics and population characteristics was compared with a binomial test. Associations between respondent characteristics and the 15D score and dimensions of speech, usual activities, mental functioning, and distress were measured using Spearman's rank correlation coefficient (two-tailed). Significance was set at $p < 0.05$.

4.7.3 Study III

The 16D score of subjects and population controls was compared with the independent samples t-test. The independent samples t-test (two-tailed) was applied when comparing mean group scores between subjects and population controls. To control for multiple comparisons in the analysis, the alpha level in testing statistical significance was set at $p < 0.01$. Spearman's rank correlation coefficients served to compare respondent characteristics, the 16D score, and each dimension. Significance was set at $p < 0.01$.

4.7.4 Study IV

The Mann-Whitney U-test served to compare the 17D score of subjects and population controls. The independent samples t-test (two-tailed) was applied when comparing mean group scores between subjects and population controls. To control for multiple group

comparisons in the analyses, the alpha level in testing statistical significance was set at $p < 0.01$. The associations between respondent characteristics, the 17D score, and each dimension were measured using Spearman's rank correlation coefficients. Significance was set at $p < 0.01$.

4.8 Ethics (I-IV)

The study protocols were approved by the Ethics Committee of Ophthalmology, Otorhinolaryngology, Neurology, and Neurosurgery of the Helsinki and Uusimaa Hospital Group (45/2003). Adult subjects gave their written informed consent and returned it by mail with the questionnaires (I, II). Parents of adolescent and pre-adolescent subjects gave their written informed consent and returned the consent by mail with the questionnaires (III, IV).

5 Results

5.1 Subjects (I-IV)

Table 1. Information about respondents of Studies I-IV. *= 31 filled out both questionnaires.

	Study I n=52	Study II n=52	Study III n=67	Study IV n=64
Respondents, eligible	33	33*	48	51
Response rate, all included	67%	67%	73%	86%
Gender				
Male	25 (76%)	24 (73%)	37 (77%)	41 (80%)
Female	8 (24%)	9 (27%)	11 (23%)	10 (20%)
Age (years) at time of study,				
Mean (SD)	34.5 (4.75)	34.2 (4.69)	14.2 (1.44)	10.1 (1.22)
Range	27.0-43.3	27.0-42.4	12.1-16.9	8.1-11.9
Age (years) at psychologists' tests,				
Mean (SD)	7.1 (0.83)	7.1 (0.83)	6.6 (0.92)	6.2 (0.86)
Range	6.0-9.0	6.0-9.0	4.3-9.8	4.4-8.9
VIQ,	(n=31)	(n=31)	(n=43)	(n=45)
Mean (SD)	76 (10.2)	75 (10.5)	87 (16.7)	90 (14.8)
Range	49-89	49-89	45-124	58-119
PIQ,	(n=33)	(n=33)	(n=41)	(n=44)
Mean (SD)	103 (10.0)	103 (9.8)	98 (12.0)	103 (11.8)
Range	90-125	90-125	75-126	84-138
Special school or class attendance (part of or entire school time)		62%	60.5%	63%
Extra tutoring at school		84%	62.5%	63%

In Studies I and II, 35 subjects returned the questionnaires, but four of them only the other one (Table 1). A maximum of two reminders were sent; however, most of the answers were received after the first mailing. There was a note of proxy administration having been used in 9 cases, not used in 19 cases, and the note was missing in 5 cases.

In Study I, two respondents were moved to the nonrespondent group, as the 15D questionnaires lacked more than three answers. In two questionnaires, the question about sexual activity had not been answered, and the values were predicted (for more information, see www.15d-instrument.net/15d). Respondents and nonrespondents differed slightly in gender distribution (84% of nonrespondents were male) and age (the average age of nonrespondents was 31 years), but not in VIQ, PIQ, or age at time of psychologists' tests (for more information, see Study I).

In Study II, 33 subjects had filled out, at least mostly, the study questionnaire. Both the study-related questionnaire and the 15D HRQoL questionnaire were filled out by 31 subjects. Thus, the respondent group in Study II differed only slightly from the respondent group in Study I (Table 1).

Of the original respondents in Study III, one was excluded from further analysis due to extremely low (<70) PIQ, and of the respondents in Study IV, four were excluded from further analysis (one had PIQ<70, three were bilingual). In Studies III and IV respondents and the nonrespondents did not differ significantly (for more information, see Studies III and IV). In Study III, four respondents and two nonrespondents had PIQ<85 (lowest value 75), and the points were missing for seven respondents, but nonverbal performance was reported as normal in psychologists' reports. In Study IV, for seven respondents, the normality of PIQ was stated, but the exact test or test-points were missing.

Information about respondents regarding educational placement and/or extra tutoring at school shows that additional assistance at school age was needed in the majority of cases (Table 1). Only 16% of the adults reported receiving no extra assistance at school. For adolescents and pre-adolescents, the figures were 13% and 8%, respectively.

5.2 Language performance at the time of psychological testing

5.2.1 Adults (I, II)

Performance on verbal subtests of the intelligence tests was on average as follows: information 5.90, similarities 7.68, arithmetic 4.83, vocabulary 7.08, and comprehension 7.34 (a score of 7 points is poor-normal). Psychologists' notes regarding speech problems were also gathered: 48% were described as having some problems in speech and 15% had naming difficulties. Respondents and nonrespondents did not differ in language performance.

As the study groups were almost identical in Studies I and II, language subtest results were also quite similar.

5.2.2 Adolescents (III)

The intelligence tests that had been applied were WISC-R in 49, WPPSI in 7, WPPSI-R in 4, and WISC-III in 2 cases. In four cases, results of VIQ were unavailable, and in one case only 2 subtests had been performed. The results of verbal subtests of the intelligence

tests and of the neuropsychological test (NEPSU) show considerable variability (Table 2), and thus, sample heterogeneity.

Table 2. Results from verbal subtests of intelligence tests and the neuropsychological test (NEPSU) measuring language performance in childhood. NEPSU test-points are listed as standard deviations from normal = 0.

Test	Number of subjects	Mean Score	Lowest Score	Highest Score	Standard deviation
Information	44	7.68	1	12	3.297
Similarities	42	9.48	1	15	3.501
Arithmetics	44	7.86	1	13	2.970
Vocabulary	43	6.26	1	15	3.324
Comprehension	42	8.29	1	13	3.047
NEPSU verbal concepts	23	-1.26	-3	1	1.453
NEPSU grammar	22	-1.23	-3	0	1.270
NEPSU naming colors	23	-0.43	-3	0	0.728
NEPSU naming numbers	17	-0.59	-2	0	0.712
NEPSU repeating numbers	11	-1.45	-3	0	0.820
NEPSU repeating words	11	0	0	0	0.000
NEPSU story-learning	16	-1.06	-3	0	1.124
NEPSU story-telling	1	-2.00	-2	-2	.
NEPSU literacy	4	-1.00	-2	0	0.816

5.2.4 Pre-adolescents (IV)

Depending on the age of the child and the time of testing, the intelligence tests used were as follows: WPPSI-R in 30, WISC-R in 9, and WISC-III in 17 cases. VIQ scores were available for 45 respondents (Table 1). Of the NEPSY subtests, understanding instructions had been most frequently administered, results were available in 20 cases. Of the speech therapists' tests, ITPA auditory closure was administered in 29 cases, Boehm

concepts in 25 cases, and the rest of the tests less frequently. To summarize, VIQ, NEPSY, and speech therapists' test results indicated that altogether 39 participants had a VIQ level of 85 or lower (below -1 SD), at least two linguistic tests below normal level, or both. Twelve participants scored within normal limits on the language tests performed.

Table 3. Results of tests measuring language performance among 51 children.

