

**UNIVERSITY OF JYVÄSKYLÄ**

**COPING WITH AND ACCOMMODATING FOR  
LINGUISTIC AND COMMUNICATIVE PROBLEMS IN ASPERGER'S  
SYNDROME**

**A Grounded Theory Study of Four Autobiographies**

**A Pro Gradu Thesis in English**

**by**

**Antti Korhonen**

**Department of Languages**

**2006**

HUMANISTINEN TIEDEKUNTA  
KIELTEN LAITOS

Antti Korhonen

COPING WITH AND ACCOMMODATING FOR LINGUISTIC AND  
COMMUNICATIVE PROBLEMS IN ASPERGER'S SYNDROME  
A Grounded Theory Study of Four Autobiographies

Pro Gradu -tutkielma

Englannin kieli  
Helmikuu 2006

105 sivua

Tutkimuksen kohteena olivat kielelliset ja kommunikatiiviset ongelmat Aspergerin syndroomassa (AS) sekä AS-henkilön ja muiden ihmisten käyttämät selviämiskeinot näiden ongelmien kanssa. Aineistona oli neljä AS-henkilöiden kirjoittamaa, julkaistua omaelämäkertaa.

Tutkimuskysymyksinä olivat: 1. Millaisia omia kielellisiä ja kommunikatiivisia ongelmia AS-henkilöt raportoivat omaelämäkerroissaan? 2. Millaisia keinoja AS-henkilöt kertovat itse käyttäneensä ja toisten käyttäneen kielellisten ja kommunikatiivisten ongelmien kanssa selviämiseen? ja 3. Miten AS-diagnoosi vaikuttaa siihen miten AS-henkilöt kokevat kielelliset ja kommunikatiiviset ongelmat ja selviämiskeinot? Tutkimus keskittyy AS-henkilöihin aktiivisina viestijöinä ja kielen käyttäjinä psykologisen hyvinvoinnin näkökulmasta. Menetelmänä käytettiin grounded theorya, jota ei ole aikaisemmin käytetty kirjoitettujen omaelämäkertojen analyysissa.

Kielellisinä ja kommunikatiivisten ongelmina voitiin erottaa kaiken kaikkiaan 15 erilaista ongelmaa, jotka jakaantuivat kolmeen pääryhmään: kielen käytön ja kommunikaation joustavuuteen liittyviin ongelmiin, ongelmiin kielen käytön ja kommunikaation kontekstuaalisten piirteiden kanssa, sekä kehityksellisiin ongelmiin kielen käytössä ja kommunikaatiossa. Kielellisten ja kommunikatiivisten ongelmien esiintyminen vaihteli läheisistä ihmissuhteista koulutus- ja työympäristöön.

Omaelämäkerroista löytyi 12 erilaista kirjoittajien omaa keinoa kielellisten ja kommunikatiivisten ongelmien kanssa selviämiseen, sekä neljä muiden ihmisten käyttämää keinoa. Suuri osa keinoista havaittiin toimiviksi, mutta joukossa oli myös sekä kirjoittajien itsensä että muiden käyttämiä keinoja jotka eivät toimineet.

Kirjoittajat kuvasivat diagnoosin merkityksen keskeisenä ongelmien määrittelyssä itselle ja muille sekä selviytymiskeinojen löytämisessä ongelmien käsittelyyn. Diagnoosin puuttuminen aiheutti kirjoittajille ongelmia mm. omien ja toisten (ml. terveydenhoitoalan ammattilaiset) tekemien väärin tulkintojen muodossa.

Tulokset viittaavat siihen, että osa aspergerhenkilöistä pyrkii käyttämään aktiivisesti ja monipuolisesti selviämiskeinoja kohtaamiensa ongelmien kanssa. Lisäksi ilmeni, että diagnoosin varhaisuus/myöhäisyys on merkityksellinen, paitsi soveltuvien interventioiden löytämisessä, myös aspergerhenkilön itsetunnon ja identiteetin kehittymisen kannalta.

Asiasanat: Asperger's syndrome, Asperger syndrome, autobiography, language, communication, coping, accommodation, grounded theory, qualitative research

## CONTENTS

1 INTRODUCTION.....	4
2 BACKGROUND	
2.1 Asperger's syndrome and typical linguistic and communicative problems associated with it.....	8
2.1.1 General characteristics and history.....	8
2.1.2 AS persons' spoken language and communication.....	11
2.1.3 AS persons' written language and communication.....	12
2.1.4 Interventions for dealing with the linguistic and communicative problems in AS.....	13
2.2 Stress and coping.....	17
3 RESEARCH AIMS, DATA AND METHODS	
3.1 Research aims.....	21
3.2 Data.....	24
3.3 Grounded theory.....	26
4 ANALYSIS	
4.1 An overview of the linguistic and communicative problems in the autobiographies.....	32
4.2 An overview of the coping and accommodation strategies in the autobiographies.....	40
4.3 Problems and coping/accommodation strategies associated with flexibility in language use and communication.....	45
4.3.1 Conflicts and confrontations.....	45
4.3.2 Non-verbal communication .....	47
4.3.3 General comprehension difficulties.....	51
4.3.4 Literal-mindedness.....	54
4.3.5 Problems with spontaneous production under social stress.....	58
4.3.6 Obsessive-compulsive language use.....	60
4.3.7 Withdrawal and unwillingness to interact with others.....	63

4.3.8 Exceptional connections between language and thought processes.....	66
4.4 Problems and coping/accommodation strategies associated with contextual aspects of language use and communication.....	69
4.4.1 General troubles with the social context.....	69
4.4.2 Lack of common ground in interaction.....	72
4.4.3 Vagueness of social situations as a source for linguistic and communicative problems.....	75
4.4.4 Problems with conversation dynamics.....	77
4.5 Problems and coping/accommodation strategies associated with developmental aspects in language use and communication.....	79
4.5.1 Early language impairments.....	79
4.5.2 Problems with reading and writing.....	80
4.5.3 Co-morbidity of communicational problems.....	83
4.7 The significance of the absence and presence of a diagnosis in the authors' definition of the problems and of the effectiveness of coping and accommodation strategies.....	86
4.8 On the analysis.....	89
 5 RESULTS AND DISCUSSION.....	 91
 REFERENCES.....	 99
 TABLES	
Table 1: Linguistic and communicative problem groups.....	34
Table 2: Linguistic and communicative problems.....	37
Table 3: Strategies for coping with and accommodating for linguistic and communicative problems.....	44

## 1. INTRODUCTION

Linguistic and communicative aspects<sup>1</sup> have been one of the main objects of interest in autism and Asperger's syndrome<sup>2</sup> (AS) studies. Studies have been made on for example social and pragmatic competence (Baron Cohen 1988), Brook & Bowler 1992), vocabulary (e.g. Volden & Lord 1991), phonology (Baron-Cohen & Staunton 1994, Ghaziuddin et al. 1996), non-verbal communication (e.g. Tantam et al. 1993), narrative ability (e.g. Losh & Capps 2003) and the neural correlates of language in persons in the autism spectrum (Jansson-Verkasalo et al. 2003, Kujala et al. 2005).

This study examined the linguistic and communicative problems in AS, as well as the coping strategies used by the AS persons and the accommodation strategies used by other people for dealing with them. The linguistic and communicative problems are a valid starting point for doing coping research on AS, as they are a significant factor in the psychological well-being of the AS persons and came up recurrently in the studied life accounts. What is more, efforts at coping with the linguistic and communicative problems represented the authors as active language users and agents who have tried to minimize the effect of the problems on their well-being.

This research project can be regarded as adding ingredients to the picture of AS, a condition often seen from an over-medicalized viewpoint (Molloy & Vasil 2002), with the negative aspects present in the diagnosis being the sole factors that characterize the AS person. Asperger's syndrome presents itself differently in various people and settings. However, this is often disregarded in AS research. The medicalized view is useful in preventing the forming of conceptions that are not based on the etiology of AS, but it does not by far present a complete picture of the syndrome, especially when considering the viewpoint of those with AS. The following remark by Marc Fleisher, one of the authors of the autobiographies, summarizes this phenomenon from the point of view of a person with AS:

(1)

It is my opinion that there are a number of questions that cannot be answered by a medical journal, such as the mental feelings within the condition. As someone

---

<sup>1</sup> This research project explored the nonverbal, verbal, written and spoken dimensions of communication as they occur in the autobiographies.

<sup>2</sup> The terms "Asperger's syndrome" and "Asperger syndrome" are used interchangeably in the literature.

affected, rather than a non-Autistic author, I liken this to trying to judge a book by its cover alone. It is on these questions that I hope to concentrate most of my book. (Fleisher 2003:13.)

The reality of Asperger's syndrome created in the existing research literature is mostly an external one. Much of the previous research on the linguistic and communicative aspects in AS has been highly decontextualized, due to standardized quantitative tests and observation in clinical or laboratory circumstances; there has not been much research using the accounts of people with AS as data<sup>3</sup>. In contrast with much of the previous research, this study used qualitative data (autobiographies) in order to bring out the individuality of AS persons. What is more, qualitative data and methodology were essential as retaining the contextuality of the phenomena in the analysis was a main goal in the study.

Some notable exceptions to the lack of context in AS research include Happé (1995) who discusses three autobiographies by AS persons from the point of view of effective communication, Kremer-Sadlik (2004) and Sirota (2004) who follow children with high-functioning autism and AS in their natural interaction environment. However, the research field currently lacks a discussion of the coping of AS persons as users of language and communication.

Studying AS autobiographies is a challenging task. Happé (1995) has tried to find deviating communicative features of AS in autobiographies by AS persons. She points out numerous problems that the researcher has to deal with during the research. First of these is the subjectivity in the interpretation of the data. According to her, attempts should be made to avoid subjectivity when studying accounts. She points out, however, that "the more sophisticated productions...deserve a more sensitive, and therefore of necessity more subjective, approach [than, for example, counting up the words the AS persons use]" (Happé 1995: 222).

Happé (1995:222) adds that the writers might choose not to write about issues that would reveal their social handicaps due to lack of interest in examining their own social interaction or social interaction in general. What is more, the co-writers might

---

<sup>3</sup> However, there are previous studies of high-functioning autistic individuals not diagnosed for AS: for instance Bemporad (1979), Grandin (1984), Volkmar & Cohen (1985). Qualitative research on autism and Asperger's syndrome is sparse in general, however, there are studies investigating friendship (Carrington et al. 2003), experiences of autism (Cesaroni & Garber 1991), the inner experience of an individual with AS (Hurlburt et al. 1994), employment (Hurlburt & Chalmers 2004) and growing up with Asperger's syndrome (Portway & Johnson 2003).

influence the accounts, creating a more positive picture of the authors than is really the case. Happé calls these errors “false negatives and positives” (Happé 1995:222).

Happé’s critique emphasizes the fact that although some of the linguistic and communicative problems might be revealed in looking at the texts as linguistic output, they cannot be adequately discovered and examined by textual analysis due to omissions and secondary influences. Thus, as regards linguistic and communicative problems, the life narratives of the authors are significantly more reliable, and closer to the real situation, as representations of the linguistic and communicative problems in the lives of the authors. What is more, the narratives put the linguistic and communicative problems in context, giving more relevance to the study as coming close to the AS persons’ daily reality. In addition, many of the linguistic and communicative problems are not associated with written language – studying merely the writing of AS persons would considerably limit the scope in discovering possible specialities in their language use and communication.

The autobiographies were analysed by using grounded theory methodology, introduced below. Grounded theory as a method is rare in research on Asperger’s syndrome as well as in autobiography research. Searches in the databases ERIC, Linguistic and Language Behavior Abstracts (LLBA), MLA International Bibliography and PsycINFO with search terms “language” and “asperger” produced no results as regards the AS persons’ own reports on the linguistic and communicative problems they encounter. What is more, although LLBA included 136, MLA International Bibliography 9682, ERIC 591 and PsycINFO 1475 results with the search term “autobiography”, no search results were found with the combination of terms “autobiography” and “grounded theory”. Search conducted within Sociological Abstracts (CSA), Social Services Abstracts (CSA) and Sociology (CSA/SAGE) with the terms “autobiography” and “grounded theory” yielded 1 result: Reimann (1982) study of autobiographical interview data of mental health patients (cf. with the respective amounts of results for “grounded theory”: 1460, 508, 528). This study thus offers a novel perspective at both the linguistic and communicative problems of AS and the use of grounded theory methodology.

## **2. BACKGROUND**

### **2.1 Asperger's syndrome, its problematic linguistic and communicative features**

#### **2.1.1. General characteristics and history**

Asperger's syndrome is a neuropsychiatric condition in the field of Pervasive Developmental Disorders (PDD), included in the fourth edition of the Diagnostic and Statistic Manual for Mental Disorders (DSM-IV, American Psychiatric Association 1994) and in the tenth edition of the International Classification of Diseases (ICD-10, World Health Organization 1993). According to the DSM-IV (American Psychiatric Association 1994), a PDD is "characterized by severe and pervasive impairment in several areas of development".

The diagnostic criteria for Asperger's syndrome in the DSM-IV (299.80 Asperger's Disorder, American Psychiatric Association 1994) include

- A) impairments in social interaction
- B) restricted repetitive and stereotyped patterns of behaviour, interests and activities.

According to DSM-IV (American Psychiatric Association 1994), the impairments should cause problems in social, occupational, or other important areas of functioning. According to the criteria, there is "no clinically significant general delay in language" nor "clinically significant delay in cognitive development or in the development of age-appropriate self-help skills, adaptive behavior (other than social interaction) and curiosity about the environment". The criteria should not be met for another specific Pervasive Developmental Disorder or Schizophrenia for an AS diagnosis to be valid (American Psychiatric Association 1994).

The ICD-10 criteria (World Health Organization 1993) include "abnormalities of reciprocal social interaction" and "stereotyped, repetitive repertoire of interests and activities" and "no general delay or retardation in language or in cognitive development". The diagnosis covers the former diagnoses of autistic psychopathy and schizoid disorder of childhood. For the diagnosis to be valid, the person should not be diagnosed for anankastic personality disorder, attachment disorders of



childhood, obsessive-compulsive disorder, schizotypal disorder, or simple schizophrenia (World Health Organization 1993.).

As can be seen, the DSM-IV and ICD-10 diagnostic criteria correspond to each other quite well. There is disagreement, however, on whether Asperger's syndrome can be regarded as a form of autism or whether it is a condition of its own as well as on the diagnostic criteria for AS (see for instance Happé 1995, Dickerson Mayes et al. 2001, Eisenmajer et al. 1996, Gillberg 1999, Miller & Ozonoff 2000). In fact, the ICD-10 criteria take a stand in the debate by stating that "the disorder differs from autism primarily in that there is no general delay or retardation in language or in cognitive development" (World Health Organization 1993). Recently, the term "autism spectrum disorders" has been widely used, suggesting that the field of autism is a continuum without clear-cut boundaries (Dickerson Mayes et al. 2001).

AS has a recognized, yet uncertain neurological basis discussed by for instance Frith (1995), Kujala et al. (2005), McKelvey et al. (1995), Welchew et al. (2005) and underlying genetic factors, discussed by for instance Gillberg & Cederlund (2005), Lauritsen et al. (2005) and Volkmar et al. (1998). Although there is agreement that both the neurological basis and the genetic factors are involved, findings on them are yet too uncertain to be considered as comprehensive facts which would receive consensus in the field.

Although a person with AS has multiple special features, his or her level of cognitive skills is often at the normal level, compared to more severe forms of PDD (World Health Organization 1993). Some individuals with AS have unique savant skills, such as unusual spatial recognition or arithmetic skills – but the proportional amount of those individuals in the AS population is small. However, in general the profile of the skills is uneven, which may show in significant differences for instance between verbal and performance intelligence tests (Attwood 2001:115).

A theory occurring often in the discussion concerning cognition in the autism spectrum is that there are impairments in a "theory of mind", an ability to understand other people's points of view (Attwood 2001, Frith & Happé 1994, Hobson 1995). Happé (1994:98-99) claims, however, that applying the theory of the theory of mind to Asperger's syndrome is problematic, as those with AS seem, in fact, to have more access to interpreting other people's behaviour. Her claim is backed up by Bowler (1992) and Ponnet et al. (2004). Happé does state that the theory of mind might be

relevant concerning communication, if represented along the lines of Sperber and Wilson's theory of communication as including the inference of other people's intentions (Happé 1995:225-239). Thus, according to this line of thought, AS persons would have problems in inference. However, Happé is cautious in specifying how wide-ranging the inference problems are in AS.

Asperger's syndrome is a relatively recent category, first used by Lorna Wing in 1980 (Wing 2000). Wing's use of the name pays homage to the groundwork done by the pediatrician Hans Asperger, who published his paper on 'autistic psychopathy' in 1944 (Frith 1995). Asperger reported on children who had "severe and characteristic difficulties of social integration". The 'autistic psychopathy' described by Asperger "manifests itself in the [children's] physical appearance, expressive functions and . . . their whole behaviour" (Asperger 1995:37). According to Asperger, in some cases the problems were "compensated by a high level of original thought and experience" (Asperger 1995:37).

After the work of Asperger, Robinson and Vitale (in 1954) had found children with "circumscribed interests" and Margaret Mahler (in 1952) children who showed "empty clinging". Heller, in turn, found children who regressed after a period of seemingly normal development. At the time of Asperger's ground-breaking work, another child psychiatrist, Leo Kanner, reported on children with repetitive routines, who were aloof and indifferent to people. Although the children were somewhat different in their behaviour compared to children described by Asperger, Kanner, coincidentally, also used the term autism, to be adopted by the clinical and research community (Frith 1995:6). The use of the term autism spectrum has roots in these similarities between children with autism and children with Asperger's syndrome. (Wing 2000.)

According to Frith (1995:10), there are several similarities between autism and Asperger syndrome as described by Asperger and Kanner. Both included a lack of social interaction, stereotyped behaviour, special interests and resistance to change as central features. What is more, both distinguished autism from childhood schizophrenia and noticed similarities in the children's and parents' behaviour. By contrast, differences occurred in the appearance of the children: Asperger described odd appearance in addition to attractive appearance, whereas Kanner only described attractive appearance. Language peculiarities were also different: Kanner described

echolalia, pronoun reversal and difficulties in generalising word meanings, whereas Asperger described clever-sounding language, oddities of non-verbal communication and word choice, lack of humour and pedantry. (Frith 1995:10-11.)

Asperger's syndrome has often been diagnosed as something else, for example, often as schizophrenia (Perlman 2000), although Asperger himself made a clear distinction between schizophrenia and 'autistic psychopathy' (Asperger 1995:39). When considering the differentiation of Asperger's syndrome from other clinical categories, the finding that the level of cognitive skills of those with AS seems to correlate with that of an able subgroup of schizophrenics (Goldstein et al. 2002) is significant. Indeed, many of the features of AS, for instance the presence of stereotyped behaviours, resemble those of schizophrenia. This is also partly why the ICD-10 criteria between schizophrenia and Asperger's syndrome are mutually exclusive (World Health Organization 1993).

Motor clumsiness is a frequent characteristic of Asperger's syndrome that is not recorded in the diagnostic criteria. There is disagreement on whether it is a defining characteristic, but evidence seems to show that a great proportion of individuals with AS manifest motor clumsiness (Attwood 2001:103, Ghaziuddin et al. 1994, Gillberg 1999:16). The clumsiness most often surfaces during childhood and adolescence in activities which require complex body movements and hand-eye-coordination.

### **2.1.2 AS persons' spoken language and communication**

As mentioned above, in Asperger's syndrome the rudimentary social and communicative skills are affected. Individuals with AS may find it hard to connect with others who do not share their characteristics. This is especially visible during childhood, when deviations from the "norm", however defined, often cause bullying among peers. In the case of AS the social segregation is caused by either the properties described in the previous section (unusual interests, motor clumsiness etc.) or the problematic aspects in interaction such as not knowing when and how to react to what is being said or done, or how to sustain or repair a conversation (Attwood 2001). One possible reason for this are problems with auditory processing (studied by for instance Jansson-Verkasalo et al. 2003).

The gaze of individuals with AS is often odd. They may not look at the other at all, or the gaze can be otherwise peculiar (Attwood 2001:29). A significant disadvantage of the lack of eye-contact is the inability to interpret the messages according to the features added to them by facial gestures. This factor may partly explain the widespread manifestation of pragmatic special features among individuals with autism and AS (Gillberg 1999, pp 14-15; Bishop 1989, Baron-Cohen 1988).

In addition to facial gestures, the tone and prosody of speech is a source of additional information concerning spoken linguistic messages. Individuals with AS may find it hard to follow the tone and prosody of others (see for instance Kujala et al. 2005), let alone add these features to their speech. This is why the speech of many with AS seems awkwardly monotonous to those unfamiliar with the features of the syndrome. It should be noted, however, that the monotonous nature of speech is not an absolutely universal feature nor an unchanging one. (Attwood 2001:79-80)

Along with the issues presented above, echolalia, repeating what the other participant has said, is a feature occurring especially in the AS person's childhood (Gillberg 1999:29, Attwood 2001:108). A person with AS may even enjoy imitating others (for instance, see Shore 2001:35). The preference for imitation might even be an underlying factor that to an extent causes echolalia.

### **2.1.3 AS persons' written language and communication**

Reading rote-based texts is in general easier for an individual with Asperger's syndrome than those that include inferences (Myles et al. 2002). When stylistic features are involved, the reading comprehension process tends to suffer. Interpreting allusions and figures of speech, in other words reaching beyond the literal meaning can be very hard for those with AS. Thus, the stylistic means can to an extent be considered as the counterparts of gestures, tone and prosody.