Test	Subtest	Number of subjects tested	Subjects performing below age level (%)
NEPSY	Understanding instructions	20	8 (40)
	Phonological processing	17	5 (29)
	Understanding sentences	16	7 (44)
	Narrative memory	9	7 (78)
ITPA	Auditory closure	29	14 (48)
	Grammatical completion	21	7 (33)
	Auditory memory	18	16 (89)
	Auditory reception	14	2 (14)
Reynell	Reception	15	4 (27)
Boehm	Concept	25	20 (80)

5.3 HRQoL, study questionnaires, and comparisons

5.3.1 Study I

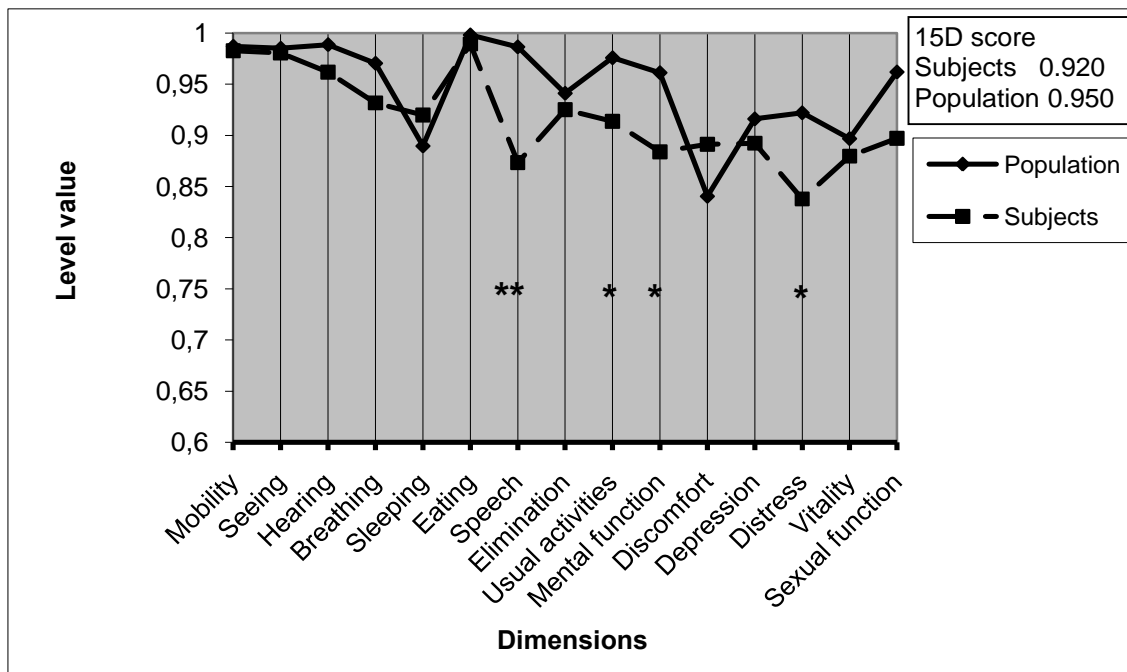


Figure 3 Health-related quality of life of study group and population controls measured by the 15D questionnaire. Significant differences were found on the dimensions of speech, usual activities, mental function, and distress using independent samples t-test. * $p < 0.05$, ** $p < 0.01$

The total 15D score of patients and age- and gender-matched controls differed little (Figure 3). Although the difference did not reach statistical significance, it was at a level (0.03) considered to be of clinical significance in earlier studies (Sintonen, 1994a). The 15D profiles show the levels of each dimension for patients (subjects) and population controls (Figure 3). Significant differences emerged on the dimensions of speech, usual activities, mental function, and distress. The distribution of the values gives more detailed information on the differences between groups (Table 4).

Table 4. Distribution of levels in respondents of the study group (n=33) and population controls (n=1915) on dimensions of speech, usual activities (Uact), mental function and distress in the 15D questionnaire. Best level=1, worst level=5. Values are percentages. ** p<0.01, * p<0.05

Dimension	Group	Level 1	Level 2	Level 3	Level 4	Level 5
**Speech	Study group	66.7	27.2	-	6.0	-
	Population controls	95.8	4.0	0.2	0.1	-
*Uact	Study group	75.8	18.2	6.0	-	-
	Population controls	92.9	6.0	0.7	0.3	0.1
*Mental	Study group	69.7	27.2	3.0	-	-
	Population controls	89.6	9.9	0.4	0.0	0.0
*Distress	Study group	51.5	39.4	6.0	3.0	-
	Population controls	75.3	21.9	1.8	0.7	0.4

A low VIQ measured in childhood was correlated with lower levels on the dimensions of usual activities (p<0.05) and mental function (p<0.01), but not with other dimensions or with the 15D score. Childhood PIQ was not associated with the 15D score or with any of the dimensions.

Difficulties in speech were mentioned in psychologists' reports for 20 respondents (61%) (for more information, see Study I). One respondent had had both naming difficulties and articulation errors. Of these 20 respondents, nine felt that they still had speech difficulties while filling out the 15D questionnaire. An additional two had no psychologist-reported speech problems in childhood, but reported problems as adults.

5.3.2 Study II

Table 5. Social characteristics of the respondent group based on a self-administered questionnaire, and of the general population based on information available in public registers. a) Population aged over 18 years, b) population aged 30-44 years, c) population aged 15-64 years, d) population of schoolchildren in primary school in 2005, and e) population of schoolchildren in primary school in 1995.

Characteristic		Percentage of respondents	Percentage of population
Living situation n=31	with a partner	41.9	-
	alone with children	3.2	2.9 (a)
	with parents	19.4	1.0 (a)
	alone	35.5	23.2 (a)
Education n=33	primary level 9 years obligatory	27.3	-
	secondary level	69.7	84.2 (b)
	tertiary level	3.0	
Employment n=31	employed	58.1	66.4 (c)
	unemployed	16.1	8.4 (c)
	entitled to pension	25.8	7.6 (c)
Special school n=32	entire school time	37.5	7.3 (d)
	part of school time	34.4	2.9 (e)
	never	28.1	> 90 (d, e)
Special tutoring at school n=31	yes	83.8	-
	no	16.1	-

The answers to study-related questions (Appendix 4) concerning the characteristics of the study group as compared with the characteristics of population cohorts gathered from the population register (Statistics in Finland, 2005) showed some interesting differences (Table 5). A significantly greater proportion of subjects lived with their parents than of the general population aged 18 years and over. All were male, and on average 36.8 years. Of the respondents, 69.7% had graduated from secondary education (post-obligatory education) (97% from trade school) and 3% (1 subject) from university. The

unemployment rate of respondents was almost twofold that of the working-aged adult population, but the difference was not statistically significant. Being pensioned was three times more frequent in the study group than in the adult population under 64 years of age; this difference was significant. An interesting detail was that three of the nine females (33%) were entitled to a pension. Special school or class attendance at least part of the school time was typical in our study population. According to the questionnaire, only 16.1% of respondents had not received any special tutoring during their school years.

The questionnaire included several questions about self-estimated reading and writing abilities to distinguish possible differences between everyday needs and external demands (Appendix 4); there seems to be none. Only 9.1% regarded their reading abilities as quite poor or poor, and 15.2% their writing abilities as quite poor or poor. Self-reported reading and writing problems in everyday life (R+Wlife) (6.1%) or at work (R+Wwork) (9.7%) were even less common. These self-estimated literacy skills were not significantly associated with respondents' social characteristics (listed in Table 5).

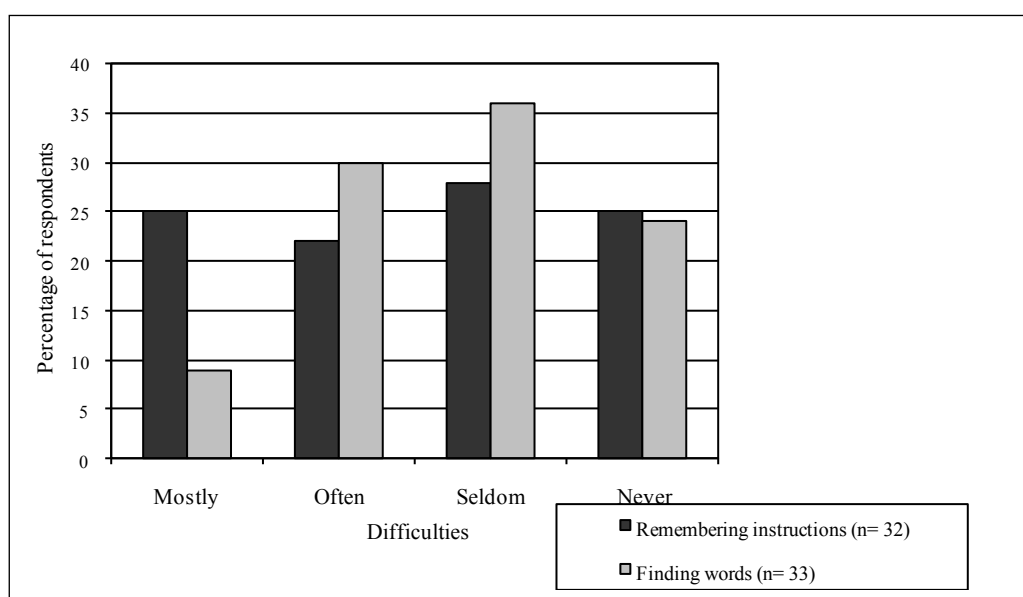


Figure 4 Self-perceived difficulties in remembering instructions and finding words in a multiple-choice questionnaire, in which response options were mostly, often, seldom, and never.

Almost half of the subjects had mostly or often self-perceived difficulties in remembering instructions, which can also indicate difficulties in understanding, whereas 39% mostly or often had difficulties in finding words (Figure 4). Difficulties in finding words and in remembering instructions were positively associated ($r=0.470$). Difficulty in finding words was associated with self-estimated abilities in reading ($r=-0.408$), writing ($r=-0.511$), R+W life ($r=-0.616$), and R+W work ($r=-0.644$), as was difficulties in remembering instructions; reading ($r=-0.388$), writing ($r=-0.358$) R+W life ($r=-0.494$), and R+W work ($r=-0.373$). Difficulties in finding words and remembering instructions were not significantly associated with respondents' social characteristics (as in Table 5).

One question was about the effect of language impairment on one's life to date. About one-third considered the effect to be very big or quite big. Significant relationships were present with reading ($r=-0.381$), writing ($r=-0.446$), R+W work ($r=-0.386$), and difficulty in remembering instructions ($r=0.377$), but not with respondents' social characteristics or with difficulties in finding words (Table 6).

Table 6. Significant associations detected between respondent characteristics from childhood records of psychological examinations, study-related questionnaire, and 15D, with Spearman's correlation coefficient (two-tailed). ^a (1 = worst, 4= best), ^b(1= best, 0=worst), ^c(1 = best, 5 = worst). *** $p<0.001$, ** $p<0.01$, * $p<0.05$. Correlation coefficient in parentheses. Remembering instructions is abbreviated by Rememb. instruct.

	Education	Employment	Reading ^a	Word finding ^a	Rememb. instruct. ^a	Effect on life
PIQ	*(0.373)			** (0.475)		
VIQ					** (0.474)	
15Dscore ^b			*(-0.382)	*(0.363)	** (0.578)	*** (0.723)
15Dspeech ^c			*(0.397)		*(-0.381)	** (-0.580)
15Dusual activities ^c		*(0.392)				** (-0.509)
15Dmental function ^c		*(0.393)		*(-0.379)	** (-0.467)	** (-0.479)
15Ddistress ^c		*(0.440)			** (-0.575)	*(-0.383)

Low PIQ in childhood was associated with less education and with word-finding difficulties. Low VIQ in childhood was associated with difficulties in remembering instructions (Table 6).

The 15D score was associated with self-estimated problems in reading (and all other questions concerning reading and/or writing skills), difficulties in finding words, and difficulties in remembering instructions (Table 6). The mean 15D scores of those subjects who had difficulties in finding words and remembering instructions were 0.882 and 0.874, respectively, while the mean respondent score was 0.920 and the mean population score 0.950. The 15D score and the estimated effect of SLI on life were significantly related.

Proxy administration while filling out the 15D questionnaire was reported in 9 cases (27%) and 5 answers were missing. The same people probably used proxy administration when filling out the other questionnaire, although this was not enquired about separately. Proxy administration was associated with less education, not being employed, special class attendance, literacy problems, and difficulty in finding words and remembering instructions, as well as with low childhood PIQ and VIQ, and problems in speech.

The study questionnaire included a question about family history of language or learning problems. Only 3 subjects (9%) reported a positive family history. In two cases, the impaired were the respondents' own children and in one case a brother.

5.3.3 Study III

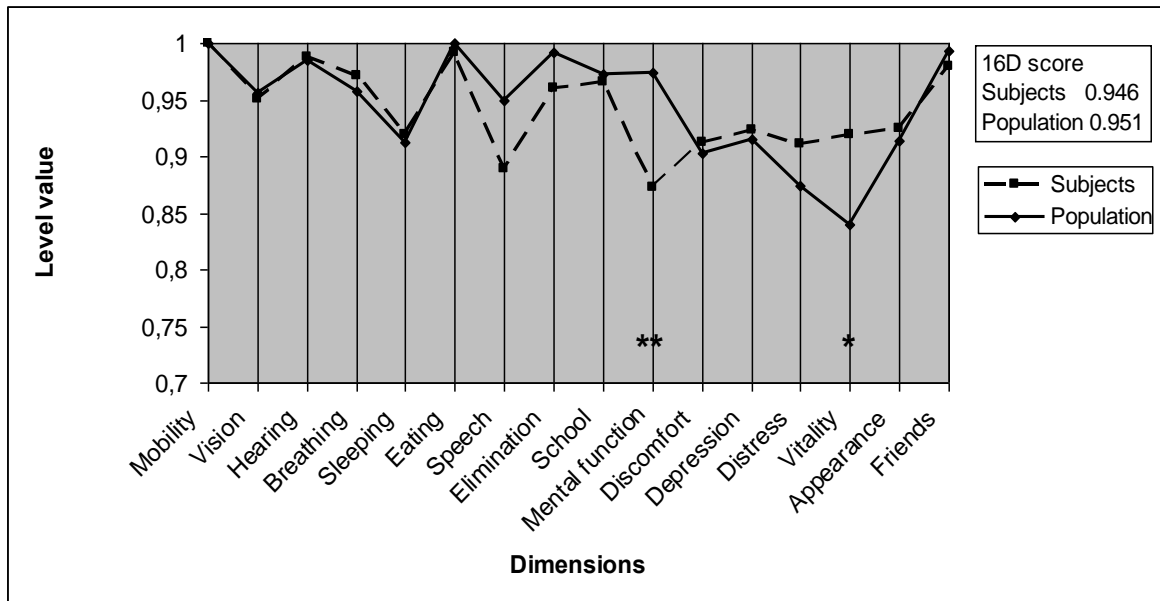


Figure 5 Health-related quality of life profiles of adolescents with childhood diagnosis of SLI (n=47) and population controls (n=235), measured by the 16D questionnaire. Significant differences emerged on the dimensions of mental function and vitality by independent samples t-test. ** p=0.001, * p=0.003.

The overall HRQoL of SLI adolescents was similar to that of normal controls. The group profiles differed somewhat, and on the dimensions of mental function (thinking clearly and logically) and vitality (feeling weary, tired, or weak) a significant difference emerged (Figure 5). Around 30% of the study group adolescents experienced some difficulties in mental functioning, whereas 31% reported some problems on the dimension of speech (ability to speak clearly, audibly, and fluently), but the difference between the study and control groups was not significant (p=0.023). Feelings of low vitality in the study group were related to low childhood VIQ (r=-0.43, p=0.004).

Table 7. Characteristics of adolescents with childhood diagnosis of specific language impairment regarding school and individual rehabilitation, based on questionnaires (Appendix 2).

Question	Response options	Proportion of subjects, n=48
Full-time special education	Never	39.5%
	Earlier	14.5%
	Presently	46%
Additional educational support	Never	38%
	Earlier	49%
	Presently	13%
Speech therapy	Only before school age	23%
	Before school and at 1 st and 2 nd grades	41%
	Before school and from 1 st grade onwards	31%
	Presently	2%
Occupational therapy	Earlier or presently	33%
Music therapy	Earlier or presently	23%
Neuropsychologic rehabilitation	Earlier or presently	4%
Physiotherapy	Earlier or presently	4%
Psychiatric care	Earlier or presently	4%
Literacy, by own perception	Good	27%
	Quite good	33%
	Quite poor	21%
	Poor	2%

Nearly half of the participants attended full-time special education at the time of the study (Table 7), and only six (13%) had neither received additional educational support nor attended special classes during their school years. Speech therapy had been the most usual form of rehabilitation, followed by occupational therapy and music therapy (Table 7). Own perception of low literacy was associated with having extra educational support ($r=0.44$, $p=0.005$). The 16D total score was not significantly related to any of the characteristics

listed in Table 7. The dimension of vitality correlated with self-reported problems in literacy ($r=0.51$, $p=0.001$), and the dimension of speech with long-term speech therapy ($r=0.38$, $p=0.007$).

5.3.4 Study IV

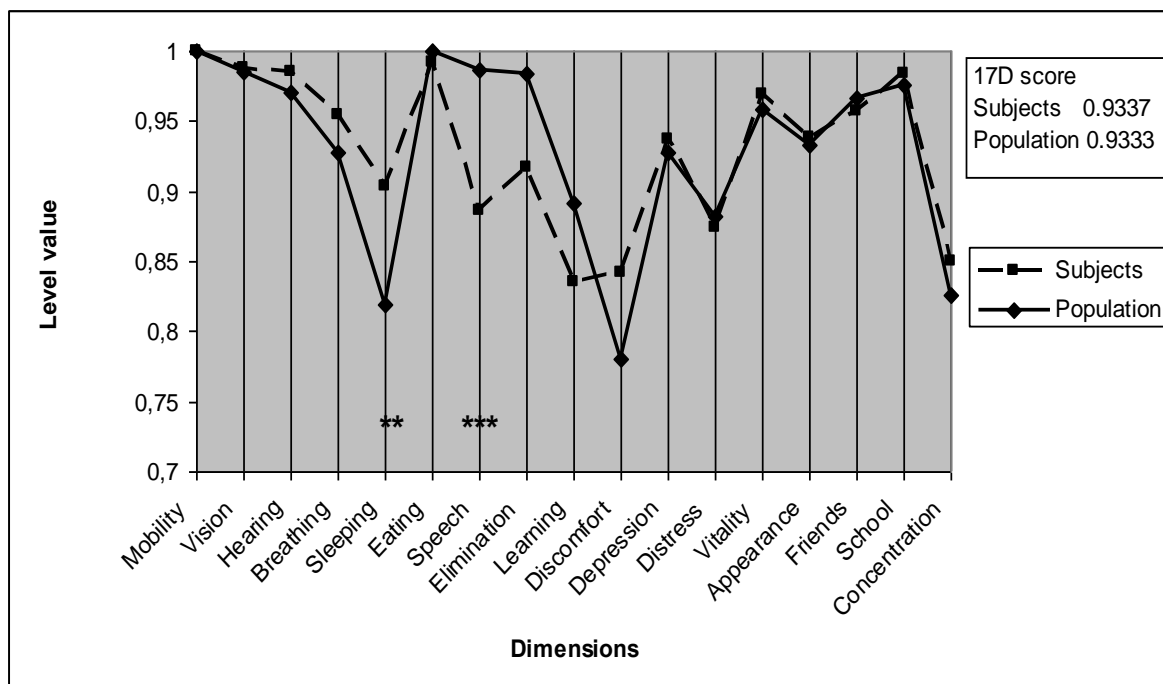


Figure 6 Health-related quality of life profiles of children (8-11 years) with diagnosis of specific language impairment ($n=51$) and population controls ($n=244$) measured by the 17D questionnaire. Significant differences emerged on the dimensions of sleep and speech using independent samples t-test. ** $p=0.001$, *** $p<0.000$