Asperger's syndrome and hyperlexia<sup>4</sup> can overlap. According to Richman (1997), AS can co-exist with a type of hyperlexia called Visual Spatial Motor Disorder (Richman divides hyperlexia into two categories: Language Learning Disorder that

---

<sup>4</sup> A person with hyperlexia is able to read technically well, that is, reading aloud poses no problems. However, there are lacks in understanding what one is reading.

can be associated with autism and Visual Spatial Motor Disorder). The coexistence creates additional problems and possible additional unbalance in language use that are not part of the core of AS described above.

The uneven distribution of skills in AS referred to on page 8 also shows in memorizing things. Individuals with AS may find it hard to remember linguistic information such as a page of written language. However, if that page contains illustrations, individuals with AS, especially those possessing the specific skill of photographic memory, may at best recall the information in its exact form after a considerable delay (Attwood 2001:116). Alternate text formatting can therefore be helpful in educating individuals with AS. In effect, even the patterns created by text (paragraphs, lines, etc.) can be helpful in making sense of the written language, as noted by Shore (2001).

Analogously to reception and comprehension of spoken language, the production of written language is affected depending on the context. If the person uses the conventional writing method, i.e. pen and paper, the outcome may be lacking. Generally, this is due to the problems in fine motor skills (Beverdorsdorf et al. 2001). One obvious alternative for writing with a pencil is computers, helping with the coordination problems.

Parents of children with Asperger's syndrome are very influential in the development of language. As it is likely that the parent of a such child has some properties of a PDD (Lauritsen et al. 2005), being informed on the syndrome is vital for successful parent-child interaction.

#### **2.1.4 Interventions for dealing with the linguistic and communicative problems in AS**

Interventions and strategies for dealing with the special (language) issues in AS include for instance parental accommodation, Applied Behaviour Analysis, Auditory Integration Training, Social Stories, speech and language therapy and social skills training. (Attwood 2001, Romanowski Bashe & Kirby 2001)

Along with the increase of knowledge on Asperger's syndrome, therapeutic and rehabilitational applications have also increased. There is a need for de-jargonized information on the syndrome. This need is partly fulfilled by guides that offer

choices for accommodating the person with AS to an environment where the dominant proportion of people are non-AS. These AS guides are often about children: nowadays those with AS get the diagnosis much sooner than when the category was absent or emerging.

Some interventions that have proven to be helpful are presented here to give background to the kind of strategies that experts on the field of autism use in their encounters. These include for instance applied behaviour analysis, social stories, comic strips and especially speech and language therapy and social skills training.

Applied behaviour analysis (ABA) is one of the most common techniques used in the therapy of autistic individuals. It is a structured technique for the analysis of the causes of effects and behaviour. The goal of ABA is the teaching of socially appropriate behaviour, self-help skills, academic skills and speech and language. This is done by breaking down the learning of the skill in steps and reinforcing desirable behaviour while ignoring or correcting undesirable behaviour (Romanowski Bashe & Kirby 2001:178-179.).

The basis of ABA lies in the formula antecedent-behaviour-consequences: when the behaviour is observed, the therapist tries to find out the reasons for the behaviour (Romanowski Bashe & Kirby 2001:180). In linguistic and communicative behaviour this might apply to for example echolalia. The person who has echolalia might in fact be demonstrating his/her need for belonging to the group by echoing them. ABA also takes into account the consequences of the behaviour: the reason the person with AS reacts in a particular way might also explain the behaviour: when possible, the reinforcer of the behaviour is removed, or other reinforcers are introduced. In more complicated cases the environment of the person with AS might be changed in order to minimize the negative influence of the behaviour. In the case of echolalia the person might either be instructed to stop the echolalia by introducing other activities or other people might be made aware of the reasons behind the imitation.

Social stories is another intervention method that is widely used (Attwood 2001, Romanowski Bashe & Kirby 2001). A social story is “a brief (100- to 500-word) narrative that describes a situation [where some part of social interaction such as greeting] . . . , explains the feelings and/or thoughts of everyone involved . . . , and gives some direction regarding appropriate response” (Romanowski Bashe & Kirby 2001:194). The basic idea behind social stories is that social behaviour is explicitly

explained to the person with AS who most likely best comprehends literal instructions. Social stories might involve things such as how and what kind of language should be used when being in public places such as a shopping mall, or how people might react to a stranger who begins a monologue in a queue. Romanowski Bashe & Kirby (2001:196) find social stories useful in for example preparing for an unfamiliar or difficult situation, learning adequate responses, recognizing social cues and understanding fiction, difficult for many people with AS.

Comic strips remind social stories but they are in a pictorial form. This format is useful for many of those with AS whose thought processes are visually oriented. In addition, comic strips are not as dynamic as social stories, so that the situation can be carefully examined – it “freezes” the action” (Romanowski Bashe & Kirby 2001:198). Romanowski Bashe & Kirby (2001:197) and Attwood (2001:71) use interruption as an example: they depict two situations in which talking might be problematic in terms of interrupting the person who is speaking.

Speech and language therapy is aimed at the social use of language, impaired in Asperger’s syndrome. That a person with Asperger’s syndrome needs speech and language therapy is not often evident during the early years, as there is generally no delay in language; the speech might even appear earlier than expected. The problems start to occur later, when the child might begin to have troubles in interpretation, maintaining the right volume, prosody, and understanding larger themes (Romanowski Bashe & Kirby 2001:210). The strategies used during speech and language therapy vary, but they might include role-playing, videotaping the child and group sessions. In order to be effective, language therapy needs to be adapted for the needs of the person with AS, taking into account her/his level of language and specific problems s/he is struggling with in language use.

Social skills training is also a fruitful intervention approach (Gillberg 1999:109, Attwood 2001:40), giving the person with AS a possibility of training the skills needed in social situations without the pressures created by authentic situation. Social skills training takes place in groups. These groups are often peer groups in which everyone has some problems in social situations. The groups might not always be homogeneous in terms of the developmental disabilities the members have (although AS children should be placed in a group where there are other people with AS), nor do they always have only people with problems. This is because models of

smooth interaction are often needed; in addition to the group leader acting as an instructor-model, these can be provided by more advanced group members. (Attwood 2001:40) The kinds of things that are practiced in the group might include issues such as turn-taking, conversation dynamics, tone of voice and facial expressions (Romanowski Bashe & Kirby 2001:214). According to Gillberg (1999:110), social skills training has not been found to have a great effect on the formal theory of mind tests measuring the comprehension of other people's point of view, but the training is recommendable in confronting the real-life social problems.

All of the interventions described above are means of dealing with the linguistic and communicative problems that Asperger's syndrome might cause. These interventions cannot be replaced by medication. This is largely because the effects of medication are not as long-lasting as those of social intervention. The overly medicalization of Asperger's syndrome, therefore, carries a risk of losing the social and therapeutic view on the syndrome, vital when considering the accommodation of an individual with AS to the society of neurologically typical people. However, just as there is no miracle medical cure, the options for intervention are not a miracle cure either. They share the lack of information on AS and persons on AS that is characteristic of a condition that has been discovered recently, especially when it comes to the potential for coping the AS persons possess.

Despite some common characteristics, there is as much variation among people with Asperger's syndrome as among those without the disorder, as well as co-morbidity, that is, coexistence of other conditions. This should be accounted for when planning and realizing strategies for accommodation. The following characterization of autism spectrum represents this variation:

(2)

We could very loosely describe Autism as a social and communication disorder, but this draws no fine lines with many other disabilities that can be present. Thus the condition is much more subtle and harder to recognise (and therefore arguably worse) than someone with an obvious disability, such as being confined to a wheelchair. (Fleisher 2003:8.)



## 2.2 Stress and coping

Being strongly connected (Lazarus 1993), the concepts of stress and coping are reviewed here in a brief manner. What is more, coping research is touched upon, as well as the emerging field of coping studies in AS. Taking stress and coping into account is important, as stress and coping influence the psychological well-being of the language user, thus having effects on language and communication.

According to Lazarus & Folkman (1984:2), the term stress has been used already in the 14<sup>th</sup> century in the meaning of hardship, straits, adversity or affliction. In addition to biology, medicine and psychology, it has also been used in the physical sciences (in the meaning of internal load).

Hans Selye's work has been the basis for much of the current stress concept. He defines stress as "nonspecific result of any demand upon the body, be the effect mental or somatic". According to him, a variety of different situations can induce stress: for instance emotional arousal, effort, fatigue, pain, fear, concentration, humiliation, loss of blood. (Selye 1993.)

Lazarus (1993) considers emotions central to stress. He believes that environmental demands, emphasized in Selye's definition of stress are not enough in explaining the mechanisms of stress, rejecting the inner experience as a cause for stress. Lazarus sees psychological stress centering on the negative emotions – the role of positive emotions is, according to him, vital in relieving stress (Lazarus 1993).

Stress has both psychological and physiological outcomes. The physiological features of stress are reviewed elsewhere (for instance, see Galinowski & Lôo 2003). The psychological outcomes include for instance altered problem solving, memory and decision-making. Mandler (1993), reviewing thought literature, notes that the task performance under emotional arousal forms an inverted U-shaped function – the persons perform better with medium stress than with low or high stress. Janis (1993) reports that stress caused by warning the person making a decision of possible associated risks influences decision-making in five ways: unconflicted inertia (the person making the decision continues ignoring the warnings), unconflicted change (the person adopts a most salient or recommended course), defensive avoidance (the person evades the conflict), hypervigilance (the person rapidly searches a way out,

becomes impulsive) and vigilance (the person searches relevant information in an unbiased manner).

Coping strategies can be defined as the ways in which an individual tries to accommodate his/her behaviour and thinking because of psychosocial stress. Lazarus (1980, as in Schlosser 1985) has defined coping as “the cognitive and behavioral efforts to master, minimize, tolerate, or reduce internal and environmental demands and the conflicts among them in stressful transactions between the person and the environment”. This definition has later changed to “constantly changing cognitive and behavioral efforts to manage specific external and/or internal demands that are appraised as taxing or exceeding the resources of the person” (Lazarus & Folkman 1984:141). Lazarus and Folkman (1984:132) differentiate between coping and automatic adaptive processes that are administered by “the person’s cognitive control mechanisms”.

The definitions above capture the core of coping, which is, in essence, adaptation to the environment. Schlosser (1985:18-19) states the importance of individuality – there is variation between individuals in responding to the same environment. This also applies to persons with AS – they vary in their coping strategies. Schlosser also questions personality as the only factor affecting the reactions, stating that the person and the environment are in transaction in the formation of stress and coping.

According to Cohen (1987), coping can be assessed in two ways: either as a disposition, trait or style, or as an episodic indicator. In this study both viewpoints are covered – coping is placed in the situational context, but the tendencies in coping are searched for as well, although not individually. Cohen (1987) presents five modes of coping: information-seeking, direct action, inhibition of action, intrapsychic processes and turning to others for support. She also discusses the adaptiveness of coping that, according to her, depends on the domain of outcome studied, the point in time and the context. The basic issue is thus that coping should not be separated from the context.

The grouping of coping strategies differs according to the researchers’ orientation. Both negative and positive strategies have been investigated. Suutama (1995:17) links coping with antidepressive behaviour, competence, hardiness, learned resourcefulness, problem solving, self-efficacy and sense of coherence. Of these, according to him, “the sense of coherence . . . has had the strongest influence on

western coping research” (Suutama 1995:17). He further regards seeing coping as adaptive behaviour as the prevalent view.

According to Suutama (1995:20), seeking social support is also a coping strategy, affecting the person’s coping with stress. In this study, social support was discussed as accommodation. Suutama (1995:20) divides social support in two forms: emotional support and informational support. The emotional support in particular has been found to have positive effects. There are differences between sexes in using social support. According to Nadler (1990:130), seeking help involves a dilemma of both having to admit failure and becoming dependent on the provider of the support. Factors such as the helper’s characteristics, helper’s similarity and social proximity are also involved.

Coping has been the subject of interest in multiple contexts. Somatic (often chronic) diseases (for instance Seiffge-Krenke 2001, Cox & Gonder-Frederick 1991, O’Leary & Jemmott 2002, Temoshok & Moulton 1991) have been a significant area in coping research. This may owe great deal to their mortal effects and large prevalence – according to Taylor & Aspinwall (1993) 50 percent of the U.S. population has a chronic condition at any given time. Other phenomena studied in the framework of coping include for instance adolescence and youth (for instance Compas et al. 1993, Rice et al. 1993), marriage and family (for instance Giunta & Compas 1993, DeLongis et al. 2004) and aging (for instance Range & Stringer 1996, Suutama 1995).

According to Suutama (1995:22-24), coping has been previously studied by interviews and using self-evaluation questionnaires. These have included either hypothetical or real changes and problematic situations. The use of interviews has been rare, including the Duke Longitudinal Studies of Aging and the Bonn Longitudinal Study of Midadulthood (Suutama 1995:22). Of the questionnaires, the Ways of Coping Questionnaire by Folkman & Lazarus is the most widely used (Suutama 1995:23). Others include Coping Inventory by Horowitz & Wilner, Coping Strategies Inventory by Quayhagen & Quayhagen and Tobin and others, Coping Strategy Indicator by Amirkhan, ECRC Coping Scale and Geriatric Coping Schedule by Kahana and others, Kand Life Situation Inventory by Feifel & Strack (Suutama 1995:23) and Billings and Moos’s checklist (Cohen 1987).

Coping in Asperger's syndrome has been studied primarily through the family members of the AS person (e.g. Gray 2002, Dellve et al. 2000, Gray 2003, Higgins et al. 2005, Little 2002, Pakenham et al. 2005). Carrington and others (2003) come close to coping of AS persons by studying how they form and maintain friendships. By and large, the field of coping studies lacks both extensive self-reports (such as autobiographies) as data and also largely a discussion of Asperger's syndrome in the AS person's context. The latter is to a great extent caused by the focus of the majority of AS studies on the cognitive laboratory performance tests rather than the everyday functioning, and not on the strategies used by AS people. Therefore, the study at hand helps to fill gaps in both AS and coping research, challenging Watson and Kendall's (1983) position of meaningful scientific research (on coping) requiring "objective data and control group comparisons" by describing the significant variation between individuals from the qualitative point of view. Although their emphasis is on coping in chronic diseases, the subjective data, obtained through interviews and other measures in which autobiographies can be counted should be a major source of interest for the researcher studying the phenomenon of coping regardless of the context, especially when individuality in coping is the point of departure.

Expert literature does offer helpful coping strategies but the personal choices people with AS make and their impact, not to mention the dexterity they might have in developing measures for adapting to the interpersonal environment of non-AS people are not viewed adequately. This in turn is partially responsible for the social labelling of those with AS as people who are unable to control their lives, while in truth many of them have managed to cope with their problems without receiving any guidance, perhaps until later years when the diagnostic criteria were already discovered. This is not to say that people with problematic neurobiological development would not need help and assistance but rather to emphasize the importance of individuality in AS counselling and therapy.

### 3 RESEARCH AIMS, DATA AND METHODS

#### 3.1 Research aims

This study can be regarded as interdisciplinary in nature, bringing together both linguistics and psychology. The mixture can be characterized by a focus on (English) linguistics in studying the authors as language users and using a language-based data of English-speaking authors as opposed to numeric, quantified data. The psychological ingredients come from examining the coping processes involved in dealing with the problems in language use. Additional features to the analysis come from social sciences in the form of methodology chosen (grounded theory).

The definition of coping for the purposes of this study has been given in the previous section. Language and communication were defined in this study as the interaction between people that consists of using symbols (phonemes, graphemes) to denote entities, intentions and mental states. The interaction takes place in both written and spoken form. It includes three aspects: form (syntactic structures), meaning (semantics) and function (pragmatics). These three aspects contribute to each interaction situation, so that for instance the information on context (part of the pragmatics involved) is necessary for producing linguistic output and interpreting it.

This study had some preliminary research questions susceptible to change in the grounded theory research process, as reported by Orona (1997). These initial research questions were:

1. What kind of linguistic and communicative aspects do the authors describe in their autobiographies?
2. What is the effect of a diagnosis in the authors' perceptions of the linguistic and communicative aspects?

The first research question was selected due to it putting the focus to the AS persons as users of language and communication. What is more, it acted as a limiting factor in the selection and analysis of the data. As discussed later, such limiting of the data was justifiable in terms of data handling and effectiveness of analysis – for instance, the question guided the researcher not to treat the autobiographies as direct sources

of data on the authors' language use and communication but rather as representations of that language use and communication as told by the authors.

The second question, in turn, was designed to shed light on the special position of the authors as AS persons who have not received a diagnosis during the childhood. The role of an AS diagnosis is central in the society as regards, for instance, applying for social and health services. It can be supposed that persons who did not receive diagnosis in their early years would view differently their lives and the significance of the diagnosis in determining their features could possibly be higher due to it having been given recently. However, the initial rationale for choosing question 2 as a research question was simply that the effect of diagnosis is a theme attracting social interest.

The two questions were also posed due to inadequate information in the research literature on the themes they cover. Both touch new, emerging areas in AS research, especially the question concerning the effect of diagnosis. During theoretical sampling, a further research question was added and the others were updated, transforming the list before further analyses as the following:

1. What kind of linguistic and communicative problems do the authors describe in their autobiographies?
2. How do the authors cope with the linguistic and communicative problems and how are they accommodated for them?
3. What is the effect of a diagnosis on the authors' perceptions of linguistic and communicative problems and coping with them?

The transformation of the research questions during the process shows that the data has guided the process. This happened through discovering that the authors had multiple problems as users of language and communication as indicated in the data. The focus being set to the linguistic and communicative problems, such phenomena as public speaking, a source of success for many of the authors, were not included in the analysis, although they were discovered in the preliminary reading and coding and would be a source of interest for the researcher interested in the differences and similarities in language use and communication between AS and non-AS people.

What the autobiographies of persons who have not been diagnosed in the childhood as having AS offer to the researcher regarding the interventions for coping with problematic linguistic features is information on strategies that these persons have used without having the possibility of relying on the information one at present has access to. This information is invaluable when considering the need for the voice of those with autism and/or Asperger's syndrome.

Studying the problematic linguistic features in their context also enables one to see the ways in which the person has coped with them. This would not be possible, if looking only at the linguistic output of the person. The coping strategies offer insights in the AS person's inner world that is both interesting to explore and widely neglected.

### 3.2 Data

The data for this study were collected from written, published autobiographies. There were several reasons for choosing this particular source of data. First, due to the availability of the autobiographies, an instant access was offered to the data. Second, the autobiographies as public representations offered a viewpoint at looking how the Asperger individuals present themselves to the reading audience. Third, as ready autobiographies, the printed works offered less ground for a possible researcher-induced bias than would be the case were the authors asked to give a description of their linguistic and communicative problems. Finally, the autobiographies offered more data than the writings of authors who were asked to write on their life in general for this particular project.

The autobiographies studied were *Congratulations! It's Asperger's syndrome* by Jen Birch, *Making Sense of the Unfeasible: My Life Journey with Asperger's syndrome* by Marc Fleisher, *Beyond the Wall: Personal Experiences with Autism and Asperger's syndrome* by Stephen Shore, and *Pretending to Be Normal Living with Asperger's syndrome* by Liane Holliday Willey. Three of the autobiographies were also published online through Ebrary(R), the access to Ebrary was available through the University of Jyväskylä library license.

The autobiographies were first considered as data pools themselves. Eventually, the data relevant to the study was collected from the autobiographies to text files for easier data handling. The collection was done following the principles of grounded theory, as introduced under the next section. The data from Shore's autobiography that was not online were typed to a text file.

The data were stored in computer files as excerpts, each excerpt eliciting a particular phenomenon. The excerpt had to include either a problematic linguistic aspect or a coping/accommodation strategy or both. Dividing the data as excerpts was a part of its initial categorizing, although changes were made to the number of excerpts and their form (for example length) later on, having the autobiographies available at all times for check-up and further collection of data. The electronic data thus acquired consisted of excerpts of linked paragraphs including various categories.

Studying several autobiographies enabled the researcher to discover if there are any similarities in the thinking and subsequent coping behaviour of the authors



beyond the obvious influence of higher education. The autobiographies by men and women were included equally; although AS is thought to be more typical of males than in females (Ehlers & Gillberg 1993), the equal balance helped to give voice to both sexes. The findings of Romanowski Bashe and Kirby (2001:13) of the increasing use of Internet services by the parents of girls with AS also support the need to acknowledge the existence of AS equally in both sexes.

The authors' age was also a significant factor as regards the purposes of the study. The authors studied were all adults; although the emphasis of Asperger's syndrome research is on childhood, a life-span perspective should be adopted in order to understand the different manifestations of AS in various life stages. The autobiographies under study were therefore also representations of Asperger's syndrome in adulthood, an issue which has received less attention in the discussion of AS as a developmental condition.

The data were also chosen because of the unifying factor of the authors' university education. Acquiring a university education implies that the person has both to great extent been able to cope with the problems and is able to report the strategies that s/he has used. On the subject, Happé (1995:207) states that "there can be little doubt . . . that those autistic adults who manage to produce autobiographical works are among the most successful cases – in terms both of their degree of social adjustment and of their intellect". What is more, the authors represented AS people who have spent a considerable amount of their lifetime without a diagnosis, being a special group within the AS population. In spite of the similarities in the authors' backgrounds, some heterogeneity was retained by choosing the authors from different English-speaking cultures - United States (2 authors), Britain and New Zealand (1 author each).

Although discourse researchers such as Fairclough (1995) state that omissions are equally important objects of analysis in texts, some data excerpts without any clear reference to language and communication were left outside analysis to avoid speculation. What is more, a significant portion of one autobiography<sup>5</sup> was not included in the data due to it being a dialogue rather than autobiographical discourse.

---

<sup>5</sup> *Beyond the Wall: Personal Experiences of Autism and Asperger's Syndrome* by Stephen Shore (2001), 25-30, 106-108, 187-199. These include, respectively, an account by the author's mother, an account by the mother's wife and a dialogue with a physician.