The 17D total score between pre-adolescents with SLI and controls did not differ. The 17D profiles visualize the differences between the groups on some of the dimensions (Figure 6); the only significant differences emerged on the dimensions of speech where subjects were worse off, and sleeping, where population controls were worse off. The distribution of answers to the most differing dimensions gives more detailed information (Table 8). Surprisingly, many pre-adolescents had sleeping problems, but further analysis of this finding was beyond the scope of this study. Learning difficulties were also common in both groups, although some more prevalent in the study group.

Table 8. Distribution of answers of pre-adolescents (8-11 years) with SLI (Subjects, n=51) and age- and gender-matched peers (Population, n=244) on some dimensions surveyed with the 17D health-related quality of life questionnaire. Best level (no problems)=1, worst level =5. ***p<0.000, **p=0.001.

17D dimension		Level 1	Level 2	Level 3	Level 4	Level 5
Sleep**	Subjects (S)	65%	35%	-	-	-
	Population (P)	42%	52%	4%	2%	0.0%
Speech***	S	63%	33%	2%	2%	-
	P	96%	3%	0.0%	0.8%	-
Elimination	S	84%	6%	8%	2%	-
	P	96%	3%	1%	-	-
Learning	S	39%	55%	6%	-	-
	P	59%	40%	2%	0.8%	-
Discomfort	S	45%	53%	2%	-	-
	P	33%	57%	8%	1%	0.8%

When comparing the 17D total score with background information and with psychologists' and speech therapists' tests (evaluating severity of language impairment), no associations reached statistical significance. Of the 17D dimensions, only feelings of distress significantly correlated with low VIQ ($p=0.008$, $r=0.40$).

Table 9. Information from the 17D questionnaire of pre-adolescents (8-11 years) regarding school and individual rehabilitation received.

Question	Response options	Proportion of subjects n=51
Full-time special education	Never	37%
	Earlier	10%
	Presently	53%
Additional educational support	Never	37%
	Earlier	22%
	Presently	41%
Speech therapy	Only before school-age	26%
	Before school and in lower grades	41%
	Presently	33%
Music therapy	Earlier or presently	31%
Occupational therapy	Earlier or presently	27%
Neuropsychologic rehabilitation	Earlier or presently	8%
Physiotherapy	Earlier or presently	4%

The questionnaire regarding school and individual rehabilitation shows that most children still attended full-time special education at the time of this study (Table 10). Of the 19 respondents attending normal classes, only four (8%) had never had any additional educational support. Every third child still received speech therapy, and 27 (53%) had also received other forms of individual rehabilitation. Ten children (20%) had undergone more than one other therapy. Full-time special class attendance at the time of the study or earlier was associated with low verbal IQ ($p=0.004$, $r=0.42$). Participants with ongoing speech therapy significantly ($p=0.002$, $r=-0.57$) more often had received other forms of rehabilitation, but did not differ from the other participants in linguistic or nonverbal performance.

5.4 Considerations and methodological issues

The results indicate that problems with language persist in the majority of school-aged SLI subjects (Tables 5, 7, 9), and also in a substantial proportion of adult SLI subjects (Table 4, Figure 4). The HRQoL was on average at population levels, but on some dimensions significant differences emerged (Figures 3, 5, and 6). In adult subjects, 25% to almost 50% reported diminished well-being on the dimensions of speech, usual activities, mental functioning, and distress (Table 4). It is probable that the control populations included also some individuals with speech, language, and literacy impairments because of the high prevalence of these disorders in the general population. However, participants in the control groups and in the SLI study groups are likely to suffer equally from common health problems (like asthma and musculoskeletal disorders). Thus, the detected differences in the dimensions of the 15D, 16D, and 17D between these two groups can be considered to result mainly from SLI.

The participants came from clinical samples of children examined in a hospital ward specialized in diagnosing and treating language impairment caused by various etiologies. Subjects, who were adults at the time of these studies (I, II), came from all over Finland, as resources for interventions when they were children were fewer. Their hospitalization occurred from 1970 to 1986; the reason for the wide range was that most treated children in the ward had nonspecific rather than specific language problems. The “diagnosis” of SLI was made retrospectively by going through the psychologists’ records and by selecting subjects with $PIQ \geq 85$ and $VIQ < 85$ and no other known cause for this discrepancy. The aim was to gather subjects as old as possible, but in sufficient numbers gain power for the statistical analysis; the total number of subjects was 56. The precise diagnosis received during hospitalization was not obtainable; nor were speech therapists’ records. However, our subjects can still be considered representative of children with SLI, and the reports from the adult phase strengthen this view; 72% had attended special schools or classes during at least part of their primary education and 84% had received extra tutoring at school. The 1915 population controls for Study I came from a national sample and were age- and gender-matched to subjects, whereas for Study II the population statistics were derived from national data.

The adolescent (Study III) and pre-adolescent (Study IV) subjects were primarily gathered based on two criteria: 1) diagnosis of receptive SLI (F80.2 or previously 3510A) from hospital data, and 2) age. The recruitment took place in fall 2003 and resulted in 67 adolescent and 64 pre-adolescent subjects. A retrospective evaluation of psychologists’ records was then performed to gather information on childhood performance, and for pre-adolescents speech therapists’ reports were also reviewed. These records revealed substantial heterogeneity in language performance in both samples; this often is the case in clinical SLI research. During the last decade our guidelines for diagnosis at the department of Phoniatics, Helsinki University Central Hospital, have mainly followed those suggested by Leonard (1998). This partly explains the high average VIQ in the pre-adolescent study group and some low PIQs in the adolescent study group. Although the respondent groups turned out to be rather small, they represent the original hospital sample well; nonrespondents did not differ from respondents in either study. The SLI samples came mainly and the population controls solely from the greater Helsinki area; the socioeconomic and other confounding environmental differences are therefore small. The gender distribution in all studies (I-IV) with a male preponderance resembles that of other clinical studies. Controls were matched to subjects by age and gender.

Available self-administered tools for measuring everyday coping are scarce, at least in Finnish. The HRQoL questionnaires, the 15D for adults and the 16D and 17D for children, were suitable for our research purposes. Generic HRQoL measures were applied to gather information relevant to everyday functioning rather than specific data on language-related performance and, in addition, to compare this information with that of a nonselected control population (I) and typical schoolchildren (III, IV). Furthermore, the HRQoL was compared with childhood language performance. Generic measures are often either single index scores or profile measures, but the 15D, 16D, and 17D provide both. This widens the possibilities for comparisons and gives more specific information.

The study questionnaires succeeded in adding knowledge on these clinical groups of subjects with SLI regarding schooling and interventions (III, IV), and in adult population also regarding social aspects and self-perceived abilities (II). More comprehensive questionnaires eliciting more information might, however, have served better. Our initial aim was to keep the questionnaires short and simple to get good response rates and representative study groups; this was achieved at least with adolescents and pre-adolescents. With longer questionnaires, the response rates would likely have dropped markedly.

One issue is the mode of administration. A questionnaire that requires reading and understanding written information can be troublesome for a population at risk of literacy problems. Adults reported proxy administration 9 times (27%), adolescents 0 times, and pre-adolescents only once. The risk of literacy problems in SLI populations is reported to be higher than 27%. The sentences in all questionnaires were quite short and simple (see appendices), and for the youngest age group a drawing illustrated each topic of the 17D-questionnaire (in the original Finnish version). Therefore, the mode of administration was no major obstacle, but some missing answers may have been due to reading problems.