### 3.3 Grounded theory

The methodological basis of this study lies in both hermeneutics and phenomenology. Grounded theory as introduced by Glaser & Strauss (1967) and Strauss & Corbin (1990) is an analysis framework that integrates these two approaches<sup>6</sup> – the researcher’s preceding understanding of the phenomenon and looking at the phenomenon with minimal disturbance from the preceding understanding. Both Glaser & Strauss (1967) and Strauss & Corbin (1990) were elected as guidance in order to find a synthesis between the roots of the methodology and its more recent developments. This position is taken as there are differences between the original proposal by Glaser & Strauss (1967) and the subsequent uses of the methodology (Greckhamer & Koro-Ljungberg 2005), and in the epistemology between the original version and its later adaptations (Lomborg & Kirkevold 2003).

In examining the linguistic and communicative problems in Asperger’s syndrome the researcher would have difficulties without prior knowledge of the phenomenon as one that has been recently discovered and that has had an impact on the society as distinguishing prior “oddly” behaving people as, depending on the case, having or possibly having Asperger’s syndrome. Without prior knowledge, the researcher would be without the context of AS in the society. However, with too much background knowledge the researcher might end up with results that have been mainly guided by this background knowledge (one of the main issues to avoid when using grounded theory (Glaser & Strauss 1967)).

Grounded theory was elected as the methodology because its merits in discovering phenomena from new angles (in social sciences the social phenomena). Most notable of these merits is the central idea of grounded theory: basing the theory on data and working from the data, rather than merely testing hypotheses. Moreover, with the help of categorizing the phenomena, grounded theory enables the researcher to arrive at a theory by looking at and analysing different situations and personal dispositions that come up in the data without being overloaded with situational specificity. In other words, although the phenomena are examined in their context,

---

<sup>6</sup> Although, according to Greckhamer & Koro-Ljungberg (2005), some researchers have tried to place grounded theory within either hermeneutics or phenomenology.

the differing contexts do not hinder the researcher from making general observations (although not mere generalizations) and finding similarities in the data.

Grounded theory as a methodology has been used in previous coping research, for instance, Busch (2005) has used it in discovering how chronic low back pain patients cope with their pain; Schulman-Green (2003) has studied the coping mechanisms of physicians who work with dying patients. Although describing a transformational process of a strategy, Busch's (2005) study includes a major limitation in that it only deals with one category (disregarding), instead of seeing coping as consisting of multiple means of dealing with stress. By contrast, Schulman-Green (2003) study is much more viable in this respect, discovering eight different categories of coping. The differences between these two studies illustrate the discrepancies between studies using grounded theory as a method.

The study at hand differs from many previous uses of grounded theory (including the above mentioned ones) in that it is used for analysing data that was originally in the written form - grounded theory has mostly been used in analysing data gathered through interviews and transcribed to written form (but see, for instance, Fleischmann (2005)). Therefore, this study can be regarded as an extension to the use of grounded theory, especially as the data consists of written autobiographies (also see section 1).

The grounded theory methodology supposes that no governing initial hypotheses are made (Glaser & Strauss 1967; Strauss & Corbin 1990). Thus, although no hypotheses were formed at the beginning of the research procedure following the grounded theory procedures, as in any grounded theory study the research aims were limited: the written narratives of those with Asperger's syndrome were approached from the viewpoint of the linguistic and communicative problems and coping and accommodation strategies for dealing with them. Keeping the focus was essential for avoiding the research data becoming too widespread to handle.

The study at hand used theoretical sampling<sup>7</sup> as introduced in Glaser & Strauss (1967:45-77) and Strauss & Corbin (1990), as a method in discovering the

---

<sup>7</sup> Collecting, coding and analyzing data, controlled by the emerging theory (Glaser & Strauss 1967:45-77). The emerging theory of the problematic linguistic aspects of AS persons with higher education required the acquisition of autobiographical data from people who had completed a university degree.

phenomenon in its own terms rather than merely through limitations that exist due to the preconceptions of the researcher. The theoretical sampling took place in three stages: first, one autobiography<sup>8</sup> was searched for linguistic and communicative aspects. As these were found, two autobiographies<sup>9</sup> were added to the data pool. The three autobiographies were then examined as representations of the linguistic and communicative problems and, subsequently, also coping and accommodation strategies. The final stage involved the inclusion of a fourth autobiography<sup>10</sup>. The data sampling resulted in retaining the four autobiographies for further analyses. As noted, there was a subsequent decision to reduce the authors' descriptions of the linguistic and communicative features of their AS to descriptions of linguistic and communicative problems. The reduction can be reasoned by both the great amount of accounts related to problematic linguistic aspects and their significance to the authors in defining themselves as persons in social interaction.

The data were coded by using a word processor. Computerized coding provided a reliable measure for further regrouping according to themes emerging from the data. The regrouping took place by handling information in two files, containing the linguistic and communicative problems (file 1) and the coping and accommodation strategies (file 2) both of which were linked together by coding the coping and accommodation strategy labels onto the linguistic and communicative problems and vice versa, as can be seen from the data excerpt below, categorized in the linguistic and communicative problems (conflicts/confrontations as the problem):

## 1. CONFLICTS/CONFRONTATIONS

### 1.1 birch

#### **Coping strategy: reflecting on the problematic situation**

Thinking quickly under pressure and in a situation of conflict is just about the worst scenario for me. This adds a heap of negative emotions to the mixture. As I greatly dislike conflict in the first place, such a situation is usually impossible for me. The other person( s) have the advantage in that they can think more quickly, and as it is usually they who have chosen to have the confrontation, this means that they have already thought ahead as to what they will say and do, whereas I am taken completely off guard. I might as well hold my breath in such a situation. I need to go away and mentally go over what happened (mentally process it), and it may take a

---

The mode of the data was initially published autobiographies and did not change during the process. By contrast, the amount of data increased during the analysis from three to four autobiographies.

<sup>8</sup> Shore (2001)

<sup>9</sup> Birch (2003) and Willey (1999)

<sup>10</sup> Fleisher (2003)

week, or much longer, for me to understand what it was all about.

Birch, Jen(Author). Congratulations! It's Asperger's Syndrome.  
Philadelphia, PA, USA: Jessica Kingsley Publishers, 2003. p 29.  
<http://site.ebrary.com/lib/jyvaskyla/Doc?id=10064483&page=29>

Although in forming the basic linguistic categories the researcher might be influenced by pre-read knowledge on Asperger's syndrome and its linguistic features, they are not followed as such when categorizing the discourse excerpts representing linguistic features in the autobiographies. The names from categories have all come up as a result of a contact with the data, through open coding<sup>11</sup> (Strauss & Corbin 1990:61-74), selective coding<sup>12</sup> (Strauss & Corbin 1990:116-142) and the method of constant comparison<sup>13</sup> (Glaser & Strauss 1967:101-115). Open coding produced the following categories:

- Anxiety and frustration created by communicational deficits
- Bad language
- Confrontations
- Connection between anxiety and literal-mindedness
- Content of conversation
- Difficulties with conversation dynamics and comprehension
- Difficulties with following instructions and directives
- Echolalia
- Foreign language learning
- Linguistic and other humour
- Isolation, withdrawal and unwillingness to use language
- Abnormal language development
- Literal use and comprehension of language
- Nonverbal communication
- Problems with writing
- Repetition
- Talking to oneself
- Tone and prosody of talk
- Problems in understanding fiction
- Problems with unpredictability

Some of the names of the categories are invented by the researcher and others are adopted from the data, both being valid ways of discovering the categories through

---

<sup>11</sup> Naming and categorizing of phenomena through close examination of the data. Open coding is done by making comparisons and asking questions (Strauss & Corbin 1990:61).

<sup>12</sup> Forming core categories and attaching subcategories to them. The crucial stage of moving from description to conceptualization, finding the patterns within the data and validating the theory with data. (Strauss & Corbin 1990:116-142)

<sup>13</sup> Generating and suggesting many categories, properties, and hypotheses about general problems. Constant comparison takes place in four stages: 1. comparing incidents, 2. integrating categories, 3. delimiting the theory, 4. writing the theory (Glaser & Strauss 1967:105).

theoretical sensitivity<sup>14</sup> (Strauss & Corbin 1990:42-43). For instance, the category name “Non-verbal communication” was acquired from the authors, whereas the name “Anxiety and frustration created by communicational deficits” was produced by the researcher.

There was some overlap in the data excerpts concerning the categories. Some of the overlap occurred between categories close to each other (for instance “Problems with conversation dynamics” and “General troubles with the social context”). Most of the overlap consisted of the descriptions of the co-morbidity of the problems, retained as a category of its own right. In general, however, there was not much overlap among the themes that would have caused troubles in discerning the categories.

Selective coding produced the core categories (problems with flexibility, problems with contextual aspects, developmental problems) presented in the next section. Initial selective coding produced four core categories: rigidity of language use, contextual difficulties, differential problems and developmental problems. Through constant comparison of the categories the final three core categories emerged, with the “differential problems” category submerging in these three categories.

Axial coding<sup>15</sup> (Strauss & Corbin 1990:96-115) was used to distinguish the connections between the categories at the micro level. Thus, connections were found for instance between literal-mindedness and general comprehension difficulties. What is more, axial coding made it possible to examine the relationship between linguistic and communicative problems and the coping and accommodation strategies at the macro level, revealing clear and often-occurring connections between the two (that is, problems were frequently accompanied by coping and accommodation strategies targeted at them).

Glaser & Strauss (1967:40-43; 79-99) make a distinction between a substantive theory (theory based directly on the data) and formal theory (theory further developed by the researcher). In the case of this study, the linguistic and

---

<sup>14</sup> The ability to conceptualize phenomena and form a theory based on the data. Sources of theoretical sensitivity include literature, professional experience, personal experience and the analytical process itself (Strauss & Corbin 1990:42-43).

<sup>15</sup> Putting the data back together after open coding and making connections between the categories. In axial coding the conditions and contexts of activities as well as intervening conditions and consequences are being investigated (Strauss & Corbin 1990:96).

communicative problems and the coping and accommodation strategies can be regarded as two substantive theories, whereas seeing the AS persons as active developers of strategies and the diagnosis as central in the development of coping and accommodation strategies are formal theories.

Glaser & Strauss (1967:35) include conceptual categories and relations among the categories as the elements of a theory generated by using the grounded theory. The theory formed in this study appears at three different levels, comprising several interrelated categories. At the micro level the accounts concerning the linguistic and communicative problems and the coping or accommodation strategies are approached paying attention to the individual differences and the way the persons see the problems and their (sometimes tentative) solutions. At the intermediate level there is a grouping of the accounts to categories that integrate the experiences of several authors. At the macro level the categories are further grouped into larger wholes that serve to indicate the overall structure of the categories. None of the levels alone reveals enough. Therefore the contents of the categories are described in detail and the connections between the categories explored at both the intermediate and the macro level, together providing a multifaceted look at the phenomena.

The emerging theory was validated with the data (Glaser & Strauss 1967, Strauss & Corbin 1990). The validation proved the theory to be accurate in describing and explaining the aspects associated with linguistic and communicative problems and the coping and accommodation strategies of the authors. Both the categories for linguistic and communicative problems and coping and accommodation strategies proved to adequately label the phenomena and describe the connections between them. What is more, the validation also proved the importance of grouping the linguistic and communicative problems under three core categories and dividing the strategies in coping and accommodation strategies.

## 4. ANALYSIS

### 4.1 An overview of the linguistic and communicative problems in the autobiographies

The linguistic and communicative problems were defined as those that have, according to the authors, caused troubles either to the author or to other people who have been in interaction with the author. Most of the problematic aspects were related to oral communication and specifically conversations which include multiple confusing factors for the authors.

The linguistic and communicative problems formed three groups. The first group, problems with flexibility in language use and communication of the authors, comprised conflicts and confrontations, non-verbal communication, literal-mindedness, comprehension difficulties, spontaneous production under stress and obsessive-compulsive language use. This group was the most notable in size. The following excerpt on non-verbal communication illustrates the effects of problems in flexibility on social interaction:

(3)

Growing into my teenage years – at least, chronologically speaking – I was left behind by my peer group in some ways . . . Though I did not realise this at the time, I did not know how to understand body language, or facial expressions apart from the most blatant ones, or eye messages, or indirect ways of using language. This kept me on the outer in many social situations . . . (Birch 2003:46.)

The statement “I was left behind by my peer group in some ways” denotes the fact that the linguistic and communicative problems have made Birch to be different from others in ways that she has noticed. What this comment does not reveal, however, is whether she noticed this issue *post hoc*, after having received the diagnosis, or during the teenage years. This question of the effects of the diagnosis is discussed under section 4.6.

The second group, contextual difficulties, consisted of subcategories “lack of common ground in interaction”, “troubles in understanding the social context”, “vagueness of social situations” and “problems with conversation dynamics”. As with the problems with flexibility, the contextual difficulties posed difficulties that



make it hard to fit in the interaction, especially taking into account the specific properties and demands of a particular communication situation:

(4)

Small group conversations make my nerves feel like they are wearing stilts on an icy pavement. When I talk to other people, I have trouble following conversation transitions. I step on other people's words, stumbling ahead with my own thoughts, in almost every conversation I have. (Willey 1999:37-38.)

On the other hand, the contextual properties of the situation can also be decisive when it comes to defining whether a situation poses problems or not:

(5)

I never experienced apprehension or fear when I spoke in public. I do not understand why so many people do. I wonder if I am missing something, if I am overlooking some obvious problem with public speaking that falls beyond my grasp. Maybe I enjoy speaking in front of a group because it is a one-way communication experience and, as such, something that is not affected by the complications of other people's body language and non-verbal styles. Given a chance, I would much rather speak to a large group than I would to an individual or two. (Willey 1999:37-38)

Willey's description shows that rather than being universal, the contextual difficulties are associated with the nature of the communication situation: some situations are more problematic than others.

The third group, developmental problems in language use and communication, included impaired language development, problems in reading and writing and comorbidity of communicational problems. That Asperger's syndrome as a developmental condition can have effects even on the emergence of language can be seen in the description by Shore:

(6)

At approximately six months or even earlier, I began to make "talking" sounds and could say "mama." But shortly thereafter I stopped and seemed unhappy when taken from my crib. I must have considered my crib a safe haven . . . (Shore 2001:15) Up until about four years of age, I was still mute and not eating anything but puréed baby food. (Shore 2001:21)

Shore's descriptions of the difficulties in the emergence of language and problems in reading and writing were unique in this study: other authors do not describe this kind of effect on language. However, this uniqueness also hints that there might be more

variance in Asperger's syndrome than is currently acknowledged.<sup>16</sup> By contrast, the co-morbidity of communicational problems was described by three authors explicitly, and also the fourth author (Fleisher) implicitly, through describing several, overlapping problems in his autobiography.

In general, the influence of developmental problems in language use and communication, especially co-morbidity of communicational problems, extends to other areas of language and communication as well, showing in situations where multiple problems appear. What is more, all of the groups included problems that made the AS person stand out from the group in ways that were problematic both for the situation and for the AS persons, as regards self-esteem and identity as a user of language and communication.

Table 1 represents the distribution of the problem groups in the autobiographies by author:

Table 1 Problems in language use and communication

<b>Problem group</b>	<b>Birch</b>	<b>Fleisher</b>	<b>Shore</b>	<b>Willey</b>	<b>Total</b>
Problems with flexibility	19	15	28	17	79
Problems with contextual aspects	11	6	4	10	31
Developmental problems	3	2	17	8	30

The numbers in the table are the raw amounts of instances in the data where a particular problem group was discovered. As can be seen, there is some variation between the proportions of the groups: problems with flexibility (79 instances in total) stand out as the most frequent group, with problems with contextual aspects and developmental problems having approximately the same proportions in the data (31 and 30 instances). However, most of the variation comes from the authors. For instance, within problems with flexibility, Shore stands out as the person reporting a considerable higher amount of problems (28 instances) compared to others. The case is the same as regards developmental problems. Similarly, Birch and Willey report more problems with contextual aspects (11 and 10 instances) than Fleisher (6 instances) and Shore (4 instances). The variation between authors is examined in more detail in Table 2. Note that the numbers in the table do not mean that, for

<sup>16</sup> Although the possibility of reading and writing problems is acknowledged in the literature, early language impairments are not included in the diagnostic criteria (for more information, see section 2).

instance, Birch had 19 different problems with flexibility – a particular problem can be present in many instances.

In addition to showing variation, Table 1 also shows consistencies between the authors. Although in varying amounts, all authors are represented in all problem groups – all of the authors have thus experienced problems with flexibility, context and developmental aspects of language use and communication. The consistencies are examined in Table 2 in more detail.

The problematic nature of the aspects was denoted in the texts in various ways. Perhaps the most common one was the use of adjectives or nouns. Adjectives appeared in such formulations as “Thinking quickly under pressure and in a situation of conflict is just about the *worst* scenario for me” (Birch 2003:29) or “politics to me had always been a *confusing* swarm of words” (Shore 2001:175). The nouns used frequently included the noun “problem”, as in “Other *problems* can occur if instructions in a workplace are not given precisely or are phrased too generally” (Fleisher 2003:118) and the noun “trouble”, as in “The *trouble* was, the teacher assumed I understood language like other children did. I did not.” (Willey 1999:23). Another, more implicit way of denoting problems was to describe the impact of the problems on interpersonal relations. Willey’s description of openness illustrates this as follows:

(7)

It was easy for me to give my opinions on things, virtually all the time. I was by far the most blunt and outspoken of our group, even when my friends suggested I had gone too far. I never knew how far was too far. (Willey 1999:32.)

Willey’s remark of her unawareness of going too far adds yet another aspect to the problems a person with AS may have: the problem might cause difficulty to other people, although the author did not have noticed its existence or the troubles it has caused. This unawareness might even be a further source for not understanding the AS person.

In addition to the interpersonal aspect, a linguistic and/or communicative problem was established by the authors through describing the negative impact of the linguistic and/or communicative problem on the authors’ functioning:

(8)

When I had to be me around peers I had not known for a long time, especially peers I was meeting for the first time, I froze. Hindsight tells me this was AS nagging my reality, bubbling up and over until it became a cold, wet hand that held my calm to an ice tray white with frost. (Willey 1999:38-39.)

In this case, not being able to fit in the situation was a problem that showed in “freezing” in the situation. The excerpt is also significant in showing that the authors characterize their problems after the situations and through information on the properties of AS.

Another interesting way of characterizing the problematic aspects in interaction was that the persons might use terms that can hide multiple problems. For instance, Birch described herself as “shy” (Birch 2003:67, 73, 204, see also excerpt 57), although she also specified related problems, such as the limited number of topics available to her in conversations, troubles in understanding the social contexts of conversations, and the uneasiness of spontaneous language production in conversations. The source for this characterization can in all likelihood be found in other people’s attempts at defining the author’s deviation from the social norms. This, in essence, is what the author stated: “at least “shyness” was what people called it” (Birch 2003:67). The use of the term thus represents the effect of others on the author’s self-concept, and also that the author is knowledgeable of that effect.

Table 2 Linguistic and communicative problems

<b>Problem</b>	<b>Birch</b>	<b>Fleisher</b>	<b>Shore</b>	<b>Willey</b>	<b>Total</b>	<b>Authors</b>	<b>Relative occurrence (%)</b>
1. Conflicts/confrontations	2	0	2	1	5	3	3,6
2. Non-verbal communication	7	0	11	0	18	2	12,9
3. General comprehension difficulties	2	4	1	4	11	4	7,9
4. Literal-mindedness	2	5	5	4	16	4	11,4
5. Spontaneous production under social stress	4	1	1	1	7	4	5,0
6. Obsessive-compulsive language use	0	0	7	4	11	2	7,9
7. Withdrawal and unwillingness to interact with others	0	5	1	2	8	3	5,7
8. Unusual connections between language and thought processes	2	0	0	1	3	2	2,1
9. Lack of common ground in interaction	4	3	2	1	10	4	7,1
10. General troubles with the social context	5	0	2	3	10	3	7,1
11. Vagueness of social situations	1	3	0	1	5	3	3,6
12. Problems with conversation dynamics	1	0	0	5	6	2	4,3
13. Early language impairments	0	0	10	0	10	1	7,1
14. Problems in reading and writing	0	0	7	0	7	2	5,0
15. Co-morbidity of communicational problems	3	2	0	8	13	3	9,3
<b>Total amount of problems</b>	<b>33</b>	<b>23</b>	<b>49</b>	<b>35</b>	<b>140</b>	<b>Median=3</b>	<b>100,0</b>

Table 2 illustrates the proportions of the linguistic and communicative problems in the data by author. Similarly to Table 1, the numbers in the data are the amounts of instances in which a particular problem category can be found. For instance, no instances were found in Fleisher's autobiography describing conflicts and confrontations. What is more, 13 instances where co-morbidity of communicational problems was present were found in the data in total, whereas problems with conversation dynamics were described in only 6 instances.

Four properties of the descriptions of linguistic and communicative problems in the autobiographies can be discerned from Table 1. First, there was much variation between the amounts of different problems as they are described in the data. For instance, non-verbal communication (18 instances) and literal-mindedness (16 instances) were the two most frequent problem categories in the data, whereas unusual connections between language and thought processes (3 instances), conflicts and confrontations and vagueness of social situations (5 instances each) were the most infrequent categories. Second, the variation was significant within the categories – the authors described differing amounts of a particular problem and all authors did not describe all problems (see for instance category “Obsessive-compulsive language use” and “Early language impairments”). Third, the autobiographies differed in total amounts of instances where problems were described: Shore's autobiography included 49 instances where problems were described whereas Fleisher's autobiography included only 23 of them. Finally, many of the authors described particular problems: there were thus many consistencies between them (the median of authors per problem was three). This is especially significant in problems described by all four authors (general comprehension difficulties, literal-mindedness, spontaneous production under social stress, lack of common ground in interaction).

The numbers in Table 2 do not tell the amount of different problems associated with a category but the number of instances where a particular category was discovered. In addition, all of the above numbers have to be dealt with as showing the differences in reporting the phenomena rather than experiencing them. However, the absence of a particular problem in an autobiography can be interpreted as at least showing that its significance has been lower for the author. What is more, the

consistencies that were present show that in spite of many individual differences, AS persons share characteristics in their language use and communication.

## 4.2 An overview of the coping and accommodation strategies in the autobiographies

The strategies that are examined in this study are used by either the person with AS (coping strategies) or those surrounding him/her (accommodation strategies). The following excerpt illustrates the use of a coping strategy (using computers) for dealing with difficult aspects of communication:

(9)

Cyberspace can be a good place for those on the autistic spectrum to meet others. For example, I have been invited to present at several conferences as a direct result of my cyberspace connections. There are a number of reasons for the advantages of cyberspace to individuals with autism. The communication bandwidth is restricted to text. As a result, there are none of the nonverbal aspects of communication that so often present difficulties for those on the autistic spectrum. Also, there are no distractions of trying to remember what someone's face looks like or what they might be trying to say via body language or tone of voice. Finally, if you no longer wish to communicate with a certain person, he or she can be ignored. (Shore 2001:142)

The decision to include both the person and her or his environment reflects the mutuality of social interaction – both the AS person and the environment must cope with and accommodate for the special needs in AS. The effect of support an AS person receives depends on the ability of others to behave in a way which acknowledges the special needs. An example of the latter is offered by Shore:

(10)

Even after the child has “left the nest” and has become involved with a significant other, there is often an extended period of time before the person on the [autism] spectrum can transfer the ability to read nonverbal communication to that other person. For me, it took a good 10 years to accomplish this with my incredibly patient and understanding wife. (Shore 2001:83.)

In addition to the division between coping strategies and accommodation strategies, the strategies can be divided to successful and unsuccessful strategies according to the perceived effects by the authors (already present in the previous example). The successful strategies are those that the authors have found to relieve anxiety and uncertainty experienced in the situation while also fulfilling the communicational purposes the situation requires from the participants. An example



of a successful coping strategy can be found in Willey's description of reflecting on the problem:

(11)

Nowadays I try very hard to gauge whether or not my reactions are being manifested by AS or by something more discrete. For instance, if I find myself in the middle of an argument with Tom, I will consciously stop speaking and run the specifics of the conversation through my mind as if it was a computer that could seek, find, and sort out all the extraneous variables that I relate to AS. I then imagine in my thoughts, two stacks of index cards – one that contains commonplace variables like stress and sleep deprivation and hormones, and one that contains AS traits like my rigid thinking or literal mindedness. Piece by piece, I then analyze a few sentences at a time, methodically analyzing which category of variables influenced each verbal exchange. For example, I typically ask myself questions like: could my understanding of this statement have been influenced by my rigid thinking; am I just under too much stress right now to hear anything properly; did I take his comment too literally; or am I misconstruing the implication of his word or words. Once I decide which influences are at play, I can then sift through the exchange again, this time throwing out the pieces that I think my AS has affected. At that point, I can finally reevaluate the conversation and determine where things began to fall off track. (Willey 1999:81-82.)

That the coping strategy described above is successful can be deduced from 1. the detailed description of the method, 2. the multiple use of the verb “can” to denote an ability to do something and 3. the effects of the strategy (“I can finally reevaluate the conversation and determine where things began to fall off track”). All of these factors are not involved in all descriptions of strategies that have been successful; however, the effects of a given strategy define its successfulness.

By contrast, the unsuccessful strategies are those that, according to the authors, either have not relieved the anxiety and uncertainty or have the relieving effect but do not have the facilitating effect to the communication itself. Birch discusses the unfortunate consequences of forcing interaction as an accommodation strategy:

(12)

This same entry continues: “Percy’s [Percy was a male nurse] ‘challenge’ to me on Monday afternoon came as a demolishing blow because the subject, my not talking enough in group, (WAS that the subject?) is already my number one sensitive area without being told off about it. It made me feel upset that he and others think what I already feel in most groups – that I’m a lump of lead. I couldn’t prove that I do try to think of helpful things to say. But the harder I try to think, especially when I feel I should be saying something, and most of all when I’m asked to say something, is when my mind freezes and there aren’t any thoughts in my head to say. It is intensely annoying to say the least, especially when people think I’m not trying.” (Birch 2003:122.)

That forcing interaction was not helpful for Birch is seen in 1. Birch choice of adjectives (“demolishing”, “sensitive”) 2. verb forms (“I couldn’t prove...”, “there aren’t”) and 3. the effects of the strategy (“...is when my mind freezes and there aren’t any thoughts in my head to say”). The third point is crucial in defining the unsuccessfulness of the strategy, although analyzing the linguistic content provides with more evidence.

The division between successful and unsuccessful strategies can be made only at the micro level – that is, in a particular situation. This is because there are differences between the authors in how they perceive the effectiveness of a given strategy in their lives that hinders the generalization of their successfulness to the macro level (generalizing over the autobiographies). In many cases the strategies have both positive and negative properties, especially as regards avoidance. Fleisher describes having had success with avoidance as a strategy:

(13)

...In addition, many students took an extra year of their BSc to go on a work placement. This was a useful thing to do provided you had a rough idea of the sort of job field you wished to embark on. I had elected not to do this, and embarked on a full-time, three-year course without work placement.

There were basically two reasons why I chose the course without work placement. First, I enjoyed the stable timetable of a rigid structure to my day, which working elsewhere would have broken and brought extra problems such as travelling times increasing and having to relate to strangers in the workplace. I probably would have dwelt on these and my work concentration ability could have suffered. (Fleisher 2003:74.)

Another description by Fleisher shows that avoidance can be problematic even for the same person who has successfully used it in other contexts:

(14)

But I need more opportunities to make further progress. Always my apprehension holds me back. I’m always afraid of invading people’s privacy when I’m not wanted, even with quite good friends, to such an extent that if I meet them one day, I may go elsewhere for the next two before returning in case I meet them again, even by accident! For if I did I would feel I had invaded their space, or that they may be fed up with saying hello again so soon. (Fleisher 2003:111)

The above comparison shows that there were several different ways that a certain category could be represented in the autobiographies, even within a single autobiography, therefore generalizations are not applicable here.

Table 3 illustrates the use of strategies by author. The numbers correspond to instances where a particular strategy was used. Thus, for instance in Fleisher's autobiography increasing other people's awareness of AS as a strategy was encountered three times in total, whereas it was absent in Shore's autobiography. Table 3 also illustrates the total amounts of particular strategies and the total amounts of strategies per author, as well as the relative positions of strategies in the autobiographies. The first 11 strategies are coping strategies and the final 5 accommodation strategies.

It can be seen in Table 3 that there is great variation in the autobiographies between authors in both describing a particular strategy and describing the strategies in general. For instance, avoiding the problematic circumstances is described by all authors but in differing amounts (6, 7, 2 and 3), whereas shifting attention from social interaction is described by only one author. Further, the total amounts of strategies mentioned by authors differ between 16 and 30 strategies per author – the authors differ in including the coping strategies in the description of problems.

Similarities between authors can be found in Table 3. Most significant of these is the finding that all four authors described avoiding the problematic circumstances in their autobiographies. Moreover, there are four coping strategies (increasing other people's awareness, consulting experts, reflecting on the problematic situation, becoming aware of one's AS and the problems associated with it) and two accommodation strategies (detailed instructions/explanations, emotional support and understanding) that were described by three authors.

As with previous tables, Table 3 should be treated cautiously as showing primarily how the autobiographies differ in the depiction of coping strategies and only secondarily how the use of the coping strategies differs in the authors' lives. More significant are the similarities between authors in choosing a particular strategy, and the high number (15) of different strategies that has been used in coping with the linguistic and communicative problems.

Table 3 Strategies for coping with and accommodating for linguistic and communicative problems

Strategy	Birch	Fleisher	Shore	Willey	Total	Authors	Relative occurrence (%)
1. Increasing other people's awareness of AS	2	3	0	1	6	3	6,3
2. Consulting experts	1	3	1	0	5	3	5,3
3. Using writing and/or electronic facilitators	3	0	3	0	6	2	6,3
4. Adopting a form of behaviour closer to social expectations	0	2	2	0	4	2	4,2
5. Reflecting on the problematic situation	1	0	2	1	4	3	4,2
6. Discussing problematic issues with others	0	0	2	2	4	2	4,2
7. Becoming aware of one's AS and the problems associated with it	5	0	6	2	13	3	13,7
8. Avoiding the problematic circumstances	6	7	2	3	18	4	18,9
9. Challenging behaviour and violence	0	0	1	1	2	2	2,1
10. Unusual communicative and other behaviour	0	0	2	4	6	2	6,3
11. Shifting attention from social interaction	0	0	0	3	3	1	3,2
12. Mixed use of strategies	0	0	0	2	2	1	2,1
13. Detailed instructions/explanations	0	1	2	4	7	3	7,4
14. Using mediating facilitators	0	0	3	0	3	1	3,2
15. Emotional support and understanding	1	0	3	6	10	3	10,5
16. Forcing interaction	1	0	1	0	2	2	2,1
Total amount of strategies	20	16	30	29	95	Median=2	100,0

### **4.3 Problems and coping/accommodation strategies associated with flexibility in language use and communication**

#### **4.3.1 Conflicts and confrontations**

Birch, Shore and Willey described conflicts and confrontation situations as especially difficult for them. The authors reported high anxiety and inability due to the quickness and emotional burden of these situations. For instance, Birch described that

(15)

The other person(s) have the advantage in that they can think more quickly, and as it is usually they who have chosen to have the confrontation, this means that they have already thought ahead as to what they will say and do, whereas I am taken completely off guard. (Birch 2003:29.)

She thus depicts herself as a victim in these situations by stating that others have usually been the initiators of the conflict. Further, Birch's perception implies an imbalance in power relations between the participants due to the differences in abilities to deal with the situation. Thus, in conflict situations the authors tend to be weaker and this is taken advantage of by their conversation partners. The AS person can also describe her/himself as an outsider, as is done by Shore:

(16)

With emotionally charged situations I often feel like I am in a foreign land where I know just enough of the language to get an idea of what is happening, but no more. This is similar to being at a party with my wife where everyone is Chinese. I know enough Mandarin for rudimentary communication of pleasantries and to have a general idea of the conversational matter. The difference is that there is no feeling of discomfort because my limited comprehension is expected as English is my primary language. (Shore 2001:122.)

Others' expectations in the communication situation thus seem to be a factor in defining the well-being of the AS person in the interaction: there is a clear contrast made by Shore between using a second language and his first language in the communication situation, as regards the expectations that are directed towards him.

The situations which could include conflicts or confrontations varied in the autobiographies from intimate relationships to work environments. A description of

the former can be found in excerpt 11. Birch gives a description of the latter environment:

(17)

A new staff member in the Booking Office, although pleasant in many other ways, had the habit of making frequent racist comments against Maori and Pacific Island people. As someone who strongly dislikes unfairness in all its forms – and who categorises prejudice and racism as types of unfairness – I found this very upsetting. At the time, I was also learning the Maori language at night class, which was a most rewarding activity for me. I expressed my disapproval of this person's remarks, but, as has happened before and since, as soon as the perpetrator learned how I felt about it, she took pleasure in doing it all the more . . . A few other staff members would agree with her attitudes, and, at the time, I could not emotionally disentangle myself from the distress it caused me. (Birch 2003:141.)

Birch's description above presents herself as a person who is manipulated by others. However, rather than a passive victim, she describes herself as an agent in the conflict, by stating that she expressed openly her views about the racist comments of a workmate.

The working environment enabled the AS persons less to use active coping strategies. The coping strategy that was reported in these environments was avoiding the conflict-provoking interaction. The typical quickness of interaction in these situations hindered the author from using the strategy of reflecting on the problematic situation, as was seen in excerpt 15. Intimate relationship presented the person with more possibilities to reflect on the problematic situations with time: for instance Willey (excerpt 11) describes how she freezes the situation and goes back to determine the source of the conflict and its possible connection to AS. What is more, support from close people, specifically his wife in interpreting communication, has also been helpful to Shore ("knowing that my wife is available to decode communications as needed is very helpful" (Shore 2001:122)).

Shore (2001:121) also found that detailed explanations another effective strategy for coping with conflicts and confrontations:

(18)

. . . I find it helpful if others can say exactly what they mean along with creating a feeling of safety and trust. If this happens, I feel freed from the concern of having to create an appropriate response. Some phrases that I keep in my response repertoire for these situations include "What can I do to make you feel better about this?" or "Look, I sense that you have some strong feelings about \_\_\_\_\_. Can we talk about it?"

While having an algorithm or method for handling these types of situations helps, it does not approach the facility others off the autism spectrum seem to have for these emotionally charged situations. (Shore 2001:122.)

In spite of the effectiveness of the strategies Shore acknowledges the fact that using them does not match with the situation of not having to deal with conflicts to same extent as AS persons do.

#### **4.3.2 Non-verbal communication**

All of the authors reported on some problematic aspects that are related to non-verbal communication; however, two of them, Birch and Shore, stood out in the data in numbers. In reporting on problems in non-verbal communication, Birch states her unawareness of these problems during the onset of teenage years:

(19)

Though I did not realise this at the time, I did not know how to understand body language, or facial expressions apart from the most blatant ones, or eye messages, or indirect ways of using language. (Birch 2003:46.)

She thus acknowledges the fact that although the phenomena can be described by more technical terms, it was not the way the author as a child conceptualised her special behaviour, or not even the adult persons surrounding her or him. This applies specifically to those who have not received a diagnosis during childhood, that is, to all the four authors.

In spite of the differences between Birch and Shore in conceptualisation, the influence of the problems in non-verbal communication has been significant in the lives of both. Birch describes the impact for her during the teenage years:

(20)

This kept me on the outer in many social situations; and, therefore, being uncomfortable and unskilful in social situations, I avoided most of them if possible. It felt like I was on a separate planet; once I commented to my Mum, "I feel like an alien from outer space." Mum did not know what to do with such a statement. Thus, another of my identity issues was: "Am I an earthling or an alien?" (Birch 2003:46.)

As Birch states, the problems have caused Birch to reflect on her identity as a person who is different from others. The non-verbal communication problems have caused her troubles in a psychiatric hospital ward which was recommended to her due to her anxiety symptoms:

(21)

The word “messages” was commonly used in the ward, and the other patients appeared to understand what was meant. I did not understand, at the time, that it referred to facial expressions, eye contact meanings, body language, and all indirect, “between the lines” communication, which is used constantly by most people . . . For me, a person who could not understand this unspoken language, the result was that I was constantly unable to understand the social life of the ward, often behaving “inappropriately” as a result, which produced more negative reactions from others, and, in turn, increased my confusion and anxiety, thus creating an on-going cycle. (Birch 2003:119-120.)

The effects of the problems with non-verbal communication for Birch have been relatively same regardless of context: not being accepted in the group. She also offered a possible causality between opting for male company and non-verbal communication:

(22)

My preference, at this time, for male company (because it was proving to be less problematic than female company) was also part of my life-long feeling of androgyny . . . I had never felt like a girl... so how, therefore, could I fit in with girl-only groups? Again, in hindsight, it seems to be a matter of the “secret language of indirect communication” which was at least one component of my deficits in all-female company – I could not decipher the code. (Birch 2003:121.)

Not being able to comprehend adequately non-verbal communication has been a major issue for Birch, shaping her identity as a person not comfortable with the extensive use of non-verbal communication in the interaction in “all-female company”.

Problems with non-verbal communication also have effects on a daily basis – for instance on sports activities:

(23)

Team sports continued to be difficult all through public school. In middle school I signed up for the 100 Mile Club, which meant running around a track with the goal of completing 100 miles by the end of the semester. I did well with this alternative activity. Running around a field was much easier for me because it was a solitary sport. Even running alongside my classmates was fine because success in this activity was not dependent on reading nonverbal cues and handling social interactions that



eventually led to my being rejected by my classmates for not having the necessary motor coordination and muscle strength to contribute to the team. My mother often told me to join the neighborhood children in games of kickball down the street, but I responded with “I hate sports.” My feelings of inadequacy in these team sports drove me away from participating in them. (Shore 2001:12.)

That Shore makes a difference between successful individual efforts and the problems with team sports is significant in showing the differences between environments – the communicational aspects can pose additional difficulties which might not be deductible from, for example, mere physical properties as above.

Although the strategies for dealing with non-verbal aspects of communication varied between the persons, both authors reporting the non-verbal problems have avoided some problematic circumstances which require non-verbal communication; this shows in excerpts 21, 22 and 23.

Both of Birch and Shore have considered awareness of AS and the problems caused by it to be a helping factor. Birch’s comments on the effectiveness of diagnosis in determining her communicative specialities (including non-verbal communication) have been discussed under section 4.6. Similarly, Shore discusses the effectiveness of feedback from others in determining the problematic parts of his non-verbal communication:

(24)

During my undergraduate days I underwent a few counseling sessions to work through some issues of family relations. Several times the social worker asked me how I felt about what she was talking about because she said she could not tell by reading my face.

When working at the large bank discussed earlier, I received a phone call one day that my parents had been involved in a car accident. Following the call I told my coworker that I would ask my supervisor for permission to leave early to see my parents. My coworker said, “You go; but don’t laugh when you tell him.” Apparently, even though I felt fearful about my parents’ conditions, an inappropriate smile or laugh must have escaped that caught my coworker’s attention. (Shore 2001:120-121.)

Feedback from others, such as in the above situation, has assisted becoming aware of the non-verbal communication problems associated with AS. Through becoming aware of them, Shore has studied the non-verbal aspects:

(25)

. . . I found psychology courses to be particularly engaging because they helped explain how people behaved. When I became aware of the meaning of “body language” or nonverbal communication through a psychology class, I became fascinated with this mode of communication. This is probably because I have to analyze it pretty closely to understand this facet of interaction. In an educational psychology course, I did an extensive empirical study on nonverbal communication around the campus. For example, I studied what it meant if a person was sitting by himself at a table, sitting right in the middle, at the edge or towards the edge. To this day I enjoy reading books on nonverbal communication . . . (Shore 2001:89-90.)

Noting that the non-verbal aspects do not come naturally, Shore has thus engaged in studying them from an outsider’s point of view. He characterizes the motivation for the studying non-verbal communication as helping him to “build a lexicon to assist in decoding its meanings” (Shore 2001:120).

Support from close people has also been helpful for Shore. He presents the help of his wife as central in learning to understand non-verbal communication in the relationship:

(26)

Even after the child has “left the nest” and has become involved with a significant other, there is often an extended period of time before the person on the spectrum can transfer the ability to read nonverbal communication to that other person. For me, it took a good 10 years to accomplish this with my incredibly patient and understanding wife. (Shore 2001:83.)

Shore has also used computers such as Internet as a means of communication. He presents several reasons why they are a successful strategy:

(27)

There are a number of reasons for the advantages of cyberspace to individuals with autism. The communication bandwidth is restricted to text. As a result, there are none of the nonverbal aspects of communication that so often present difficulties for those on the autistic spectrum. Also, there are no distractions of trying to remember what someone’s face looks like or what they might be trying to say via body language or tone of voice. Finally, if you no longer wish to communicate with a certain person, he or she can be ignored. (Shore 2001:142.)

Shore’s description highlights the differences between face-to-face communication and communication through computers, the latter having less non-verbal aspects. Rather than treating using computers as merely a means of avoiding difficult interaction, they can be seen as a way of finding a medium through which the person can express himself with less anxiety.

The most adaptive coping strategy is perhaps described by Shore (2001:58). When listening to and not comprehending jokes, he pretends to understand, thus trying to adapt his behaviour to the social environment in an unnoticeable way. The pretending does not aid the comprehension (“Often I don’t realize a joke is being made until the person talking specifically explains it to me” (Shore 2001:58)), but the strategy has aided to maintain the flow of interaction.

In addition to helpful strategies, Shore describes having used those which have proved less successful:

(28)

I started dating a Chinese woman two years my senior . . . . As in past dating experiences, she, too, was the initiator in crossing the borderline . . . . We found a beach near a restaurant and walked to the end of a long pier, while looking at the ocean, she suddenly made a small sound and hugged me. Not knowing why she hugged me, I hugged her back. Again, not being able to read the nonverbal cues, I defaulted to imitating her behavior. Finally she said that being Chinese, she couldn’t act the way Americans do. Not knowing what she meant by that, I said “okay” and we held hands as we walked back to the car and drove to my parents’ house. (Shore 2001:101-102)

As can be seen from the extract, being in a situation where non-verbal communication is central can produce behaviour such as copying that might carry the situation somewhat further but that does not resolve the problems. In this case, the problems with non-verbal communication were eventually voiced out, but some hidden content remained that continued to cause problems to Shore.

### **4.3.3 General comprehension difficulties**

All four authors described comprehension difficulties in relation to instructions, learning difficulties and understanding of other people’s point of view. Most of the comprehension difficulties in the autobiographies arose in the working place and in intimate relationships, but some also took place in educational institutions. Shore’s inability to understand appropriately the instructions has influenced his vocational performance and the subsequent loss of work:

(29)

After receiving my bachelor's degree in music education and accounting and information systems, I set forth to work in a medium-sized certified public accountants firm. Boy, was that a mistake. And as a result, I was let go after only three months . . . Even though I had just graduated as an honors student with a bachelor's degree in the field, I often felt my coworkers were speaking in another language when they explained procedures and told me where different documents were located. It seemed as if I had been dropped into a foreign culture. I felt as though I needed to be shown step by step in a discrete manner to get a grasp of what was expected of me, but no one was willing to do that. (Shore 2001:111.)