6 Discussion

Normal variation regarding achievement of developmental milestones is quite wide, which makes evaluation of developmental disorders, including SLI, challenging. Most late-talkers do catch up (Rescorla, 2002; Dale et al., 2003), but family history and comprehension problems increase the risk of persistence (Lyytinen et al., 2005; Flax et al., 2009). Rutter (2008) calls for broad-based clinical assessments to differentiate normal variation from disorders that require more elaborate attention. He states that a disorder is more likely than normal variation “if the child’s babble is impaired in quantity or abnormal in quality; if there is limited use of babble in social communication; if an understanding of language is limited; if there is little attention to other people’s talk; if there is little communicative use of gesture; if there is poorly developed pretend play; if there is positive history of definite language problems; if socioemotional functioning is impaired; and/or if there are problems in motor control as indexed by marked drooling, problems in chewing, and/or problems in blowing.” If any of these problems are present, a disorder (SLI or other) should be considered and investigated. Our study participants had been in a hospital ward specialized in language impairments for broad-based, multidisciplinary clinical assessments to receive a diagnosis and plans for rehabilitation and follow-up.

In Finland, the earliest age of SLI diagnosis is around 3 years; this is when the first referral to specialist healthcare is usually made (Hannus et al., 2009). A Finnish study from a specialist clinic in one university hospital area reported that children referred to examinations were from 4 to 7 years (on average 5 years 9 months) (Asikainen, 2005). Hence, many of the children were close to school age when they received a diagnosis, but the majority (85%) had already had speech therapy intervention prior to the investigations. We do not have data on how early our study participants were first referred to specialist healthcare, but all adolescents and pre-adolescents reported having received speech therapy before the start of school.

A substantial number of children, but not all, who are diagnosed as having SLI, especially the receptive type, continue having impaired language performance later on (Beitchman et al., 1996a; Stothard et al., 1998; Tomblin et al., 2003), even as adults (Records et al., 1992; Johnson et al., 1999; Clegg et al., 2005). When trying to predict who are at greatest risk for later language problems, it is important to note that even the subjects with resolved language impairment continued to have problems in tasks involving verbal short-term memory (STM) (Stothard et al., 1998; Conti-Ramsden et al., 2001b), which, in turn, is often associated with problems in sentence comprehension and lexical learning (for review, see Montgomery, 2003), and even with diminished sociability (Donlan and Masters, 2000).

Individuals with a childhood diagnosis of SLI are at risk of later literacy problems (Snowling et al., 2000; Catts et al., 2008), lower educational (Records et al., 1992; Snowling et al., 2006; Conti-Ramsden et al., 2009) and occupational (Felsenfeld et al., 1994; Howlin et al., 2000; Clegg et al., 2005) attainments, poor social competence (Jerome et al., 2002; Conti-Ramsden and Botting, 2004; Tomblin, 2008), and psychiatric (Beitchman et al., 2001; Conti-Ramsden and Botting, 2008) and other comorbidities (Beitchman et al., 1996b; Hill, 2001; Conti-Ramsden et al., 2006). However, relatively little is known about the personal views and self-perceived everyday functioning of these individuals.

Self-perception regarding general well-being and functioning can be evaluated by interviews or by self-administered questionnaires. The emphasis on patients' own perceptions of their physical, mental, and social well-being has grown among health professionals, and different HRQoL measures have served as tools in numerous studies (Garratt et al., 2002, Sajid et al., 2008). An advantage of general HRQoL measures is the possibility of using them in healthy populations, thus enabling comparisons of populations with and without certain diseases or disorders. A disadvantage is the lack of sensitivity (Eiser, 1997). Cummins and associates (2004) strongly criticize the use of HRQoL measures for describing general well-being, even in relation to health. They speak in favor of an entity known as subjective well-being (SWB) in the social sciences, regarding it as a much more positive construct. They argue that SWB is a highly stable measure under homeostatic control; good or bad events can change SWB for a short while, but the homeostatic system will eventually return SWB to its previous level. A single question "Are you satisfied with your life?" could be sufficient for measuring SWB. Perhaps the homeostatic theory partly explains the insensitivity for which total HRQoL scores are often criticized. We used a statement "The effect of my childhood language impairment on life has been ..." in our study questionnaire (Study II, Appendix 4), and this single item correlated significantly with the 15D score.

6.1 Adults (I, II)

Studies that describe the life of adults with histories of SLI are few. Clegg and colleagues (2005) investigated 17 men in their mid-30s who had received a diagnosis of receptive SLI in childhood and had been followed up at several time-points. Their language performance still tended to be quite poor as adults (equivalent to that of 11-year-olds), but average PIQ was normal, as it was in childhood, despite a drop in late childhood and early adulthood. Compared with their peers matched for nonverbal IQ and with same-sex siblings, they considerably more often lived with their parents (30%) or otherwise nonindependently (60%). They were less educated and almost two-thirds had experienced prolonged unemployment. Half had a limited range of friendships, and 40% were awkward in social situations. Self-perceptions were not inquired. Living with parents and receiving a pension was very common in our adult subjects and differed significantly from the general population (Study II). Our age range was much wider than in Clegg's study, but the mean was about the same. The average PIQ was higher in our study group, the lowest score being 85 compared with their 70. The 19% of our subjects who still lived with their parents reported no more self-experienced problems than other participants, nor were they unemployed or on a pension more often, or needed help in filling out the questionnaires. Possible reasons for their non-independent form of living, other than childhood SLI, are unclear, but their self-perceptions of daily functioning and well-being were good. Study subjects who were unemployed or received a pension reported lower levels on the HRQoL dimensions of usual activities, mental functioning, and distress. This association can go both ways; not being employed exposes to impaired functioning on these dimensions, and impaired functioning exposes to difficulties in getting a job or can even lead to permanent displacement and a pension. Higher than average unemployment rates may result from lower educational levels, a finding also reported in other studies (Records et al., 1992; Felsenfeld et al., 1994). Furthermore, individuals with language impairments may be worse

off than other applicants trying to find a job. They can have problems in expressing themselves, and difficulties in dealing with social situations (Howlin et al., 2000; Voci et al., 2006), such as job interviews.

Self-perceived problems in finding words, remembering instructions or literacy were evident for nearly half of the adult participants, and because significant associations existed, many participants had a couple or all of these difficulties. Questions concerning these difficulties were asked to determine the level of everyday language functioning. Only a few subjects reported problems in reading and writing and even a smaller proportion felt that literacy problems had any effect on their daily life at home or at work. This is perhaps surprising considering current knowledge on this topic (e.g. Snowling et al., 2000). It is possible that had tests on literacy been performed, the results would have been subnormal, but the skills were deemed sufficient for the subjects themselves. Experiencing problems in remembering instructions were more prevalent. These problems can reflect deficiencies in short-term memory (STM), which is considered to be a predominant deficiency in SLI, and has even been proposed to be a clinical marker (Montgomery, 2003). Difficulties in remembering verbal instructions can also result from deficient vocabulary; young adults with SLI, especially with receptive problems, had poorer vocabularies than controls (Beitchman et al., 2008). It can also be a combination of both, resulting in difficulties in recalling long sentences with unfamiliar words. The question concerning difficulties in finding words when explaining things was included in the questionnaire because of clinical experience and studies reporting that naming difficulties are often present in SLI (Lahey and Edwards, 1999; McGregor et al., 2002). These difficulties are apparently present in a substantial proportion of adults with childhood SLI. The underlying causes for naming problems are unclear, but in their review Brackenbury and Pye (2005) summarize that they may result from difficulties with both word retrieval and word storage, although these have often been considered competing hypotheses. Participants who still reported problems in remembering instructions and/or finding words also had lower 15D scores, and lower levels on the 15D dimensions of mental functioning, distress, and speech. They were also more likely to use proxies. Hence, it seems that these were the subjects with the most problems in everyday functioning and self-perceived well-being.

A quality of life study of young adults with a history of SLI reported good satisfaction with life and various life domains, with no difference compared with controls, but feelings of less control over their lives. The authors speculate that, due to the early phase of their adult life, they possibly were too young to realize the opportunities denied them (Records et al., 1992). Our adult population was already in a later phase of adulthood, but their self-perceived total HRQoL was on average only slightly lower than that of their peers. Taking a closer look at the 15D scores and self-reports of adult life situations, those adults who reported problems in finding words and in remembering instructions had on average much lower 15D scores. In the study group, the individual differences were large, perhaps because they had different types of SLI, and the persistence rate varied, which is often the case in studies of SLI (Felsenfeld et al., 1992; Stothard et al., 1998; Mawhood et al., 2000, Conti-Ramsden and Durkin, 2008). However, the wide variation can also result from other things. Conti-Ramsden and Durkin (2008) reported that shyness, a temperament feature, played an important mediating role between low language ability and low global self-esteem. The role of temperament features in SLI and its long-term consequences would be an interesting topic for future research.