For Birch, the working environment has also been problematic because of her incomprehension of jokes and a “difficulties with learning new tasks” (Birch 2003:245). The learning aspect also appears in Fleisher's story: he describes how “The staff [at a college] just thought I was being awkward, and not picking up the ideas presented perhaps because [he] wasn't trying hard” during a college communication course (Fleisher 2003:43). His description closely resembles Shore's one above in how the environment has not been able to take into account the person's speciality in relation to other people.

Willey describes the lacks in her point of view comprehension in reporting how she was “misconstruing [her husband's] thoughts” and how her husband “was left to think [she] had just failed to listen to him” (Willey 1999:80). The metaphor of “foreign language”, used by Shore in the working life context (excerpt 29), is also being made use of by Willey (1999:81). Willey's description gives a picture of her as helpless and even frustrated in the flow of conversation. She attributes the problems to AS: “It did not take long for me to realize that once again, I was not following a normal path. Once again, I found myself face to face with my Asperger traits.” (Willey 1999:81).

The difficulties result in suffering, although it might not always be visible to the outside. The suffering is especially strong, because the authors think of these properties as permanent:

(30)

Try as I might to catch and contain them, these are the qualities I will never lose and only rarely hide. I would not mind, so much, these reminders of my unique character, if they were of a different sort. (Willey 1999:77-78.)

The coping strategies that are implemented by the authors in situations that require accurate comprehension include detailed instructions and explanations, increasing other people's awareness of AS, consulting experts and support from close people.

Detailed instructions and explanations were both used by the people surrounding the authors and wished by the authors. The authors suggested that it is a successful strategy in coping with the comprehension difficulties. Willey describes the use of the strategy in her life:

(31)

Sometimes, I will be able to fix things up by asking Tom to redefine or elaborate a specific point . . . When I have an inkling the crux of my confusion and my inability to follow his thoughts is more influenced by my AS than anything else, I will directly say to Tom – I think my AS is confusing me. Please start over and tell me again what you are trying to tell me. This confession of mine has never failed to help both of us stop the arguing immediately, whereupon Tom can begin his point all over again, but this time with a great deal more care and precision behind his words. (Willey 1999:82.)

The use of the strategy depends heavily on the other participant who must be willing to make explicit everything vital to the comprehension. Therefore the explaining can also be considered to be a form of support. Although the strategy has according to the authors proved to be an effective one, Willey's additional comment reminds of the danger of over-optimism: "But sometimes, even the most telling and detailed sentences are not enough to help me comprehend what is being said to me." (Willey 1999:79-80).

Willey has also received other forms of emotional support and understanding from her husband. She states that when the circumstances get complicated "I desperately look for the only person who can almost instantly save me from reeling beyond control. I reach for my husband." (Willey 1999:77-78). Not all of the authors have had the same possibilities of support offered in the intimate relationship, but the other's awareness of AS has helped them in other ways. Fleisher states how

(32)

The staff at the college (which incidentally has now become a university in its own right) were never made aware of my condition and were treating me as any other student. Whereas in previous years I could always fall back on sympathetic help from the unit in times of high anxiety or pressure, now there was none . . . With no sign of any real help in sight, things quickly spiralled out of control. (Fleisher 2003:43.)

The absence of disclosure seems to have influenced how the staff saw Fleisher. The author regrets the situation and the difference between the amount of support available when others were aware of his AS and when they were not: “whereas in previous years . . . now there was none”. The excerpt suggests that the lack of help was significant in determining the outcome (“things . . . spiralled out of control”).

Birch also looks back on the absence of disclosure (her situation was somewhat different in that she had not received a diagnosis at all during childhood) (Birch 2003:200). She notes how making the environment aware of one’s AS is not merely a solace to the AS person – telling about it might prove to be difficult:

(33)

However, in this particular case – as I had already worked in the same place two or three times – I could not face the issue of telling the supervisors that I *now* had Asperger Syndrome, which would raise the questions of “Is this a new illness? If you had it last time, why didn’t you tell me before?” . . . (Birch 2003:200.)

Nevertheless, she also acknowledges the possible value of informing others of the features that might come up in the working environment.

#### 4.3.4 Literal-mindedness

All four authors described themselves as being more or less literally-minded. The most apparent consequence of literal-mindedness is their inability to understand what people mean by such utterances as imperatives. Willey describes a situation in which her teacher instructed her to take a nap on her mat:

(34)

That same year, we were required to take naps each day. I vividly remember my teacher announcing, ‘Children, find your mats and take your nap.’ I refused. Again, the teacher called my parents. Again, my parents made their way to the school. ‘Liane, why won’t you take your nap?’ my parents wondered of me. ‘Because, I can’t.’ ‘You see!’ the teacher said smugly. ‘Why can’t you take your nap?’ my parents continued. ‘Because I don’t have a mat.’ ‘You most certainly do have a mat. There it is in your cubby,’ the teacher replied. ‘I do not have a mat.’ ‘You see what I mean?’ the teacher asked my parents. ‘She is an obstinate child.’ (Willey 1999:22-23.)

On the surface, the literal comprehension seemed to be resistance to the teacher's orders. It was only later that the underlying reasons were discovered. Willey has had similar problems with her parents: "My parents, assuming I was acting audaciously, were constantly baffled as to why I found it so necessary to challenge their authority" (Willey 1999:21-22).

Taking things literally has also interfered with the authors' sense of figurative speech and humour. Shore (2001:57) describes how, during the third grade, he had difficulties in understanding that a classmate stating he "felt like a pizza" did not try to communicate the actual content of his words. Fleisher's reports depict the influence of literal-mindedness on, for instance, his sense of humour:

(35)

I was also unable to distinguish between remarks and light humour, so that when a couple of my workmates teased me by saying 'You have to come in to work every Saturday now' I took their remarks literally, and ended up worrying even on the Saturdays I had off in case they had meant it, or there had been a change of dates by my boss. (Fleisher 2003:48.)

According to himself, Fleisher is not able to comprehend or use so-called "pub language" and the humour related to it, conceptualising the comprehension as "suitable social knowledge" (Fleisher 2003:121).

The authors also reported on inabilities in understanding the literary expression of emotion and other subtleties. This can be considered to be at least connected with their literal-mindedness and its influence on figurative speech specialities. For instance, Shore and Birch reported on having trouble with poems. Shore describes poetry as "scary, as it represents unknown meanings to [him]" (Shore 2001:88), also extending his troubles to lyrics ("The deep feelings brought on by poetry or music had always escaped me" (Shore 2001:119-120)).

The coping strategy that emerged as the most frequent one in the data in relation to literal-mindedness is avoiding the problematic circumstances. Fleisher's avoidance manifest itself in his joke-telling: he restricts his joke-telling (" . . . normally I only study jokes about topics which I know and can relate to." (Fleisher 2003:121)). Willey also discusses avoidance, from the literary perspective:

(36)

By around eight years old, I had become a very proficient comprehender as well as word caller. So long as the material was of a factual nature. Fiction was more difficult for me for it forced my thoughts to go beyond the literal. I preferred biographies and eventually made my way through every biography we had in our library, despite the librarian's repeated request that I check out something new and different. I liked reading about real live people and their real life experiences. (Willey 1999:24.)

Here, as in many other instances, the avoidance is rather opting for another alternative – in this case books dealing with fact rather than fiction.

From the point of view of effective language use and communication as well as other social behaviour, the avoidance strategy can be regarded as negative because of its possible effects of producing socially problematic effects such as limiting human contacts. However, the authors do not explicitly consider the strategy negative when applied to literal-mindedness. In fact, Willey considers her avoidance to have produced her happiness: “I liked reading about real live people . . .”, “I was attracted to the reality of the words I was reading” (Willey 1999:24).

Receiving detailed instructions and explanations has proved to be an effective accommodation strategy. Willey's previously discussed example in the school environment (excerpt 33) included the use of this strategy:

(37)

‘Why do you say you don't have a mat?’ the folks asked, not giving up on me.  
 ‘That is not a mat. That is a rug,’ I honestly and accurately replied.  
 ‘So it is,’ said my father. ‘Will you take a nap on your rug?’  
 ‘If she tells me to,’ I said matter-of-factly.  
 ‘Tell her to take her nap on her rug,’ my father said as my parents turned to take me home. (Willey 1999:22-23.)

Although the situation did not end in Willey doing as she was instructed, the parents were able to provide the teacher with background for dealing with possible further situations of same kind. Willey describes that in the parent-AS child interaction of her family the parents have had to adjust to her language use “weighing their every directive to be certain [she] would not find a way to weave their words with [hers]” (Willey 1999:21-22). Therefore, their experience has provided strategies for dealing with situations such as above.

The kind of support offered by Willey's parents has also been available to her in the intimate relationship. Willey describes how her husband can “restructure his



conversations” (Willey 1999:82) and “ride time until [she] can settle [her] dizzying thoughts onto something untouched by [her] panic and [her] confusion” (Willey 1999:83). The author needs a conversation partner who can take into account her literal-mindedness in the conversation and finds a way to express him/herself in a manner which conveys the wanted message and not just the possibly misleading surface meaning.

As with many other linguistic and communicative problems, becoming aware of one’s AS or at least its aspects have helped the authors to cope with literal-mindedness. Birch reports a confrontation which was caused by her lack of comprehension of the underlying meaning of utterances:

(38)

One night, one of the flatmates (the one who owned the house) was ranting and raving all night about her girlfriend. “I’ve finished with her! Anyone can have her now, because I don’t want her!” . . . A few weeks later, there was trouble in my flat. The house-owner, Vanessa, was angry that I was going out with Jessica. She now let it be known that it wasn’t true that “I’ve finished with her – I don’t want her.” Another of the flatmates remarked to me, “People don’t always say what they mean, you know! You shouldn’t have assumed that she meant it.” (Birch 2003:52-53.)

Although Birch was undoubtedly in a great conflict with her flatmate, the other flatmate’s helpful comment seems to have opened up the situation for Birch, thus enabling her to see why her flatmate was angry.

Listening to music has helped Shore to learn the underlying meaning of words, in his case lyrics:

(39)

It wasn’t until about the age of 35 that, through text put to music, I learned the potential emotional impact of words. This occurred as I was teaching a course in music appreciation. After listening to “A Survivor From Warsaw” by Arnold Schoenberg, I was suddenly overcome by emotion and was not able to speak for a couple of minutes afterwards. My students asked me if I was okay. All I could say was that this was a very moving piece that deserved a few moments of silence when it was finished.  
(Shore 2001:119-120.)

Shore’s learning seems to have taken place without conscious attention paid to the lyrics, through sudden unlocking of the emotional content of the music. Shore has also been helped by music elsewhere, especially with his early language impairments.

#### 4.3.5 Problems with spontaneous production under social stress

All four authors have found it hard to spontaneously produce linguistic output in situations where social stress is involved, although most of the descriptions found are by Birch. Birch describes how “Speaking was, for me, often slow and hesitant, as I had to translate from my pictures to words, but this became a problem only when I was pressured and rushed by other people to hurry up.” (Birch 2003:118). She says how, as a result, her “mind would freeze and [she] would be totally unable to do the translation into words” (Birch 2003:118). Birch has experienced the pressure especially in the psychiatric context, being “an inpatient in a New Zealand psychiatric hospital three times, the longest stay being for eight months, in the mid-1980s, when [she] was 29 to 30 years old.” (Birch 2003:114). Her diary entry represented in the autobiography reveals how the environment was clearly unhelpful to her:

(40)

It made me feel upset that he and others think what I already feel in most groups – that I’m a lump of lead. I couldn’t prove that I do try to think of helpful things to say. But the harder I try to think, especially when I feel I should be saying something, and most of all when I’m asked to say something, is when my mind freezes and there aren’t any thoughts in my head to say. It is intensely annoying to say the least, especially when people think I’m not trying.” (Birch 2003:122.)

Birch’s experiences might be near the extreme considering the social pressure formed by the environment, but she also reported how “On the occasions when the teacher asked me a question, my brain would often “freeze.”” in the educational setting (Birch 2003:182). The problem thus seems to have extended further than one context. Birch also expresses togetherness with a person who had similar problems which was, according to her, a relief in confronting the problematic issue: “I found his company a refreshing change from the fraught atmosphere surrounding the other patients.” (Birch 2003:120).

Willey described the impact of social pressure on her language production among peers:

(41)

Speech competitions taught me a great deal about myself, especially when I was off the stage. On stage, I could try on the entire range of human emotions, even the emotions I typically had nothing to do with, and then as easily as I slipped them on, I

could take them off and re-shelf them until the next time. But offstage, I did not have the luxury of pretending. I remember the first time I knew there was a vast difference between what I was able to make myself do in front of an audience, and what I could coax from myself when I was left without the stage lights. When I had to be me around peers I had not known for a long time, especially peers I was meeting for the first time, I froze. (Willey 1999:38-39.)

Willey's description resembled those by Birch in the use of "freezing" as a metaphor. The difference between her stage performance and normal social interaction is an interesting reversal of the more occurring stage fright – the author likes performing as she is able to express herself more to an audience than to the peer group.

The social pressure of a group seems to be a factor affecting the spontaneous language production also for Shore and Fleisher. Shore reports on how "It was hard to talk about [school guidance issues] in a group", "Even now it's easier for me to talk on a one-on-one basis" (Shore 2001:79-80). Fleisher reports how, more recently, "I had also found something to say to other people instead of standing there like a zombie not knowing what to say because of my lack of social confidence." (Fleisher 2003:120), having previously experienced similar problems with spontaneous production.

The strategies for coping with situations of problems with spontaneous production were varied. Willey uses withdrawal as a strategy ("...I would concentrate instead on blanking out my thoughts, counting over and over and wishing I was in a still spot away from the noise.", Willey 1999:38-39)). Her description does not depict its successfulness. By contrast, Shore explicitly prefers using questions as mediating facilitators in the interaction ("I find it even easier if someone asks me questions as opposed to having to initiate conversations by myself" (Shore 2001:79-80)).

Birch and the people around her have also used numerous strategies. Birch uses writing to enable her to express herself in a more comprehensive manner, but the strategy was not available in the psychiatric context described above: "Now that there was a ban on writing, I could barely communicate" (Birch 2003:118). She had also been a target for forced interaction (see excerpt 12). As noted, the forcing increased Birch's anxiety and was not a successful strategy.

#### 4.3.6 Obsessive-compulsive language use

Shore and Willey describe obsessive-compulsive language use in their lives. Most of the obsessive-compulsive aspects have to do with imitating or copying other people and repeating what others have said, also termed echolalia. Willey also reports an obsession with words. Most of the copying occurs in social interaction.

##### Imitation and copying

Shore depicts imitation as an integral part of his behaviour which has been present throughout his life:

(42)

As mentioned earlier, I have always had very strong tendencies to imitate. This often result in my taking on others' speech, movement and sometimes emotional characteristics when I am in their presence without realizing at first. (Shore 2001:35.)

As can be seen from the excerpt above, according to Shore, his imitation is mostly unconscious to him. In the kindergarten where he “most of the time . . . was not able to . . . determine whom [he] was copying” even when asked to (Shore 2001:38). The imitations continue to cause him inconvenience in his adulthood, resulting in the likes of the following situation:

(43)

During part of my tenure as a music instructor at a college, I would spend much time with the president's assistant. Many times I caught myself in horrified realization that I was talking like him to his face, copying his intonation and speaking style. He called me a homie so I'd refer to him as one. The word “homie” is used by African-Americans as a term of friendship or closeness. If he referred to me as a “brother,” I would automatically do the same. But I would immediately stop and I never knew if he perceived my imitation. (Shore 2001:37.)

The copying has, according to Shore, not always been unconscious. He recalls an incident where the copying was intentional:

(44)

I remember my third-grade teacher often telling me that I acted babyish. At the end of the year when she asked me how I felt about myself during that school year, I just

repeated her words back to her as I thought this would make her happy. (Shore 2001:53.)

Copying others has also had other functions, such as being a coping strategy in unclear situations where non-verbal communication has been involved (see excerpt 28).

Willey's point of view on her copying is somewhat different. She describes herself as "uncanny in [her] ability ability to copy accents, vocal inflections, facial expressions, hand movements, gaits, and tiny gestures." (Willey 1999:27-28), thus stressing the meaning of copying to herself as a skill rather than an annoying feature. She also acknowledges the unconscious nature of the copying ("I don't know how I choose who to copy") (Willey 1999:27-28) and that copying can nevertheless be a problem for others, such as her parents:

(45)

My parents tell me they were often confused not so much by my ability to copy others, but rather by my desire to do so. They thought I was giving in to peer pressure or wanting to be someone I was not. (Willey 1999:27-28.)

Willey states that her parents were unaware of the real causes of her copying, one of which during the childhood was shutting other people out of her world:

(46)

This was not the case during that time in my life. Until I was somewhere around ten years old, I held myself separate from others. I never really compared who I was to who they were. It didn't dawn on me to see myself as a fellow third grader or as a member of a team. I felt almost like I was invisible. (Willey 1999:27-28.)

Similarly to Shore's accounts of the copying, Willey refers to identity issues. However, the authors conceptualise the copying from opposite viewpoints. Willey states that she could "take in parts of who the [others] were and never worry that I was a copy cat, never worry I had lost me." (Willey 1999:27-28). This makes a sharp contrast with Shore, who considers the copying to be "a problem in separating oneself from the environment as a distinct and separate entity" (Shore 2001:37).

Analogously to Shore, Willey continues to copy during the adulthood. Although the copying is somewhat unconscious, she has been enough conscious of it to reflect on its causes. Willey notes that she has a compulsory need to copy certain kinds of

voices (those with “heavy nasal or high shrill qualities”). She conceives the copying as “working [her] voice”, comparing it to giving performances (“public speaking competition[s]”) (Willey 1999:36). Willey also describes copying as a deeply-ingrained form of behaviour: “Old habits are hard to break and sometimes I notice myself echoing even though I work at home now and rarely feel compelled to fit in at all.” (Willey 1999:71-72). This characterization also gives an alternative explanation to her copying - seeing copying also as a means of belonging to the social environment, “fitting in”.

There are differences between Shore and Willey in their views on the transparency of the copying to the person who is being imitated. Shore states uncertainly that “I wonder if they realize that I am imitating them” (Shore 2001:37). Willey is more certain in expressing that “Interestingly enough, I do not think anyone else realizes I am echoing, not even the people I am copying.” (Willey 1999:71-72). She does acknowledge, however, that the people who know her better are sometimes able to notice her copying, including “A few very observant friends” and her AS daughter (Willey 1999:71-72).

### Obsession with words

In addition to copying, Willey also discusses her “fixation” with words, which can “throw me into an obsessive compulsive ritual”. The problem is that of selecting words for written text. The impact of the fixation is a total consumption of concentration: “When I get like this, I cannot concentrate on anything else, not a thing, until I have found the perfect term or phrase I need.” (Willey 1999:36). Willey also expresses an accepting attitude towards the obsession: “This tendency can make my experiences with the written word tedious, at least in terms of time and other missed opportunities, but never meaningless or futile.” (Willey 1999:36)

Due to the lack of possible coping/accommodation strategies available to the authors as described in the narratives (only three instances where strategies are described contrasted with a total of 11 instances where problems are described), the obsessive-compulsive language use is represented as a difficult problem to deal with. Willey’s

daughter uses the strategy of making the person aware of the properties related to AS. Willey accounts this ability to her daughter's AS:

(47)

A few very observant friends have noticed an occasion or two when I had lost myself in the shadows of someone else, but no one has ever noticed as quickly or completely as my AS daughter does. She recognizes the moment I bend my voice or my motions to match someone else's and it drives her to distraction. In no uncertain terms she will demand I stop acting like whomever, that I quit walking this way or that, that I stop pretending to be someone I am not. Though she does not yet fully understand the weight of her words, there is little that keeps me from comprehending the fact that she is right on track with her observation. Funny that she, another Aspie, is often able to see my pretence before I am. (Willey 1999:71-72.)

In addition to making the person more aware, other strategies that have been used are avoiding the copying and reflecting on the problematic situation. The latter involves the non-echolalic forms of copying. Shore tries to be conscious of his copying so as to determine the origins of his behaviour. Even then he reports the overwhelming nature of the copying:

(48)

Whenever I get a very strong emotion and I am not clear as to where it comes from, I have to consider whether someone I am in communication with is displaying a similar emotion, which I am picking up from them. Sometimes I feel as if I am fused with that other person's emotions and can't separate myself (Shore 2001:37.)

#### **4.3.7 Withdrawal and unwillingness to interact with others**

Although avoidance was considered a coping strategy in the analysis, withdrawal and unwillingness to interact were also a linguistic and communicative problem themselves. Fleisher, Shore and Willey present withdrawal and unwillingness to interact in their narratives. Three of the four descriptions of avoidance are situated in the childhood, but Willey also tells about her unwillingness to interact with others in the professional environment (teaching).

Fleisher describes how he used to opt for not interacting with others in the childhood:

(49)

In my early years often I made no distinction between times when the whole family was present and when they were not. I would much rather go and play with my toy train and track set, for example, instead of sitting and talking with the others. (Fleisher 2003:17.)

Although being alone was preferable for Fleisher, his behaviour can be considered problematic, as he “. . . later . . . became more aware of the importance of family relations” (Fleisher 2003:17). Shore comments on how he could “identify with Dibs [the protagonist in “Dibs in the Search of Self” by Virginia Axline (1961)], who seemed so closed up but with the hard work of his therapist was able to open up and talk.” (Shore 2001:58). For him the behaviour which for others might have appeared as withdrawal was not a wished state, but rather a phase of not being able to communicate adequately.

Both of the above mentioned instances are more or less related to the family environment. Willey adds a vital part in describing what the interaction was like in the school environment:

(50)

Children in school were always running and shouting and moving. They were always busy, always mixing things up, never content to play quietly or by themselves. I liked to play at the kitchen center in our kindergarten room. In fact, I rarely wanted to play anywhere else, another ‘problem’ of mine that caused my teacher great distress. If I wasn’t playing with the kitchen toys, I was reading. (Willey 1999:23-24.)