Looking beyond the single index score of the HRQoL, some differences between the 15D profiles of adults with histories of SLI and their population controls emerged. When considering which dimensions of the 15D could best describe daily functioning and participation according to the ICF framework (ICF, 2001), speech, usual activities, and mental functioning (Appendix 1) seem to be good candidates. On all of these dimensions, the study group was worse off than the population controls. Self-experienced problems in speech can be explained by the subjects' background in SLI. The psychologists' reports of speech problems in childhood are very inaccurate, and no further conclusions can be drawn from them. In addition, self-perceived problems in mental functioning and in usual activities can be explained by the long-term effects of SLI; these findings are in agreement with earlier studies that have included adult phases of life (Felsenfeld et al., 1994, Howlin et al., 2000, Clegg et al., 2005). Feelings of distress were also significantly more common in the study group, which is also in line with studies reporting higher rates of anxiety disorders in SLI populations (Beitchman et al., 2001; Conti-Ramsden and Botting, 2008). In conclusion, our results indicate that childhood SLI predisposes to impaired adult daily functioning. Conti-Ramsden (2008) states that it is difficult from an individual's language profile to predict associated difficulties and later outcome, but the diagnosis of SLI per se clearly puts one at risk of poor outcome on domains ranging from literacy impairment to emotional health.

Childhood VIQ seemed to have some prognostic value for certain components of self-perceived functioning and participation in adulthood (mental functioning, usual activities, and remembering instructions), but low VIQ was not significantly associated with living situation or employment status, factors in which the study group differed significantly from the general population. Childhood VIQ reflects, to some extent, the severity of SLI and measures mostly its receptive components. Therefore, our study further strengthens the view that receptive difficulties are more likely to persist and have more negative long-term effects (Felsenfeld et al., 1992, Clegg et al., 2005, Beitchman et al., 2008). Low childhood PIQ predicted difficulties in finding words and lower educational level in adulthood. Higher PIQ perhaps offers a means for compensating language difficulties, thus maintaining the individual's motivation for further education. The influence of the level of nonverbal performance has been questioned recently by Tomblin (2008); 16-year-olds with SLI and general delay (language difficulties and low nonverbal performance) showed little differences regarding school performance and social participation outcomes. The participants had, however, not yet started their independent phase of life and some differences may emerge later.

A strong hereditary predisposition for SLI (Bishop, 2006) was not seen in our study (II). The low figures of reported family history of SLI in the adult study group could be explained by subjects' awareness of language and literacy difficulties and their long-term persistence having been - and still being - quite low. Even now, when parents are asked about language and/or learning difficulties in the family, their first answer is negative, but later, as their awareness of the problem increases and they start talking about it with their relatives, they report cousins or aunts or nieces with similar problems.

6.2 Adolescents and pre-adolescents (III,IV)

Some studies of children with SLI have utilized subjects' self-perception. Young school-aged children with SLI had positive self-perceptions (Lindsay and Dockrell, 2000; Jerome et al., 2002), even though their parents and teachers reported behavioral difficulties (Lindsay and Dockrell, 2000). Slightly older children (10-13 years) perceived themselves more negatively than their normal language peers (Jerome et al., 2002). Our pre-adolescent (8-11 years) study group did not differ from controls on dimensions of the 17D that reflect self-esteem i.e. school, friends, and personal appearance. Our participants did, however, perceive themselves significantly more negatively than peers on the dimension of speech, where about 35% reported some problems. Self-perceived problems in learning were also more prevalent in the study group (61%), although surprisingly common among controls as well (41%). Social comparison behaviour likely increases with age and growing demands for language competence at school (both academic and social) may increase awareness of one's difficulties (Farmer, 2006). For problems in expressing themselves and in learning, the pre-adolescent study group continued to get support including special education, extra tutoring, and/or speech therapy. Continuing support at this age seems to also be the case elsewhere (Conti-Ramsden, 2008). The supportive actions that the pre-adolescents receive can be considered successful since even though the majority still experienced language-related difficulties and needed extra support, the total HRQoL score was similar to that of their peers.

Two large-scale follow-up studies of children with SLI and controls, the Iowa Longitudinal Study (Tomblin, 2008) and the Manchester Language Study (Conti-Ramsden, 2008), have recently entered a phase where the subjects are finishing compulsory education. The studies also included some self-reporting. Adolescents with SLI reported good overall satisfaction with life and showed no difference from peers with typical language development (Tomblin, 2008). This is in line with our results of total HRQoL score (Study III). In Tomblin's study, adolescents with SLI described lower levels of social activity than normal language peers; 5.4% had levels considered sufficiently low to be of clinical significance. They also had poorer self-worth than peers with regard to mental competence and global self-esteem, but not social appearance (Tomblin, 2008). The results regarding mental competence resemble our findings; adolescents with SLI differed significantly from peers on the dimension of mental functioning, with 30% reporting some problems in thinking clearly and logically. In the study by Durkin and Conti-Ramsden (2007), self-perception of the quality of friendships was poorer among 16-year-olds with SLI than among non-SLI peers, but 60% still experienced good quality of friendships. In their study, poor receptive language at 7 years of age was a strong predictor of poor quality of friendships at age 16. In our study, by contrast, adolescents did not experience problems in making friends. Of the childhood measures, low VIQ was related to reporting lower levels in the dimension of vitality (feeling healthy and energetic). Conti-Ramsden and Botting (2008) reported that adolescents with SLI had significantly more anxiety and depression, and although these were not directly the result of poor language, an association existed between emotional health and receptive language. Receptive language difficulties put individuals with SLI at risk for feelings of distress and anxiety, and these certainly have negative effects on personal well-being. More adolescents in our study group received educational support than the 15-year-olds investigated by Stothard and colleagues (1998). Of our study group, 46% were still receiving full-time special education, which is clearly more than reported by other studies (Stothard et al., 1998; Conti-Ramsden, 2008).

This indicates not only continuing problems, but also continuing support for those who need it.

When combining the results from our studies on adolescents and pre-adolescents (III, IV), measuring HRQoL appears to give professionals useful information regarding subjects' self-perceived everyday functioning and well-being, information that has usually been lacking. Childhood performance offered some clues for recognizing the children at greatest risk for problems in daily functioning and participation. Measuring HRQoL could thus serve as one of the tools in clinical follow-up on a more individual level, enabling changes to be detected and appropriate actions taken. Good response rates in these studies indicate good applicability of the tool, and, in the future, it could perhaps be applied to larger populations of language-impaired children such as those in special classes.

7 Conclusions

- A substantial proportion of adults with childhood SLI reported diminished HRQoL and daily functioning, were still living with their parents, or were receiving a pension. Continuing difficulties in remembering instructions and in finding words indicated other problems as well. Most subjects had received educational support when attending school. Childhood receptive language problems showed some prognostic value regarding negative outcome.
- The adolescents with childhood SLI reported mainly good HRQoL, but more problems in mental functioning than their controls. The majority received extra support at school, even in the upper grades, but speech therapy had finished earlier.
- The pre-adolescents with a diagnosis of SLI reported mainly good HRQoL, but more problems regarding speech than their controls. The majority received educational support at school, and one-third continued to receive speech therapy.
- The HRQoL tools showed good applicability and could be used in a more individualized manner in the follow-up of children with SLI, especially those with receptive-type SLI.

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Appendices

Appendix 1

QUALITY OF LIFE QUESTIONNAIRE (15D©)

Please read through all the alternative responses to each question before placing a cross (x) against the alternative which best describes your present health status. Continue through all 15 questions in this manner, giving only one answer to each.

QUESTION 1. MOBILITY

- 1 () I am able to walk normally (without difficulty) indoors, outdoors and on stairs.
- 2 () I am able to walk without difficulty indoors, but outdoors and/or on stairs I have slight difficulties.
- 3 () I am able to walk without help indoors (with or without an appliance), but outdoors and/or on stairs only with considerable difficulty or with help from others.
- 4 () I am able to walk indoors only with help from others.
- 5 () I am completely bed-ridden and unable to move about.

QUESTION 2. VISION

- 1 () I see normally, i.e. I can read newspapers and TV text without difficulty (with or without glasses).
- 2 () I can read papers and/or TV text with slight difficulty (with or without glasses).
- 3 () I can read papers and/or TV text with considerable difficulty (with or without glasses).
- 4 () I cannot read papers or TV text either with glasses or without, but I can see enough to walk about without guidance.
- 5 () I cannot see enough to walk about without a guide, i.e. I am almost or completely blind.

QUESTION 3. HEARING

- 1 () I can hear normally, i.e. normal speech (with or without a hearing aid).
- 2 () I hear normal speech with a little difficulty.
- 3 () I hear normal speech with considerable difficulty; in conversation I need voices to be louder than normal.
- 4 () I hear even loud voices poorly; I am almost deaf.
- 5 () I am completely deaf.

QUESTION 4. BREATHING

- 1 () I am able to breathe normally, i.e. with no shortness of breath or other breathing difficulty.
- 2 () I have shortness of breath during heavy work or sports, or when walking briskly on flat ground or slightly uphill.
- 3 () I have shortness of breath when walking on flat ground at the same speed as others my age.
- 4 () I get shortness of breath even after light activity, e.g. washing or dressing myself.
- 5 () I have breathing difficulties almost all the time, even when resting.

QUESTION 5. SLEEPING

- 1 () I am able to sleep normally, i.e. I have no problems with sleeping.
- 2 () I have slight problems with sleeping, e.g. difficulty in falling asleep, or sometimes waking at night.
- 3 () I have moderate problems with sleeping, e.g. disturbed sleep, or feeling I have not slept enough.
- 4 () I have great problems with sleeping, e.g. having to use sleeping pills often or routinely, or usually waking at night and/or too early in the morning.
- 5 () I suffer severe sleeplessness, e.g. sleep is almost impossible even with full use of sleeping pills, or staying awake most of the night.

QUESTION 6. EATING

- 1 () I am able to eat normally, i.e. with no help from others.
- 2 () I am able to eat by myself with minor difficulty (e.g. slowly, clumsily, shakily, or with special appliances).
- 3 () I need some help from another person in eating.
- 4 () I am unable to eat by myself at all, so I must be fed by another person.
- 5 () I am unable to eat at all, so I am fed either by tube or intravenously.

QUESTION 7. SPEECH

- 1 () I am able to speak normally, i.e. clearly, audibly and fluently.
- 2 () I have slight speech difficulties, e.g. occasional fumbling for words, mumbling, or changes of pitch.
- 3 () I can make myself understood, but my speech is e.g. disjointed, faltering, stuttering or stammering.
- 4 () Most people have great difficulty understanding my speech.
- 5 () I can only make myself understood by gestures.

QUESTION 8. ELIMINATION

- 1 () My bladder and bowel work normally and without problems.
- 2 () I have slight problems with my bladder and/or bowel function, e.g. difficulties with urination, or loose or hard bowels.
- 3 () I have marked problems with my bladder and/or bowel function, e.g. occasional 'accidents', or severe constipation or diarrhea.
- 4 () I have serious problems with my bladder and/or bowel function, e.g. routine 'accidents', or need of catheterization or enemas.
- 5 () I have no control over my bladder and/or bowel function.

QUESTION 9. USUAL ACTIVITIES

- 1 () I am able to perform my usual activities (e.g. employment, studying, housework, free-time activities) without difficulty.
- 2 () I am able to perform my usual activities slightly less effectively or with minor difficulty.
- 3 () I am able to perform my usual activities much less effectively, with considerable difficulty, or not completely.
- 4 () I can only manage a small proportion of my previously usual activities.
- 5 () I am unable to manage any of my previously usual activities.

QUESTION 10. MENTAL FUNCTION

- 1 () I am able to think clearly and logically, and my memory functions well
- 2 () I have slight difficulties in thinking clearly and logically, or my memory sometimes fails me.
- 3 () I have marked difficulties in thinking clearly and logically, or my memory is somewhat impaired.
- 4 () I have great difficulties in thinking clearly and logically, or my memory is seriously impaired.
- 5 () I am permanently confused and disoriented in place and time.

QUESTION 11. DISCOMFORT AND SYMPTOMS

- 1 () I have no physical discomfort or symptoms, e.g. pain, ache, nausea, itching etc.
- 2 () I have mild physical discomfort or symptoms, e.g. pain, ache, nausea, itching etc.
- 3 () I have marked physical discomfort or symptoms, e.g. pain, ache, nausea, itching etc.
- 4 () I have severe physical discomfort or symptoms, e.g. pain, ache, nausea, itching etc.
- 5 () I have unbearable physical discomfort or symptoms, e.g. pain, ache, nausea, itching etc.

QUESTION 12. DEPRESSION

- 1 () I do not feel at all sad, melancholic or depressed.
- 2 () I feel slightly sad, melancholic or depressed.
- 3 () I feel moderately sad, melancholic or depressed.
- 4 () I feel very sad, melancholic or depressed.

5 () I feel extremely sad, melancholic or depressed.

QUESTION 13. DISTRESS

1 () I do not feel at all anxious, stressed or nervous.

2 () I feel slightly anxious, stressed or nervous.

3 () I feel moderately anxious, stressed or nervous.

4 () I feel very anxious, stressed or nervous.

5 () I feel extremely anxious, stressed or nervous.

QUESTION 14. VITALITY

1 () I feel healthy and energetic.

2 () I feel slightly weary, tired or feeble.

3 () I feel moderately weary, tired or feeble.

4 () I feel very weary, tired or feeble, almost exhausted.

5 () I feel extremely weary, tired or feeble, totally exhausted.

QUESTION 15. SEXUAL ACTIVITY

1 () My state of health has no adverse effect on my sexual activity.

2 () My state of health has a slight effect on my sexual activity.

3 () My state of health has a considerable effect on my sexual activity.

4 () My state of health makes sexual activity almost impossible.

5 () My state of health makes sexual activity impossible.

Appendix 2

QUALITY OF LIFE QUESTIONNAIRE (16D©)

Instructions:

This questionnaire is all about how you are right now. Please, read the questions carefully.

Each question has five answers to choose from. Choose the answer that is closest to the way you are today and mark it with a cross (X).

Question 1 [VITALITY]

I feel healthy and energetic

I feel slightly weary, tired or weak

I feel moderately weary, tired or weak

I feel very weary, tired or weak

I feel extremely weary, tired or weak

Question 2 [VISION]

I can easily see words in books and TV text without glasses

I can easily see words in books and TV text with glasses

I cannot easily see words in books and TV text, even with glasses

I cannot read books and TV text, even with glasses, but I can see well enough to walk without a guide

I cannot see well enough to walk without a guide, i.e. I am almost or totally blind

Question 3 [BREATHING]

I do not have any breathing problems

I get breathless during heavy work or sports, or when walking fast on flat ground or slightly uphill (not the same as being out of breath after running)

I get breathless when walking on flat ground

- I get breathless even with the lightest activity, e.g. washing or dressing myself
- I am breathless almost all the time, even when resting

Question 4 [DISTRESS]

- I do not feel at all anxious, stressed or nervous
- I feel slightly anxious, stressed or nervous
- I feel moderately anxious, stressed or nervous
- I feel very anxious, stressed or nervous
- I feel extremely anxious, stressed or nervous

Question 5 [HEARING]

- I hear normal speech well without a hearing aid
- I hear normal speech with slight difficulty, but I don't need a hearing aid
- I need a hearing aid, but I can hear well with it
- I hear poorly even with a hearing aid
- I am totally deaf

Question 6 [SLEEP]

- I have no problems with sleeping
- I have slight problems with sleeping, e.g. it is sometimes difficult to fall asleep, or I sometimes wake up at night
- I have moderate problems with sleeping, e.g. restless sleep, or feeling I have not slept enough
- I have great problems with sleeping, e.g. I have to take sleeping pills often or every night, or I usually wake at night or too early in the morning
- I find sleeping almost impossible, even with full use of sleeping pills, or I stay awake most of the night

Question 7 [EATING]

- I am able to eat without any difficulty
- I am able to eat with slight difficulty (e.g. slowly, clumsily or with special appliances)
- I need some help from another person in eating
- I am not able to feed myself at all, so I must be fed by someone else
- I am unable to eat at all, so I must be fed by tube or directly into my blood

Question 8 [DISCOMFORT and symptoms]

- I have no physical troubles or symptoms, e.g. pain, ache, feeling sick or itchy
- I have slight physical troubles or symptoms, e.g. pain, ache, feeling sick or itchy
- I have moderate physical troubles or symptoms, e.g. pain, ache, feeling sick or itchy
- I have severe physical troubles or symptoms, e.g. pain, ache, feeling sick or itchy
- I have unbearable physical troubles or symptoms, e.g. pain, ache, feeling sick or itchy

Question 9 [SPEECH]

- I am able to speak clearly, audibly and fluently
- I have slight difficulties with speaking, e.g. I sometimes stumble over words, or mumble, or my voice breaks
- I can make myself understood, but my speech is e.g. disjointed, faltering, stuttering or stammering.
- Most people have great difficulty understanding my speech
- I can only make myself understood by gestures

Question 10 [APPEARANCE]

- My weight, height and what I look like do not bother me
- My weight, height or what I look like bother me slightly
- My weight, height or what I look like bother me moderately
- My weight, height or what I look like bother me seriously
- My weight, height or what I look like bother me extremely

Question 11 [SCHOOL and hobbies]

- My state of health does not interfere with going to school or having hobbies
- My state of health makes it slightly difficult to go to school or have hobbies
- My state of health makes it moderately difficult to go to school or have hobbies
- My state of health makes it almost impossible to go to school or have hobbies
- My state of health makes it impossible to go to school or have hobbies

Question 12 [MOBILITY]

- I can walk easily without an appliance (e.g. crutches or wheelchair)
- I have difficulty in walking, but I am able to walk without an appliance, e.g. crutches or wheelchair
- I cannot walk without an appliance, e.g. crutches or wheelchair, but with it I can move around well
- Moving around is very difficult, even with an appliance
- I cannot move around at all and I am bedridden

Question 13 [FRIENDS]

- My state of health does not interfere with making friends or being with them
- My state of health makes it slightly difficult to make friends or be with them
- My state of health makes it moderately difficult to make friends or be with them
- My state of health makes it almost impossible to make friends or be with them
- My state of health makes it impossible to make friends or be with them

Question 14 [MENTAL FUNCTION]

- I am able to think clearly and logically
- I have slight problems in thinking clearly and logically
- I have moderate problems in thinking clearly and logically
- I have serious problems in thinking clearly and logically
- I am totally confused and unsure of the time and where I am

Question 15 [ELIMINATION]

- My bladder and bowels work normally
- I have a slight problem with my bladder or bowels, e.g. difficulties with urination, or hard or loose stools
- I have moderate problems with my bladder or bowels, e.g. occasional ,accidents', or bad constipation or diarrhoea
- I have serious problems with my bladder or bowels, e.g. frequent ,accidents', or need for enemas or catheters
- I have no control at all over my bladder or bowel functions

Question 16 [DEPRESSION]

- I do not feel at all sad, melancholic or depressed
- I feel slightly sad, melancholic or depressed

- I feel moderately sad, melancholic or depressed
- I feel very sad, melancholic or depressed
- I feel extremely sad, melancholic or depressed

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Text in square brackets [] is added later by author EA .