The withdrawal can thus also include elements of language use even if others might be avoided. There is a clear contrast between withdrawal and the problems with early language development described later, characterized by an inability to use language in any form in spite of a will to do it.

Willey has also experienced unwillingness to interact with others, while teaching in elementary school. Forced interaction with workmates and parents of the children she taught, according to her description, led Willey to abandon her occupation as a teacher. She writes how she “had to interact with the administrators . . . no matter the discomfort”, “had to force myself to attend staff meetings”, “will myself to smile” (Willey 1999:69-70). The interaction with parties extraneous to her actual work required significant efforts, although she says to having managed to appear as taking wilfully part in the interaction.



Willey needed ways to deal with the anxiety that the unwanted interaction provoked in her. These strategies included not paying conscious attention to the interaction and her obsessive-compulsive rituals. Willey describes the former as “fragmenting herself” (Willey 1999:69-70), having two sides to her being in these situations, the one that listens to what others are saying and the other that is absent. Willey does not specify whether the rituals are conducted in the situation or after it. In any case, both of the strategies can be considered as maladaptive to the situation when successful communication is concerned.

For Fleisher, the others’ strangeness has also been a factor which has made him unwilling to interact with others. He describes how, in attending a special hostel for young people with disabilities, he experienced anxiety due to not having lived with other disabled people before.

(51)

... it was my relation to the other disabled people that really worried me. Sleeping at night was the worst time since I was often kept awake by loud TVs and chatting until the early hours of the morning. At times the others swore at me and I misinterpreted this as a risk of physical violence stemming back to my school days. One night I was so anxious I ran home (about two miles) to my Mum’s house at about 1.30 in the morning and burst into tears. And here I was, a grown man of 23. That’s what Autism can do under stress. (Fleisher 2003:60.)

Other, more unfamiliar contexts also created apprehension in Fleisher in a way which reduced his ability to function flexibly. He later describes what kind of fears he had if he were to go to a student’s house:

(52)

What if they had a big dog that attacked me? What if I had to ask them for a lift home because I can’t drive and they or their family ended up kidnapping me? What if they hated me in secret and gave me a drugged drink or poisoned food? What if their partner or husband got the wrong idea and thought I wanted more than just helping them with their Maths, and promptly smashed my face in to teach me a lesson? (Fleisher 2003:96.)

Fleisher’s description reflects his distrust for unfamiliar people. The same reason has at least partly prevented him from choosing to include work placement in his studies (“I had elected not to do this, and embarked on a full-time, three-year course without work placement” (Fleisher 2003:74)), because it would have probably included “having to relate to strangers in the workplace” (Fleisher 2003:74).

Avoidance seems to stand out as the most common strategy for Fleisher for dealing with the situations in which strange people induce anxiety in him. However, there are other strategies that work to reduce the anxiety as well.

Being involved with the disabled (people with autism) in the professional context as well, Fleisher gained experience of communicating with them while teaching, noting that “Often it was quite hard to keep their attention” (Fleisher 2003:95). He gives other people’s awareness of the person’s Asperger’s syndrome as a good strategy for dealing with the problems that AS might cause for instance in the professional/working environment by stating: “On the other hand, working here was better than before because I felt in a safe environment with staff who totally understood me.” (Fleisher 2003:95). The safe environment would thus seem to reduce the withdrawal related to stress caused by strangeness of others.

#### **4.3.8 Exceptional connections between language and thought processes**

The autobiographies of Birch and Willey, include descriptions of unusual connections between language and thought processes that have been found problematic by either the author (Willey) or the people surrounding the author (Birch’s case). Willey talks about how her rigid thinking affects her language use and communication:

(53)

I do not feel my rigid thinking would be a big impairment to my ability to communicate if I did, in fact, move on completely. However, I rarely do . . . Unfortunately, each time I begin perseverations on one particular issue, I am very likely to recant a litany of similar instances and sets of circumstances, even from as far back as a decade or more ago. (Willey 1999:83.)

Willey was able to cope with her rigid thinking with the help of her husband:

(54)

Thankfully, Tom has a strong threshold for my perseverations and my rigid thinking patterns. I suppose he has finally come to accept that this chink in my character is as much a part of me as are my blue eyes. (Willey 1999:83)

Birch discusses how central writing and images were to her thought processes:

(55)

Writing, although an intense interest for me, was far more than that: it was one half of my thought processes. The other half was thinking in pictures. I had an original, creative way of understanding everything via mental images in moving technicolour. (Birch 2003:118.)

Birch depicts herself as different from others when it comes to her way of thinking. According to her, taking away writing in the psychiatric hospital had severe consequences for her, as she regarded reading and writing as her “necessities of life” (Birch 2003:118). This is partly because writing also acted as a coping strategy in conversations, as Birch was able to convey her thoughts better through writing, for instance when dealing with spontaneous production under stress. The psychiatric context eventually influenced her way of thinking to an extent that she became negatively aware of being different and tried to learn away from it:

(56)

Another result of the treatment was that I had been moulded to think of myself, and my very thought processes, as inadequate. Feeling hounded, every day, because I was communicating differently from others – and, moreover, because my differences were responded to as though they were wrong and undesirable – I misguidedly put all my efforts into learning to speak as other people did . . . Finally, a switch in my brain switched from pictures to words. Now, at last, I could think in words, which enabled me to speak like a native speaker of English. There was a cost attached to this, however: I can no longer think in pictures – this creative side of my being is gone. Now that, very late in life, I have discovered that certain other people DO think in pictures, as I did – and that it is, therefore, a valid (as well as an original and inventive) way of thinking – I feel cheated that I was made to feel that I had to change my very thought processes in order to become “well,” and “normal.” It feels like another “sell-out” into which I was manipulated by this hospital experience. Knowing what I know now, if I could go back and reclaim my previous cognitive individuality – that stolen part of my soul, my self – I would. (Birch 2003:129.)

Birch’s description shows that her ways of thinking about herself have changed from viewing her speciality of visual thinking as a deficit (“inadequate thought processes”) to regarding it as “a valid, original and inventive way of thinking”. This change acts as a background for the bitterness she expresses through claiming that she has lost her visual thinking. Becoming more aware of the aspect was thus not necessarily a change for the better – in this case a speciality conceived by others as a problem was

essential for the AS person and socializing away from it resulted in more problems with coping rather than in an enhanced interaction with the environment.

#### 4.4 Problems and coping/accommodation strategies associated with contextual aspects in language use and communication

##### 4.4.1 General troubles with the social context

Three of the four authors, Birch, Shore and Willey, report troubles with the social context. The authors experienced these problems in private, educational, professional and parental contexts. Birch gives an illuminating description of how the social context and its nuances can be lost:

(62)

On another day in the country – another of Lindsay’s well-known haunts – we had a lush paddock to ourselves, fringed by trees and a stream with a little bridge . . . Lindsay then suggested that we take off our clothes . . . Our feet felt the rough concrete of the little bridge to nowhere. Not for the first or last time, I lost my balance. The tumble downwards seemed to take a long time, terrified as I was. I did not know how deep the water below was, and I could not swim . . . On scrambling out, it was apparent that I had several large grazes on my back and elsewhere. Lindsay helped to wipe off the slime and to dab at my wounds with a clean cloth. We had nothing in the way of antiseptics with us, of course, so we headed back to my Mum’s place, where I then lived.

It was a Sunday night tea, with an elderly aunt for company. Proudly relating, by now, the events of the day, I told of my misadventure and subsequent injuries. My aunt enquired “And did you have to take off your clothes, for Lindsay to wash your grazes?”

“They were already off!” I blurted out.

After Aunty had left, Mum spoke to me sternly: “Don’t say things like that in front of your Aunty!” (Birch 2003:78.)

There is a clear tension between the earnestness of Birch’s story and the social constraints the other participants (especially her mother) assume in the situation in terms of what is appropriate for the situation and what is not. Birch does not comment on the incident further but the description of the event shows that the openness and the mother’s judgmental approach against it have made the event stand out in her life story. She describes her unawareness of the social context as a factor which has further complicated the matters:

(63)

. . . as I did not know that I could not pick up social cues (understand what was going on with other people) most of the time, I could not do anything to assist myself. . . I knew that something was wrong, but I had no way of figuring out the mechanism of

exactly what was going wrong, and why, and (therefore) what I could do about it. . . (Birch 2003:206.)

Similarly to Birch, Shore describes a setting where he is misunderstood because of the unmet demands of the situation in the working environment:

(64)

Before I got to know and trust this man the way I do, we had a falling out. I had approached him during his tenure as chair of the Business Department with an idea of developing a music business program at our college. He told me that while this was a great idea, it wouldn't work "...due to the fact that the Business Department was stretched to the maximum at this time, along with there being no budget for publicity." He is honest and hard-working, so I took him at his word and didn't think more of it. Later that week when my dean asked me to write a memo about my conversation about a music management program, I repeated the words of the Business chair verbatim. The memo was later forwarded to the vice president of academic affairs, who interpreted the statement as my saying that the chair of Business was lazy and had no energy to consider another program.

The Business Department chairman got angry with me and much yelling ensued. With the assistance of a friend of mine, the problem was cleared up and the chair of Business and I ended up becoming good friends.

It had never occurred to me that whatever I wrote to my dean would be repeated verbatim to somebody else and misinterpreted. The lesson for me is that all memos must be written as if anyone in the entire college might read them and that whenever there is a possibility that someone might look bad, special pains must be taken to prevent it. (Shore 2001:3-4.)

Like Birch, Shore was not careful in choosing his words and considering the context where the interaction took place, which resulted in him being put in a difficult position because of miscomprehension. Both descriptions show that the AS person's earnestness and lack of understanding of the social context is interpreted by other participants as something else by others (such as disrespect).

Willey reports troubles during a position as an elementary education teacher. The problems occurred not with the children but because she appeared "awkward around the adults I worked with" (Willey 1999:68-69). Willey did not find other ways of being in the situation than by adopting the role of a performer which she was familiar with (see also excerpt 5):

(65)

. . . I would rather naturally resort to my stage talents. Literally. I smiled, made witty remarks and told interesting stories, and when I ran out of stories to tell, I left as if I was walking off the stage. (Willey 1999:68-69)

Without the comfort of the role she could not handle the situation and had to leave it. Willey also discusses performing in the relationship:

(66)

He never missed a beat when he discovered I was different. He never discusses it unless I bring it up. He never alludes to it during my long-winded monologues. He never uses it as a sword to kill my enthusiasm for our relationship. And because he never uses who I am against me, I came to trust him. (Willey 1999:89-90.)

The paragraph above depicts both a problem (conducting a monologue instead of participating in a dialogical fashion in the interaction) and a strategy (support and understanding as an accommodation strategy) – a pattern that came up repeatedly in the data related to linguistic and communicative problems. Like Willey, Shore was also supported by other persons in dealing with the outcome of the problems in the example from the professional environment above (excerpt 64).

Birch explains how foreign language learning has helped her to partly overcome the difficulties with context :

(67)

Regarding my language skills, although I had always been able to write to an above-average standard, I had trouble carrying on a conversation in English. This was because of such factors as my marked “shyness,” my usual inability to understand the social situation into which the conversation fitted, and my relative slowness in mentally processing the rapid-fire nature of conversation, which in turn was partly due to my thinking processes being carried out via pictures, rather than in words. However, the fact that in German class we were encouraged to memorise sentences and whole conversations meant that I was, for the most part, more able to converse in German than in English... as long as I possessed a stock of sentences which would fit the required topic. Decades later, still unable to talk freely and easily in English, I would return to this foreign language teaching method for the purpose of teaching myself to speak my native tongue! Thus, it can be said that, in some ways, I taught myself English as a foreign language. (Birch 2003:73)

Birch thus regards a repertoire of communicational devices as essential in producing contextually appropriate linguistic output. Developing this kind of a repertoire shows the additional efforts that the author has had to put in processing spoken communication compared to written communication.

Another strategy that has been made use of by Birch is avoidance of situations. Interaction with a classmate’s baby becoming a major stressor for her (Birch 2003:154), Birch chose to not be a part of the interaction: “As all the other students knew what to say and do, and as the baby was being constantly looked after and

cuddled anyway, I decided to leave it to them.” (Birch 2003:154, 156), eventually deciding not to continue the course. This ultimate decision reflects the impact of the contextual inability as a stressor to the person’s mental well-being.

Although the majority of the authors experienced problems with contexts, Fleisher’s autobiography illustrates the opposite case. He talks about how jokes should be adjusted to different situations:

(68)

. . . there are certain situations where a joke may not be appropriate to a particular individual. For instance, if I knew one of my friends had another friend or one of her family critically ill in a hospital, then I would not proceed to tell her any jokes about patients and doctors on the wards of hospital, since this may then make her sad thinking about her loved one. (Fleisher 2003:121.)

The excerpt is significant in showing that there are situations when the AS person is able to adapt to the environment, even when the processing of contextual information is involved. What is more, it shows clear a clear difference between the authors in being able to cope with differing contexts (cf. the descriptions above).

#### **4.4.2 Lack of common ground in interaction**

All four authors report instances that have included lack of common ground in interaction. The most commonly reported type of interaction in this category was that with peers – eight of the ten instances that describe lack of common ground include aspects of this type. The lack of common ground is thus important from a developmental perspective. Other types are more involved with adult life, although clear connections to the childhood can be found, which is illustrated in the following excerpt by Birch:

(57)

Throughout my childhood, teenage years and young adulthood, I had been very shy; at least “shyness” was what people called it. I could more or less speak with my mother and brother – on some topics, at any rate. With other people, my communications were very restricted . . . I had, from my early years, a sense which told me that others would not be able to understand my innermost experiences. This sense has proved to be correct, because even in my adult years, when I eventually became more eloquent in my communication skills, the situation was no better – especially when dealing with the helping professionals. (Birch 2003:67.)



Birch describes the lack of common ground as “shyness”, although she makes it clear that this term is actually used by others. The use of the term “shy” and the subsequent description highlights the weak permeability of the AS person’s thoughts to the non-AS people. The person is classified as “shy”, due to differential nature of her outward communicative appearance, although the actual problem might underlie in the AS person’s differential experience of the world when compared to others.

The differences in background for interaction between the AS person and others are described by Birch in relation to hobbies, habits and sensitivities. In Shore’s life, the school environment has been the context for many of the difficulties, both during the childhood and adolescence and during the adulthood (Shore 2001: 148-149). Shore makes a connection between his occupational difficulties as a teacher and the peer interaction problems he has experienced in his childhood:

(58)

As a student teacher at the middle school level, I had found that I had problems with classroom management. Quite often I couldn’t seem to get the student to understand and follow what I wanted them to do . . . I felt as if there was a communication barrier between these elementary-school children and me that I couldn’t break through . . . The challenge I just described stems at least partly from the fact that my development during primary school was atypical. Since I did not experience typical interactions with my schoolmates, I lacked a basis upon which to develop a positive teaching relationship upon returning to the classroom as a student teacher. (Shore 2001:148-149.)

Offering the causality between childhood peer group interaction and subsequent interaction is an example of the attributions the authors make for problems in their autobiographies.

Willey describes her problems with peer group interaction, stating that she did not share the others’ language (or “vernacular”, Willey 1999:56-57). This seems to cause the comprehension problems for Willey, as she is unable to get the message in spite of the fact that the grammatical comprehension is normal. Thus, the unfamiliar lexicon is the key cause for interaction problems, with possible connections to non-verbal communication (“Subtext and innuendo may as well have been birds flying by my window” (Willey 1999:57)).

The description of coping strategies was rare in relation to the lack of common ground. Out of the ten instances where the lack of common ground was described, three also included coping strategies. Avoidance and behaviour that is closer to the social expectations can be regarded as the poles in the coping strategies, with other strategies being situated between them. Avoidance comes up as Willey tells how she “managed to fade away, out of [the] company” (Willey 1999:70) of her friends who she did not accept the linguistic and other habits of. In contrast, Fleisher describes how he uses jokes to handle better situations where there is not much common ground for interaction:

(59)

I normally tell other people jokes as a way of showing them I want to be friends, or that I appreciate them talking and being friendly to me, and of course hopefully to make them happy by bursting out laughing! But sometimes it can be because I don't feel I have anything else to discuss of interest to them, for not many others are interested in solving a complex cubic equation or in talking about how big the known universe is. (Fleisher 2003:121.)

Similarly to Birch, Fleisher's account reveals how special, absorbing interests in AS (see section 2.1.1) are an important factor in creating the difference between the AS person and the non-AS person as regards their points of departure for the interaction. What is more, using joking as a means for dealing with difficult situations is a rather revealing strategy, considering the existing deficit-centered reports in AS literature.

In coping with the lacks in common ground, Shore described having behaved unusually (by repeating sounds) in the school peer group interaction situations:

(60)

I had a repertoire of strange sounds and sayings that I repeated incessantly. Starting in kindergarten, for a period of time I would say the letter “B” over and over. I thought it was an ugly sound but I felt compelled to repeat it. When the kids asked me to stop, I wouldn't . . . This familiar repertoire of actions provided me with a comfortable, predictable way of interacting with the other children. (Shore 2001:53-54.)

The repetition proved to be somewhat unhelpful, provoking ambiguous reactions in his peers:

(61)

Unable to make me stop producing this sound, my classmates stopped associating with me and went about their school activities without me. In retrospect, perhaps this behavior was the root of kids making fun of me and bullying. However, it was

impossible for me to draw a connection between the sounds and my classmates' reactions at that time . . . Some of the other students would also adopt these sounds and faces. (Shore 2001:53-54)

Shore himself depicts the strategy as problematic, by stating that “In retrospect, perhaps this behavior was the root of kids making fun of me and bullying”. Shore thus acknowledges that although the “repertoire of actions” was “a comfortable, predictable way of interacting”, it did not solve the problems that occurred in interacting with peers, rather the opposite.

#### **4.4.3 Vagueness of social situations as a source of linguistic and communicative problems**

Three authors, Birch, Fleisher and Willey, consider the vagueness of social situations as problematic for them. The vagueness shows itself in both the personal and the working environment. Fleisher compares social interaction to mathematics:

(69)

Socialising is harder than any Maths equation for me. What works for one person doesn't for another. People do not always say what they mean, or stick to what they say. (Fleisher 2003:110.)

Fleisher's depiction of social interaction as “harder than any Maths equation” includes a sense of not knowing what happens next. He hopes for a way to get into a position where he is aware of other's intentions:

(70)

I'm always afraid of invading people's privacy when I'm not wanted, even with quite good friends, to such an extent that if I meet them one day, I may go elsewhere for the next two before returning in case I meet them again, even by accident! For if I did I would feel I had invaded their space, or that they may be fed up with saying hello again so soon. This is not allowed, under my resolutions of operation. And there are always the little things. Did that person see me or not? If I say hello they may be busy and not want to stop. If I don't greet them they may be hurt, thinking that I just ignored them on purpose. If only I could read their minds, and what they wanted me to do. (Fleisher 2003:111.)

Fleisher's fear of “invading people's privacy” makes him fabricate rules (“If I meet them one day, I may go elsewhere for the next two before returning in case I meet

them again” for the interaction, so that it follows a clear logic. His rule-making is illustrated in his use of the words “under my resolutions of operation” which highlights his intellectualization of the interaction. At the same time his behaviour can be classified as an attempt at avoiding the problematic circumstances which would cause possible invasion of privacy.

In a similar fashion, Birch (2003:27) describes rules being “elusive and liquid” in the interaction as opposed to other areas of life:

(71)

I found that each sphere of knowledge had its own set of facts, or rules. Certainly, as soon as I became five and could read, I could discover many more facts than was possible through my own observations. Of course, there were thousands more species of animals in books than in my real life, so I read about every species I could, from ants to spiny anteaters. Everything in the world was run by rules, it seemed: reproduction, genetics, arithmetic, cooking, motor mechanics, snakes-and-ladders. To find out the facts, the rules, was to achieve mastery over life. Alas, the older I became, the more the uneasy feeling grew, that the rules for living amongst people were elusive and liquid. This was the only set of rules that could not be nailed down and kept down. (Birch 2003:27.)

Birch’s need to find a repertoire is discussed in relation to excerpt 67. This excerpt offers additional information on Birch’s need to find stable rules in the interaction and on failing to do so, with the interaction being too vague to be mastered by simple rules.

Willey widens the scope of problems with vagueness by discussing the changing roles of the participants in interaction:

(72)

Even now, I cannot find one reliable reason for keeping my thoughts to myself. The world seems fickle on this point. Sometimes people want an opinion, sometimes they do not. Sometimes they say something so incredible an opinion has to be given. Other times they sit in silence seemingly unaware of the situation that lies before them. The entire dichotomy is too confusing. . . I realized long ago that it would be easier for me to stop a dog from going after a bone, than it would be for me to stop my thoughts from escaping my mouth. (Willey 1999:32.)

Although the vagueness complicates the interaction for Willey, it does not prevent her from openly expressing herself. The intensity of the effect of vagueness seems to differ significantly between the authors, producing avoidance in Fleisher, and not affecting Willey’s course to the point of inhibiting communication production.

#### 4.4.4 Problems with conversation dynamics

Two authors, Birch and Willey, discuss problems with conversation dynamics. For example, Birch describes her problems as follows:

(73)

. . . if I could scarcely cope with a conversation, or with the power dynamics of social situations, then I was not socially and emotionally ready for boy– girl encounters and all that they might bring, that is, an introduction to the romantic and sexual realm. (Birch 2003:75.)