Appendix 3

QUALITY OF LIFE QUESTIONNAIRE (17D©)

This questionnaire is all about how you are right now. Please, read the questions carefully. Each question has five answers to choose from. Choose the answer that is closest to the way you are today.

Question 1 is about how well you can see

How well can you see words in books and on the classroom board?

1. Well, without glasses
2. Well, with glasses
3. Poorly, even with glasses
4. I cannot see writing even with glasses, but I can see well enough to walk around without a guide
5. I cannot see enough to walk around without a guide (I am almost or totally blind)

Question 2. How well can you hear?

1. I can hear normal speech well without a hearing aid
2. Normal speech is a bit difficult to hear, but I do not need a hearing aid
3. I need a hearing aid, but I can hear well with it
4. I hear poorly even with a hearing aid
5. I am totally deaf.

Question 3 is about moving around

Can you walk without using an aid?

1. Yes, without difficulty
2. Yes, but walking is hard without an aid (like crutches or wheelchair)
3. I cannot walk without an aid (like crutches or wheelchair), but with it I can move around well
4. Moving around is hard even with an aid (like crutches or wheelchair)
5. I cannot move around at all

Question 4. Are you able to feed yourself?

1. Yes, without any difficulty
2. Yes, with a little difficulty (I am a bit slow, or clumsy, or I need a special aid, for example)
3. Yes, if someone helps me a little all the time
4. I cannot feed myself, so I must be fed by someone else
5. I cannot eat at all, so I must be fed by tube or directly into my veins

Question 5. How well do you sleep?

1. I fall asleep easily and I sleep well
2. It is sometimes hard to fall asleep, or I sometimes have nightmares or wake up at night
3. It is often hard to fall sleep, or I often have nightmares or wake up at night
4. It is nearly always hard to fall asleep, or I have nightmares or wake up almost every night
5. I am awake most of the night

Question 6. Do you have any problems going to the toilet?

1. No
2. I have small problems (sometimes it takes a long time in the toilet, or I have to go often)
3. I sometimes have ‚accidents‘ (I mess or wet my trousers or bed), or I often get diarrhoea, or I can't go to the toilet for days
4. I often have ‚accidents‘, or I need a catheter or medicine to help me go to the toilet
5. I nearly always mess or wet my trouser

Question 7. Everyone gets out of breath when they run fast, but do you otherwise get breathless or have other breathing problems?

1. No

2. Yes, when running slowly or walking fast
3. Yes, when walking slowly
4. Yes, even after light activity like washing or dressing myself
5. Yes, almost all the time, even when resting

Question 8. Do you have physical troubles or symptoms like pain, ache, feeling sick, or itchy?

1. Not at all
2. A little
3. Quite a lot
4. Very much
5. It is unbearable

Question 9. People can feel healthy and energetic, or they can feel ill, tired and weak.

Do you feel

1. healthy and energetic
2. a little ill, tired or weak
3. quite ill, tired or weak
4. very ill, tired or weak
5. extremely ill, tired or weak

Question 10. Do you feel scared or tense?

1. Not at all
2. A little scared or tense
3. Quite scared or tense
4. Very scared or tense
5. Extremely scared or tense

Question 11. Are you happy with your weight, your height and how you look?

1. I am completely happy
2. I am quite happy
3. I am rather unhappy
4. I am very unhappy
5. I am extremely unhappy

Question 12. Does your state of health make it difficult to go to school or have hobbies?

1. Not at all
2. A little (like not being able to do sports classes)
3. Quite a lot (like I have difficulty walking or I miss school often because of sickness, or I am not able to have some hobbies)
4. My state of health makes it almost impossible to go to school or have hobbies
5. My state of health makes it impossible to go to school or have hobbies

Question 13. Does your state of health make it difficult to make friends or be with them?

1. Not at all
2. A little
3. Quite a lot
4. My state of health makes it almost impossible to make friends or be with them
5. My state of health makes it impossible to make friends or be with them

Question 14.

Sometimes it is hard to concentrate on the same thing for long, when thoughts jump from one thing to another

How long can you concentrate on the same thing?

1. a long time
2. quite a long time
3. only a short time
4. my thoughts are always jumping from one thing to another, and I can't really concentrate much
5. I'm so restless that I can't concentrate for a moment,

Question 15. How well can you learn new things and remember them?

1. I learn new things easily and remember them well
2. It is a little hard for me to learn new things or remember them

3. It is quite hard for me to learn new things or remember them
4. It is very hard for me to learn new things or remember them
5. I cannot learn or remember things

Question 16. How clearly can you speak?

1. I can speak clearly
2. It is a little hard for me to speak clearly
3. It is quite hard for me to speak clearly
4. Most people have difficulty understanding me when I speak
5. I can only make myself understood with signing

Question 17.

People are not always cheerful and happy. Sometimes they can feel quite sad, unhappy and depressed.

Do you feel

1. cheerful and happy
2. a little sad, unhappy or depressed
3. quite sad, unhappy or depressed
4. very sad, unhappy or depressed
5. extremely sad, unhappy or depressed

Thank you very much!

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Appendix 4

1) Name

2) Date of birth

3) Form of living: 1. married or living with a partner, 2. alone with children, 3. with parents, 4. alone

4) Education: 1. primary school level (minimum of 9 years obligatory education), 2. trade school (secondary level), 3. gymnasium (secondary level), 4. college level (tertiary level), 5. university level (tertiary+ level)

5) I went to a special class: 1. yes, entire school time, 2. yes, part of school time, 3. never

6) I received special tutoring during school: 1. yes, 2. no

7) Employment: 1. employed, 2. unemployed, 3. pensioned

8) I think my ability to read is 1. good, 2. quite good, 3. quite poor, 4. poor

9) I think my ability to write is 1. good, 2. quite good, 3. quite poor, 4. poor

10) In everyday life, I cope with my abilities to read and write 1. well, 2. quite well, 3. quite poorly, 4. poorly

11) At work, I cope with my abilities to read and write 1. well, 2. quite well, 3. quite poorly, 4. poorly

12) When talking, I have difficulties in finding words 1. mostly, 2. often, 3. seldom, 4. never

13) I have difficulties in remembering long or complicated instructions 1. mostly, 2. often, 3. seldom, 4. never

14) My parents, siblings, or children have literacy problems or linguistic problems

1. no, 2. yes, who: _____

15) The effect of my language impairment diagnosed in childhood on my life has been 1. very big, 2. quite big, 3. quite little, 4. very little

Appendix 5

Choose the most suitable alternative for each question and circle it.

1. What is your form of school?

1. normal class
2. special class
3. special before, now normal class
4. normal before, now special class
5. other _____

2. Have you received special education (extra support)?

1. no, never
2. yes before, not any more
3. yes

3. Are you having speech therapy?

1. not any more, only before school-age
2. not any more, but before school-age and in the first and second grades
3. yes, all through the lower grades (first six)
4. yes

4. Have you had other rehabilitation? What?

1. music therapy
2. occupational therapy
3. neuropsychological rehabilitation
4. other _____

5. If you have finished school, are you now

1. in trade school
2. in gymnasium (secondary level)
3. working
4. unemployed

6. Do you consider your reading and writing abilities to be

1. good
2. quite good
3. quite poor
4. poor

THANK YOU FOR YOUR ANSWERS!

Appendix 6

QUESTIONNAIRE for 8-11 year old children

Name: _____

Date of birth: _____

Choose the most suitable alternative for each question.

1. What is your form of school?

1. normal class,
2. special class,
3. special before, now normal class,
4. normal before, now special class.
5. other _____

2. Have you received special education (extra support)?

1. no, never
2. yes before, not any more,
3. yes.

3. Are you having speech therapy?

1. not any more, only before school-age
2. not any more, but before school-age and on 1. and 2. grade
3. yes.

4. Have you had other rehabilitation? What?

1. music therapy
2. occupational therapy
3. neuropsychological rehabilitation.
4. other _____

THANK YOU FOR YOUR ANSWERS!