Birch's autobiography includes only one instance (above) of the problems with conversation dynamics. By contrast, Willey's description is full of instances where the conversation dynamics have been difficult for her. She notes, how she "never understood group dynamics, particularly casual friendship dynamics that work on giving and taking, role playing and modeling, rule following and turn taking" (Willey 1999:20). Willey also makes a contrast between public performances and group interaction (see excerpt 41). Willey gives control over the event as one possible underlying cause:

(74)

Maybe I enjoy speaking in front of a group because it is a one-way communication experience and, as such, something that is not affected by the complications of other people's body language and non-verbal styles . . . Once my thoughts were spoken aloud, I could finally move on to another thought or concern. (Willey 1999:37-38.)

Willey describes how in the professional environment the gestures made the task of following the dynamics even more complicated:

(75)

. . . back when I taught, I had to fight with myself to stay on track. I would try to keep my eyes very still, concentrating intently on people's faces, but not their gestures. Gestures took on dialogues of their own, making it even harder for me to keep up with the conversation. (Willey 1999:70-71.)

According to Willey, her attention is turned away from the actual topic of the conversation by the non-verbal aspects of communication. This is because following and interpreting the dynamics does not come automatically for her.

Willey has used various strategies in different stages of her life to cope with the dynamics. In her childhood she used challenging behaviour and violence to help her deal with a difficult situation:

(76)

Somewhere along the way, I had learned to cope with the intricacies of young friendships well enough to manage one friend. Any more spelled disaster sometimes in very real forms. One day, I suppose I had had enough of Maureen's having other friends. She and a little girl from next door were playing outside in the yard when I marched myself up to the little girl and asked her just why she was at Maureen's house. I can't remember what she told me, but I do remember I punched her right in the belly the moment she finished her explanation. I guess she said something I didn't like! (Willey 1999:20.)

Willey has also had other forms of unusual behaviour such as the use of toys as conversation partners and copying other people. According to Willey (1999:70-71), the latter "worked to keep [her] connected" in the interaction, serving as a construct to hold on to when she cannot otherwise cope and to be a part of the interaction in spite of the fact that she cannot follow the conversation as an active participant.

Willey also tends to adopt the role of a performer, whenever she feels the pressures of the situation are too much for her:

(77)

. . . unless the person is extremely straightforward and blunt, I usually end up climbing back on stage, reciting the old lines and the old jokes, as my stomach starts to knot and my thoughts remind me how difficult this all is for me. (Willey 1999:73-74.)

By adopting the role of a performer Willey aspires to gain more control over the communication situation. However, she is not happy with forcing the interaction to another format:

(77)

I worry about this inability of mine, not so much because of how it affects me, but more because of how I think it might affect my children or the people whom I do not seem to grow close to. (Willey 1999:73-74.)

Thus, although it takes advantage of her personal interests and preferences, the strategy is not satisfying for her due to its incompatibility with the expected course of interaction and the possible consequences.

## **4.5 Problems and coping/accommodation strategies associated with developmental aspects of language use and communication**

### **4.5.1 Early language impairments**

Of the autobiographies examined in this study, only one (by Shore) included clear descriptions of early language impairment. The descriptions he has included in his autobiography have mostly to do with not being able to use oral language at the early years. According to himself, Shore showed signs of language use at the age of six months (Shore 2001:15), stopping at the age of 18 months (Shore 2001:161). He remained mute until the age of four (Shore 2001:21), exhibiting peculiar voice tone imitation and reversed pronouns in the childhood (Shore 2001:19).

Shore's mother was aware of the impairments and in spite of them tried to find ways to communicate with the child by using music, talk and play as devices for activating the child who "didn't appear to be aware of her" (Shore 2001:24-25). According to Shore (2001:24-25), the combination has been helpful, as he "slowly admitted her into my world". Shore depicts his mother as a person who has determination to continue although the results were initially not promising, and eventually one who has succeeded in getting a contact to the child due to the determination.

Shore's early linguistic and other problems have made his parents consult experts in the form of a therapy program at the age of four. He reports that "According to my nursery school teacher, I had some verbal skills but was unable to make my likes and dislikes known [at the time]" (Shore 2001:33.). The therapy program lasted until Shore changed to another nursery school. The linguistic problems continued to cause Shore trouble and frustration. The latter emerged to the surface through challenging behaviour, such as hitting a girl and poking another to the stomach to make her produce a strange sound (Shore 2001:39). Shore gives his limited verbal capacities as an explanation for the challenging behaviour:

(78)

Since my verbal skills were not developed to a point where I could easily interact with others, perhaps these two instances of challenging behaviors were a way for me to communicate with these children. (Shore 2001:39.)

Shore's explanation is valuable in denoting that the frustration that he felt due to not being able to communicate adequately was not the only reason for the behaviour, rather, the behaviour was at the same time a means of communication itself. Shore later gives his opinion on the subject from the point of view of an expert who has become familiar with other people with autism:

(79)

As I work with children on the autism spectrum, it has become clear to me that many challenging behaviors are a result of an inability to interact with the environment in a manner that is sensible to them . . . Finding the source of the behavior via an understanding of how the child perceives the environment is key, as merely punishing for the behavior doesn't remove its cause. (Shore 2001:39-40.)

Shore's description of his language impairments follows the plot of a "rags to riches" story. He states that "By primary school, my verbal ability was just about on a par with that of the other children in my class." (Shore 2001:161). Considering that the initial stages of the development involved mutism, the change was significant. There were issues which continued to be problematic though: "My reading ability was better than my expressive language. I recognized many words in the printed form but not in the spoken." (Shore 2001:161). Although Shore states that his reading ability was better, he also suffered from reading problems, which will be discussed under the next section.

#### **4.5.2 Problems in reading and writing**

The autobiographies include numerous descriptions by Shore of his reading and writing problems. The reading problems somewhat outnumber the writing problems. Birch's autobiography also includes some instances of writing problems, but as she states they are due to Occupational Overuse Syndrome (Birch 2003:263), they are not included in this study.

Shore's problems in reading were noticed in the second grade of school. His teacher informed the parents who had not noticed his ability to decode meaning from text (Shore 2001:55). Shore offers hyperlexia as a name for his problems. However,



the reading abilities seem to have changed over time from hyperlexia to problems in finding a deeper meaning behind the words:

(80)

The interpretation and analysis involved in reading *King Lear* or *A Tale of Two Cities*, for example, was overwhelming. Beyond the incredibly long opening sentence in the latter book, about it being both a good and bad time, and the mention of a king having a large jaw, decoding the meaning behind or between the words was impossible. (Shore 2001:87.)

In addition to reading texts, Shore discusses reading comprehension assignments as problematic for him:

(81)

Reading comprehension assignments in elementary school and beyond were always very difficult for me . . . I remember being infuriated at one of these assignments in fifth grade because it was entitled “How the Earth Was Formed.” I *knew* how the earth was formed. Astronomy was my current special interest and I spent many hours reading astronomy books and copying their pictures and diagrams onto pieces of paper . . . Now that I am older, I can appreciate the story for what it is – an American Indian legend. (Shore 2001:57.)

Shore’s infuriation seems to be connected with literal comprehension of the content. Shore was not able to view the story’s symbolic value, rather, he interpreted its content as being merely contradictory to his knowledge on astronomy. As Shore notes, he was able to subsequently overcome the literal interpretation of the story, which implies positive development in other cognitive skills. However, the reading problems have continued in the adult age (“I still have difficulties with reading comprehension as determined by a neuropsychological exam I took in November of 1996” (Shore 2001:57)).

Shore’s problems with writing were twofold. The first and the more fundamental problem was his inadequate motor coordination. He presents manual writing as a significant challenge to him from that perspective (Shore 2001:60). His awareness of the problems has, according to him, not been helpful due to the insurmountable nature of the difficulties:

(82)

Even though I am well aware of my difficulties in penmanship and drawing, having to provide that structure from within myself makes it impossible for me to do these activities well. (Shore 2001:60.)

Shore thus offers the lack of structure as a possible explanation. The coping strategies discussed below show a way of dealing with the lack of structure.

The other facet of Shore's writing problems involved creativity. He states that at high school "creative writing became a significant challenge" (Shore 2001:85-86). According to him, "This was not surprising since I often had difficulty putting ideas on paper already in elementary school." (Shore 2001:85-86). And later: "By the time I got into high school, I seemed to be locked into getting a B minus on any English paper I turned in. (Shore 2001:86-87). Shore further describes his creative writing problems:

(83)

In second grade, for a class assignment, I wrote a story about some kittens that alternated between existing as little cats and puppies. In fact, they were in so much demand that they fetched \$47,000 each; or the price of a house at the time. The ideas for this story were spun out of my current life events. Cats were a special interest at that time. One of my family's many cats had recently given birth to five kittens, we had acquired a puppy, and our house was on the market for the same price as these mythical felines sold for. My teacher discounted the assignment as being babyish. However, if she had asked me where my ideas for the paper had come from, perhaps she would have been more understanding and helpful in getting me through the writing assignment. (Shore 2001:86-87.)

As the events came from Shore's life at that time, he wished that the teacher would have tried to discuss the matter with him, rather than discarding his performance. Shore's wish reflects a challenge for the environment to better take into account his special needs (by for instance discussing the problems). In this particular situation that challenge was not answered. However, Shore has found a help for the fine-motor controls in writing – using a computer:

(84)

An accommodation for this fine-motor control issue for me is to use a computer. In many instances a computer can bridge the fine-motor issues between what I have envisioned and the manual graphical output. Like the watch, the computer frees me from having to devote energies to creating the structure and allows me to concentrate on the task at hand. (Shore 2001:60.)

The description above shows that using a computer has been an effective strategy in dealing with problems in writing, helping Shore to realize his plans without interference from fine-motor control.

### 4.5.3 Co-morbidity of communicational problems

The authors made it clear in their accounts that the communicational problems did not occur in isolation and as separate difficulties, rather, they tended to be co-morbid, a combination making communication overtly difficult. As three of the four authors, Birch, Fleisher and Willey, discuss the co-morbidity of communicational problems, it rises as a significant theme in the data.

One way of denoting this co-morbidity was the use of diagnostic criteria for giving a concrete list of the factors that might be involved in the behaviour of a person with AS. Birch (2003:196-197) and Fleisher (2003:14) use the criteria in their descriptions. It seems that the authors have made use of the diagnostic criteria they have received from experts to construe their story, naming the problematic phenomena in their life according to the diagnostic labels. This might partly have been the case, however, the picture provided by the author was much more extensive than might be expected from a mere adherence to the diagnostic criteria. In any case, it should be noted that the authors did not tie the lists of characteristics to their own life, which their presentation too susceptible to be considered as representative of the co-morbidity in the authors lives.

Another approach to presenting the co-morbidity was conveying a more personal viewpoint - describing the co-occurrence of features in the author's life. In fact, the autobiographies were very rich in this aspect, because many of the descriptions of linguistic features tended to be collections of multiple features which have interfered with the author's social functioning. This is illustrated by Birch's long list of her behaviours that she believes is associated with AS:

(85)

Other hints of an Autistic Spectrum Disorder were: difficulty in knowing which way around my clothes were meant to go; my extreme "shyness" with anybody I did not know; my difficulty in participating in a conversation; not knowing how to play with the little girls, therefore mixing with an "inappropriate" group, the little boys; my unusual and obsessional interests which persisted long after the "appropriate" age for them was past (e. g. marble alleys, collecting bottle tops, catching water beetles, harvesting acorns, chestnuts and turnip seeds); my repetitive activities of, for instance, digging with a stick in the ground and walking repeatedly around the perimeter of the school; wanting, as a child, to spend a lot of time alone; preferring my solitary fantasy games to playing with other children; being a "walking dictionary" compared with other children; experiencing difficulty with decision-making; having a low threshold

for frustration; and being excessively fearful, especially about changes, e. g. going up into the next class, which was a drama every new year. (Birch 2003:204.)

The challenging co-morbidity has required a combination of strategies. Willey is the most representative of the ability to combine several strategies:

(86)

If we were at home I could do quite a lot to contain my most obvious AS traits. I could control the environment, taking away those things that annoyed me or I could choose to ignore those problems I had not learned to control. At the very least, I could rely on my husband to bail me out if something was happening that would not go away or be ignored. (Willey 1999:99.)

The excerpt above includes two different coping strategies (controlling the environment and problems, ignoring the problems) and one accommodation strategy (support and understanding). In fact, Willey has also used accommodation strategies herself with her child who has AS. For instance, Willey has tried making her child more conscious of AS through teaching in order to reduce the effect of the problematic aspects:

(87)

I walk a fine line when I begin to try to teach my daughter how to act in public, how to understand abstract language, how not to be so outspoken and brash. (Willey 1999:113-114.)

Willey finds a conflict between trying to teach her child to be more independent and socially able and the lack of independence and possible shame that the teaching might provoke due to the discovery of being different:

(88)

In one respect, it is very difficult for me because I want her to feel the freedom I did, but without paying the price I did before I came to figure me all out. I never want her to feel ashamed of the qualities that give her the gift of complete honesty. (Willey 1999:113-114.)

This conflict does not prevent her from the teaching, though:

(89)

But then, there is a part of me who knows if she is ever going to find peace with herself completely and if she is ever going to be given the opportunity to succeed in a society as reluctant to accept any deviation from the norm as ours is, I must teach her all I know... and then some. (Willey 1999:113-114.)

Fleisher also reports acquiring knowledge on AS as a helping factor in dealing with the co-morbidity:

(90)

In my teenage years, I was already aware that there was a natural reaction from some people to ignore me or stay away from me, simply because they did not understand Autism and feared the unknown. With improving awareness, as knowledge and research start to grow in each county in more recent years, I have encountered this situation less frequently, and instead, more people seem to be generally sympathetic to my condition. Many parents I have known in later life have been able to recognise the symptoms in their young ones more readily, for as well as the obvious lack of social interaction, there are also many other tell-tale clues to look for. (Fleisher 2003:114.)

Fleisher's description shows a clear tendency from others' ignorance to awareness of AS. Much of the increased awareness has to do with the presence of an acknowledged diagnosis for AS. The effects of the diagnosis will be discussed in the following section.

#### 4.6 The significance of the absence and presence of a diagnosis in defining the effectiveness of coping and accommodation strategies

The significance of diagnosis as providing information to the authors' coping is a frequent theme in the data. As noted previously on many instances, not all of the coping or accommodation strategies the authors report on have been used in their lives or in all of the situations in which they would have been helpful. Many of the descriptions of strategies are speculative, and many can be considered to be issues than can be learned from mistakes. For instance, Willey considers her past lack of knowledge on her special characteristics as an inhibiting factor for her in using helpful strategies:

(91)

I know in my heart and in my head, that if I had owned more AS knowledge, if I had been able to objectively understand that terms like rigid thinking, semantic pragmatic disorder, social impairment, echolalia, bilateral coordination problems, sensory integration dysfunction and auditory discrimination, were very real words that defined who I was, I would have made small changes in my course. I would have gone to a smaller and perhaps more empathetic school. I would have realized I had a different set of needs and wants that set me apart from many of my classmates, but that never meant I was undeserving or incapable. And most important, I would have asked for the support I really needed. (Willey 2003:60.)

Becoming aware of one's AS helps to reanalyze the problematic situations that have occurred and prepare for future situations. This information has not obviously helped the person in the problematic situation before getting a diagnosis, but it helps her or him to analyse and understand the situation better. Birch gives the following description which describes the impact of the lack of diagnosis in her life and is similar to that of Willey's:

(92)

My difficulties with relationships – tending to worsen as I progressed through adult life – had a lot to do with Asperger's syndrome, especially undiagnosed Asperger's syndrome . . . As I did not even know that I had difficulty reading facial expressions and body language (except for the most blatant ones: smiles and frowns); as I did not know that I often could not detect sarcasm, double meanings, hidden agendas and deception; and as I did not know that I could not pick up social cues (understand what was going on with other people) most of the time, I could not do anything to assist myself. If you know that you have a cut finger, you can put a band-aid on; but if you are unaware of the cut, you can't do anything about it. I knew that something was wrong, but I had no way of figuring out the mechanism of exactly what was going

wrong, and why, and (therefore) what I could do about it. I could not improve my performance without knowing the answers to these questions – although I had tried to improve. (Birch 2003:206.)

The authors' cognitive development as users of coping strategies is clear. Childhood experiences are often described as full of helplessness with the problems, whereas the adult experiences most often include the use of a coping strategy. Shore's description of his nursery school experiences is representative of the early stages without the help of strategies gained through knowledge of the diagnosis:

(93)

Around this time, a second floor was added to our house as we needed more space. I was fascinated by the work, but was taken away to my grandparents' house for part of the construction. I wanted to stay but couldn't find the words to communicate it. (Shore 2001:42.)

Shore's inability to communicate leaves him with no alternatives and totally under the guidance of others without a possibility to express his own intentions and/or free will. This situation is very different from the kind described by Willey:

(94)

As the girls grew older, new horizons shed a bright light on virtually each of my Asperger traits. And while I could find ways to deal with, or at least mask, my sensory integration dysfunction problems, I could not shirk away from those traits that would follow me no matter what. If we were at home I could do quite a lot to contain my most obvious AS traits. I could control the environment, taking away those things that annoyed me or I could choose to ignore those problems I had not learned to control. At the very least, I could rely on my husband to bail me out if something was happening that would not go away or be ignored. But my husband was not always with me. If I was out on my own when I got too distracted by too many images and situations, I would run the risk of losing my edge over the AS. My language would become too pedantic, my facial expressions too exaggerated, my thinking too rigid, my temper too rude and my pragmatics too problematic. (Willey 1999:99.)

Willey describes several approaches to her problematic behaviour (controlling the environment, ignoring the problems, relying on the husband). She is able to treat her problems through using Asperger's syndrome as a denominator for them ("Asperger traits"). The two excerpts can be considered as the opposite ends with reference to coping strategies: the absence of strategies vs. the abundance or mixture of strategies.

The authors' eventual AS diagnosis seems to be a central issue in determining the use of subsequent coping strategies. Fleisher gives evidence to these arguments from

his life (see excerpt on page 72). In addition to Fleisher's account, the comments by Birch and Willey on the accuracy of strategies used in difficult situations presented above and Birch's experiences of incorrectness and harmfulness of medical care seem to point to the necessity of correct observations and a correct diagnosis:

(95)

I had, from my early years, a sense which told me that others would not be able to understand my innermost experiences. This sense has proved to be correct, because even in my adult years, when I eventually became more eloquent in my communication skills, the situation was no better – especially when dealing with the helping professionals. Therefore, I can only be thankful that I did not expend a lot more energy and adrenaline than I already did, trying to get such people to validate that which they could not. (Birch 2003:67.)

Willey also offers yet another strategy in the appendix of her autobiography: she suggests that the AS person should make others aware of the problems so that they could be taken into account:

(96)

If literal thinking interferes with your ability to problem solve and complete higher level thinking projects, discuss this in detail with your teacher who will have to work with you and probably your counselor to determine exactly what kinds of support and assignments you would most need to be successful. (Willey 1999:133-134.)

Willey's account can be regarded as an attempt to pass on the life experience that the AS person has gathered on her speciality. This perspective is significantly different from the one that a clinician with experience accumulated from interacting with AS people can possess – both are needed.



#### 4.8 On the analysis

The autobiographies proved to be fruitful sources for discovering linguistic and communicative problems and coping and accommodation strategies. As has been presented above, there was variation between 1. authors, 2. the contexts in which the problems occurred, 3. the amounts of description devoted to particular problems and 4. the amounts of coping strategies presented in relation to the problems.

The variation between the authors shows that AS manifests itself differently in different contexts. The personality factors and the environment in which the AS person lives contribute to these differences. The differences between contexts both reinforced the finding that the linguistic and communicative problems are wide-ranging and showed that the problems do not appear in all contexts, the amount of accommodation being a crucial factor in determining their impact. The differing amounts of description devoted to particular problems showed that the authors view differently the impact of the problems – some are foregrounded whereas others receive less space. As noted, these relations do not necessarily correspond to the real amounts of problems. The differences between amounts of coping and accommodation strategies discovered show that some problems are more difficult to deal with than others. This relationship should also be approached with caution (the authors might have omitted important material) but similar tendencies between authors in terms of the presence or absence of coping/accommodation strategy in relation to a problem give evidence to the claim.

There were also many similarities between the authors that made it possible to categorize the phenomena over all four autobiographies. In general, the categories have been presented in a fashion which takes equally into account all authors, except in cases where a particular author is dominant in the discussion – these relations are intently integrated in the description of the data. Another exception are those instances where the authors offer connections between different linguistic and communicative phenomena, explanations for them or other type of tendencies – these have been discussed in more detail.

The excerpts and quotes above validate the categories presented in the analysis. The grounded theory that was formed takes into account both the individual differences and the similarities between the authors. It also includes categories that

might be regarded as sub- rather than central categories (for instance the relationship between literal-mindedness and general comprehension difficulties). However, due to the need to discover in detail the variety of the problems these have been kept separate.

Having most of the autobiographies electronically available and the computerized analysis of data proved to be effective ways of dealing with a changing set of categories. It enabled the researcher to modify the categories flexibly to meet the nature of the data. Further assistance would perhaps be received from software dedicated to the analysis of qualitative data.

Grounded theory principles were found to be an effective way of discovering the categories through openness to the content of the data. The advantages and disadvantages of the method in relation to the results it yielded are discussed in the final section.

## 5. RESULTS AND DISCUSSION

The authors whose autobiographies were examined in this study have encountered a large variety of linguistic and communicative problems in their lives and utilised a number of strategies for coping with the problematic aspects. However, they have not been able to use coping strategies or to be targets for accommodation strategies for all of the linguistic and communicative problems.

From the narratives, three groups of linguistic and communicative problems can be distinguished: rigidity of language use and communication, contextual problems and developmental problems in language use and communication. There is some overlap between developmental problems in language use and communication and all the other groups. In total, the groups included fifteen different problems:

### **Problems associated with flexibility in language use and communication**

1. conflicts/confrontations
2. non-verbal communication
3. general comprehension difficulties
4. literal-mindedness
5. spontaneous production under stress
6. obsessive-compulsive language use
7. withdrawal and unwillingness to interact with others
8. unusual connections between language and thought processes

### **Problems associated with contextual aspects of language use and communication**

1. lack of common ground in interaction
2. general troubles with the social context
3. vagueness of social situations as a source for linguistic and communicative problems
4. problems with conversation dynamics

### **Problems associated with developmental aspects of language use and communication**

1. early language impairments
2. problems in reading and writing
3. co-morbidity of communicational problems

Of the problems, four were described by all authors. They included general comprehension difficulties, literal-mindedness, spontaneous production under social stress and lack of common ground in interaction. Problems reported by three authors included conflicts and confrontations, withdrawal and unwillingness to interact with others, general troubles with the social context, vagueness of social situations, and co-morbidity of communicational problems. Non-verbal communication, obsessive-

compulsive language use, unusual connections between language and thought processes, problems with conversation dynamics and problems in reading and writing were described by two authors, while early language impairments were reported by one author only.

Problems associated with flexibility were most frequent (79 instances), followed by contextual difficulties (31) and developmental problems in language use and communication (30). Of the problem subcategories, non-verbal communication (18 excerpts), literal-mindedness (16), co-morbidity of communicational problems (13), general comprehension difficulties (11), obsessive-compulsive language use (11), general troubles with the social context (10) and lack of common ground in interaction (10) stand out as the biggest categories shared by multiple authors. Early language impairments was also a major category when measured by the excerpts (10) but it only occurred in one of the autobiographies.

Further, sixteen different coping and accommodation strategies were identified. Of these, 12 were coping strategies and four accommodation strategies.

#### **Coping strategies**

1. increasing other people's awareness
2. consulting experts
3. using writing and/or electronic facilitators
4. adopting a form of behaviour closer to social expectations
5. discussing problematic issues with others
6. reflecting on the problematic situation
7. being/becoming aware of one's AS and the problems associated with it
8. avoiding the problematic circumstances
9. challenging behaviour and violence
10. unusual communicative and other behaviour
11. shifting attention from social interaction
12. mixed use of strategies

#### **Accommodation strategies**

1. detailed instructions/explanations
2. using mediating facilitators
3. emotional support and understanding
4. forcing interaction

Of the strategies, only one – avoiding the problematic circumstances – was used by all four authors. Strategies used by three authors were: increasing other people's awareness of AS, consulting experts, detailed instructions and explanations,

conscious learning to deal with problems, reflecting on the problematic situation and becoming aware of one's AS and the problems associated with it. Strategies used by two authors included writing and electronic facilitators, adopting a form of behaviour closer to social expectations, challenging behaviour and violence, unusual communicative and other behaviour, emotional support and understanding, discussing problematic issues with others and forcing interaction. A mixed use of strategies, using mediating facilitators and shifting attention from social interaction appeared in only one autobiography.

There was much variation between the authors in both the linguistic and communicative problems and the coping/accommodation strategies. The variation showed in the structure of the categories – not all authors contributed to all categories, the calculated median being 2 authors for problematic aspects and 3 for the coping/accommodation strategies. The data also reflect both situational specificity and dispositional nature of coping.

The varying success of the coping and accommodation strategies reflected a need for taking the situational context into account when assessing them: for instance, avoidance was a successful strategy in many instances for the authors but it also posed many problems through limiting the person's possibilities to interact with the environment.

It should be noted that consulting experts was been a successful strategy for only one of those who have used the strategy. Another author stated that consulting experts was a source for many harmful experiences – in her case, no consultations were helpful. There have thus been differences in the experts' ability to help AS persons with limited or no knowledge on the condition.

The authors are all adults who have not received an AS diagnosis during their childhood. This has made the attributions of their early behaviour varied in nature. All of the authors have perceived themselves as notably different from others, but they have not been able to pinpoint the reason or denominator for the differences.

The diagnosis was found to be an effective means of enhancing the authors' coping. The diagnosis enabled the authors to both name and pinpoint their difficulties in social interaction and through increased awareness develop measures for dealing with them. What is more, the authors speculate on the positive effect the diagnosis would have had on their childhood, youth and early adulthood coping.

In the light of the results, grounded theory as a method proved to be a viable means of studying autobiographies. It revealed both consistencies between the authors and individual differences. The discovery of individual differences and individually significant phenomena (such as Shore's early language impairments) was possible, since the initial categories were formed by paying attention to the excerpts per se, rather than artificially trying to force several authors under same category. The subsequent categorizing took into account the many similarities that were found in the data.

The use of quantitative measures in tables 1-4 to back up the qualitative data by showing the numeric differences between the authors is justified in that they show both similarities and discrepancies between the authors. The measures have been used primarily for illustrations, not for statistical calculations (except for the medians calculated for the average sharing of strategies and coping and accommodation strategies and the percentages showing the proportions between the strategies). The numeric data should be treated with caution, as they do not reveal the underlying qualitative difference and do not inform of their accurate proportions in real life – these can be discovered only through in-depth interviews and cognitive testing of AS persons.

Not treating the authors as whole persons but rather as sources of data for categories shared by authors could be argued to be one significant weakness of the grounded theory method in this study, although the individual differences were described as well. Another alternative to approaching the AS persons' linguistic and communicative problems would have been to describe the autobiographies as cases, representing different ways of being and experiencing the world, including coping behaviour. However, this would in part have hindered the researcher from seeing similarities and finding consistencies between the authors. The combination of the two approaches through acquiring data of a case by different instruments while retaining the categorization between the cases is also possible, depending on the number of cases. Using a combination could account for both the differences between the authors and the real individuality and personality of the persons with AS.

Many of the emerged categories describing AS persons' linguistic and communicative problems, such as non-verbal communication and obsessive-compulsive language use, are included in the diagnostic criteria of Asperger's syndrome. The data therefore support many aspects of the current diagnostic criteria. However, the existence of early language impairments in the case of one author (Shore) contradicts the notions of "no clinically significant general delay in language" in DSM-IV and "no general delay or retardation in language" in ICD-10. Therefore, this study has relevance in questioning these diagnostic criteria.

The diagnostic criteria for Asperger's syndrome are a factor that can influence the narratives. The impact of the label of Asperger's syndrome has been significant for the authors, which might result in them being much less critical in characterizing and evaluating the reasons for their linguistic and communicative behaviour, especially that after the diagnosis. That is, factors such as personality and individual differences are much less frequently acknowledged as a source for linguistic and communicative problems.

The label of Asperger's syndrome functions as a convenient denominator, which is sometimes welcomed with perhaps too little criticism. Asperger's syndrome is often regarded as the sole reason for the special or deviant features of the authors' behaviour. Even though AS has many effects, some of the deviance in the authors' lives could perhaps be accounted for by the fact that the authors are different from others, rather than overemphasizing the effect of the diagnosis. In fact, uniqueness and deviance is celebrated by the authors with the exception of Fleisher. The label of Asperger's syndrome and the special features related to it are a significant part of the authors' recognizing themselves as different.

The results indicate that a diagnosis made as early as possible is vital in enabling the person with AS and the surrounding people to develop coping strategies from early on. They also give evidence to the assumption that Asperger's syndrome cannot be treated as a homogeneous phenomenon within strict diagnostic boundaries. The developmental paths vary as regards language acquisition and use, as do the abilities of AS persons to cope with problems they encounter in their everyday interaction. As Birch (2003:204) puts it: "persons with Asperger's syndrome are still individuals as well, not all peas in the same pod." Another important point is the very notion that many AS individuals find suitable ways of dealing with the problems. This, together

with the strengths AS persons have – that is, the positive factors in AS, have been largely neglected when considering the diagnostic criteria.

In this study, the problematic linguistic and communicative aspects and the coping/accommodation strategies were retained as the primary phenomenon to explore. However, the data related to the problematic linguistic and communicative features of AS as well as the autobiographies in general also provided a possibility of looking at how the AS persons construct themselves in the narratives. Identity is therefore also a valid point for further research on accounts written by AS persons (some of the groundwork on the field of identity in Asperger's syndrome has been done by Molloy & Vasil (2004)). For instance, the distinction between personal/autobiographical discourse and expert discourse would be of interest to the researcher discovering the differential being in both Asperger's syndrome compared to non-AS population and within the AS population. Further research projects might focus on these or other autobiographies from these viewpoints, as they are also a valid point of departure for looking at the phenomenon of AS.

Evidently, given the amount of data and the wide variety in the outcome of AS in different individuals, the results cannot be generalized to the overall AS population. A further reason for caution in dealing with the results is the fact that the opinions of experts have had an effect on the authors' conceptions considering language-related events. In addition, the nature of a published autobiography enables the omission of some material as well as the highlighting of other parts - the editorial and authorial have an influence on the picture given by the autobiographies on the linguistic and communicative problems and the strategies used for coping with them in their lives. The linguistic and communicative problems, along with other features of AS, can thus be overemphasized and over-interpreted in the accounts of people writing about their life with the syndrome functioning as a frame of reference.

The influence of experts or editorial and authorial choices cannot, however, explain away those descriptions of linguistic and communicative phenomena that appear frequently in the narratives. The number of different contexts involved demonstrates that there are somewhat general key problems in the authors' communication and language use. What is more, the autobiographies serve as valuable representations of how persons with AS see their condition. This information adds to the overall picture of Asperger's syndrome, combining the voice



of those with AS with that of the widening number of experts such as researchers, clinicians and educators in the area.

The results on the significance of individual differences urge one to ask with more force the question: is the treating Asperger's syndrome as a condition requiring medication enough for description and accurate intervention? The neural and genetic factors are undeniable in the etiology of AS, but its differential outcome in individuals is underrated. Therapy, counselling and tuition of those with AS should take into account this difference in order to develop methods that are flexible enough and suitable for them. The diagnostic criteria are needed in professional contexts, where the discovery of Asperger's syndrome can be decisive in many aspects, such as the assignment of social support. In spite of this need for diagnostic classification, autism and Asperger's syndrome are, in essence, differences that are not "curable" in the medical sense. The social intercourse with AS people should take this into account, treating AS people as human individuals, not merely by grouping them according to the label or different models of AS.

The study at hand includes a major lack in that it is based solely on published autobiographies. The editorial choices and omissions and additions by the authors may have limited the scope in which coping can be studied and also somewhat distorted the data available to the researcher. Therefore, future qualitative research on coping in Asperger's syndrome will need interviews that enable the researcher to get into dialogue with the persons with Asperger's syndrome, in order to acquire more contextual information and personal views on the effectiveness of the strategies used. This was not possible in the framework of this project

Although this study examines the strengths and weaknesses in the authors' coping with problems, another significant lack in it is the absence of the linguistic and communicative strengths of the authors. The authors have reported on them (such as not being nervous when speaking in public, the ability to play with words), but they have been left outside the analysis because coping and accommodation strategies do not come up with the successes, although the success might indeed influence the person's use of coping strategies. Finding connections between the linguistic advantages and disadvantages might thus prove fruitful in further studies on the subject.

The diagnostic criteria can also be criticized for the lack of strengths – they by and large only describe the weaknesses and impairments of the AS person's, painting a picture that is mostly negative. As the influence of diagnosis is significant to the AS person, updating the diagnostic criteria with strengths would prove to be a viable method for both having a positive influence on the way the person sees her/his AS and on the effectiveness of rehabilitation, relying largely on the initial strengths of the person.

In sum, the implications of this study are threefold: the relevance of Asperger's syndrome diagnosis was revealed but also a need for updating the diagnostic criteria through the discovery of coping involved in AS, as well as acknowledging the variation and individuality within AS. These somewhat conflicting implications are related to the fundamental question of the role of disability in society. Disability is often treated as inconvenient deviation from the norm. In many cases those that are disabled are treated primarily as disabled and not as human beings with their personal qualities, strengths and weaknesses. The society has opened with a continuing increase in the general knowledge considering disabilities but much remains to be done.

## REFERENCES

### Primary sources

Birch, J. 2003: *Congratulations! It's Asperger's syndrome*. London: Jessica Kingsley Publishers.

Fleisher, Marc 2003. *Making Sense of the Unfeasible: My Life Journey with Asperger's syndrome*. Jessica Kingsley Publishers [online]. (31 Jan 2006)

<http://site.ebrary.com/lib/jyvaskyla/>

Shore, S. 2001. *Beyond the Wall: Personal Experiences with Autism and Asperger's syndrome*. Kansas: Autism Asperger Publishing Co.

Willy, L.H. 2003. *Pretending to Be Normal Living with Asperger's syndrome*. London: Jessica Kingsley Publishers.

### Secondary sources

American Psychiatric Association 1994. *Diagnostic and statistical manual of mental disorders, fourth edition*. American Psychiatric Association.

Asperger, H. 1995. 'Autistic psychopathy' in childhood. In U. Frith (ed.), *Autism and Asperger syndrome*. Cambridge: Cambridge University Press, 37-92.

Attwood, T. 2001. *Asperger's syndrome A Guide for Parents and Professionals*. London: Jessica Kingsley Publishers.

Baron-Cohen, S. 1988. Social and Pragmatic Deficits in Autism: Cognitive or Affective? *Journal of Autism and Developmental Disorders* 18, 379-402.

Baron-Cohen S. and R. Staunton 1994. Do children with autism acquire the phonology of their peers? An examination of group identification through the window of bilingualism. *First Language* 14, 241-248.

Bemporad, J.R. 1979. Adult recollections of a formerly autistic child. *Journal of Autism and Developmental Disorders* 9, 179-197.

Beversdorf, D.Q, J.M. Anderson, S.E. Manning, S.L. Anderson, R.E. Nordgren, G.J. Felopulos, and M.L. Bauman 2001. Brief Report: Macrographia in High-Functioning Adults with Autism Spectrum Disorder. *Journal of Autism and Developmental Disorders* 31, 97-101.

- Bishop, D.V.M. 1989. Autism, Asperger's syndrome and semantic-pragmatic disorder: Where are the boundaries? *British Journal of Disorders of Communication* 24, 107-121.
- Bowler, D.M. 1992. Theory of Mind in Asperger's Syndrome. *Journal of Child Psychology and Psychiatry* 33, 877-893.
- Brook, S.L. and D.M. Bowler 1992. Autism by another name? Semantic and Pragmatic Impairments in Children. *Journal of Autism and Developmental Disorders* 22, 61-81.
- Busch, H. 2005. Appraisal and coping processes among chronic low back pain patients. *Scandinavian Journal of Caring Sciences* 19, 396-402.
- Carrington, S., E. Templeton, and T. Papinczak 2003. Adolescents with Asperger Syndrome and Perceptions of Friendship. *Focus on Autism and Other Developmental Disabilities* 18, 211-218.
- Cesaroni, L. and M. Garber 1991. Exploring the Experience of Autism Through First Hand Accounts. *Journal of Autism and Developmental Disorders* 24, 303-313.
- Cohen, F. 1987. Measurement of Coping. In S.V. Kasl and C.L. Cooper, *Stress and health: Issues in Research Methodology*. New York: John Wiley & Sons, 283-305.
- Compas, B.E., P.G. Orosan, and K.E. Grant 1993. Adolescent stress and coping: implications for psychopathology during adolescence. *Journal of Adolescence* 16, 331-349.
- Cox, D.J. and L.A. Gonder-Frederick 1991. The Role of Stress in Diabetes Mellitus. In P.M. McCabe, N. Schneiderman, T.M. Field and J.S. Skyler (eds.), *Stress, Coping and Disease*. Hillsdale: Lawrence Erlbaum Associates, 119-134.
- Dellve, L., Cernerud, L., and L. R.-M. Hallberg 2000. Harmonizing dilemmas - Siblings of children with DAMP and Asperger syndrome's experiences of coping with their life situations. *Scandinavian Journal of Caring Sciences* 14, 172-178.
- DeLongis, A., M. Capreol, S. Holtzman, T. O'Brien, and J. Campbell 2004. Social Support and Social Strain Among Husbands and Wives. *Journal of Family Psychology* 18, 470-479.
- Dickerson Mayes, S., S.L. Calhoun, and D.L. Crites 2001. Does DSM-IV Asperger's Disorder Exist? *Journal of Abnormal Child Psychology* 29, 263-271.
- Ehlers, S. and C. Gillberg 1993. The epidemiology of Asperger's Syndrome – A total population study. *Journal of Child Psychology and Psychiatry* 32, 1327-1350.

- Fairclough, N. 1995. *Critical Discourse Analysis: the Critical Study of Language*. London: Longman.
- Fleischmann, A. 2005. The hero's story and autism: Grounded theory study of websites for parents of children with autism. *Autism* 9, 299-316.
- Frith, U. and F. Happé 1994. Autism: Beyond Theory of Mind. *Cognition* 50, 115-132.
- Frith, U. 1995. Asperger and his syndrome. In U. Frith (ed.): *Autism and Asperger syndrome*. Cambridge: Cambridge University Press, 1-36.
- Galinowski, A. and H L o 2003. Biologie du stress, Biology of stress. *Annales M dico-psychologiques, revue psychiatrique* 161, 797-803.
- Ghaziuddin, M., E. Butler, L. Tsai, and N. Ghaziuddin 1994. Is clumsiness a marker for Asperger syndrome? *Journal of Intellectual Disability Research* 38, 519-527.
- Ghaziuddin, M. and L. Gerstein 1996. Pedantic Speaking Style Differentiates Asperger Syndrome from High Functioning Autism. *Journal of Autism and Developmental Disorders* 26, 585-595.
- Gillberg, C. 1999. *A guide to Asperger Syndrome*. Cambridge: Cambridge University Press.
- Gillberg, C. and M. Cederlund 2005. Asperger Syndrome: Familial and Pre- and Perinatal Factors. *Journal of Autism and Developmental Disorders* 35, 159-166.
- Giunta, C.T. and B.E. Compas 1993. Coping in Marital Dyads: Patterns and Associations with Psychological Symptoms. *Journal of Marriage and the Family* 55, 1011-1017.
- Glaser, B. and A. Strauss 1967. *The Discovery of Grounded Theory Strategies for Qualitative Research*. London: Weidenfeld and Nicolson.
- Goldstein, G., N.J. Minshew, D.N. Allen, and B.E. Seaton 2002. High-functioning autism and schizophrenia. A comparison of an early and late onset neurodevelopmental disorder. *Archives of Clinical Neuropsychology* 17, 461-475.
- Grandin, T. 1984. My experiences as an autistic child and review of selected literature. *Journal of Orthomolecular Psychiatry* 13, 144-175.
- Gray, D.E. 2003. Gender and coping: the parents of children with high functioning autism. *Social Science & Medicine* 56, 631-642.

- Greckhamer, D. and M. Koro-Ljungberg 2005. The erosion of a method: examples from grounded theory. *International Journal of Qualitative Studies in Education* 18, 729-750.
- Happé, F. 1994. *Autism an introduction to psychological theory*. London: UCL Press.
- Happé, F. 1995. The autobiographical writings of three Asperger syndrome adults: problems of interpretation and implications for theory. In U. Frith (ed.): *Autism and Asperger syndrome*. Cambridge: Cambridge University Press. 207-242.
- Higgins, D.J., S.R. Bailey, and J.C. Pearce 2005. Factors associated with functioning style and coping strategies of families with a child with an autism spectrum disorder. *Autism* 9, 125-137.
- Hobson, R.P. 1995. *Autism and the development of mind*. Hove: Lawrence Erlbaum Associates.
- Hurlburt, R.T., F. Happé, and U. Frith 1994. Sampling the form of inner experience in three adults with Asperger Syndrome. *Psychological Medicine* 24, 385-395.
- Hurlbutt, K. and L. Chalmers 2004. Employment and Adults with Asperger Syndrome. *Focus on Autism and Other Developmental Disabilities* 19, 215-222.
- Janis, I.L. 1993. Decisionmaking under Stress. In L. Goldberger and S. Breznitz: *Handbook of stress*. New York: The Free Press, 56-74.
- Jansson-Verkasalo, E., R. Ceponiene, M. Kielinen, K. Suominen, V. Jääntti, S-L Linna, I. Moilanen, and R. Näätänen 2003. Deficient auditory processing in children with Asperger Syndrome, as indexed by event-related potentials. *Neuroscience Letters* 338, 197-200.
- Kremer-Sadlik, T. 2004. How Children with Autism and Asperger's syndrome Respond to Questions: a 'Naturalistic' Theory of Mind Task. *Discourse Studies* 6, 185-206.
- Kujala, T., T. Lepistö, T. Nieminen-von Wendt, P. Näätänen, and R. Näätänen 2005. Neurophysiological evidence for cortical discrimination impairment of prosody in Asperger syndrome. *Neuroscience Letters* 383, 260-265.
- Lauritsen, M.B., C.B. Pedersen, and P.B. Mortensen 2005. Effects of familial risk factors and place of birth on the risk of autism: a nationwide register-based study. *Journal of Child Psychology and Psychiatry* 46, 963-971.

- Lazarus, R.S. and S. Folkman 1984. *Stress, appraisal and coping*. New York: Springer.
- Lazarus, R.S. 1993. Why We Should Think of Stress as a Subset of Emotion. In L. Goldberger and S. Breznitz: *Handbook of Stress*. New York: The Free Press, 21-39.
- Little, L. 2002. Differences in Stress and Coping for Mothers and Fathers of Children with Asperger's Syndrome and Nonverbal Learning Disorders. *Pediatric Nursing* 28, 565-570.
- Lomborg, K. and M. Kirkevold 2003. Truth and validity in grounded theory – a reconsidered realist interpretation of the criteria: *fit, work, relevance* and *modifiability*. *Nursing Philosophy* 4, 189-200.
- Losh, M. and L. Capps 2003. Narrative Ability in High-Functioning Children with Autism or Asperger's Syndrome. *Journal of Autism and Developmental Disorders* 33, 239-51.
- Mandler, G. 1993. Thought, Memory, and Learning: Effects of Emotional Stress, in L. Goldberger and S. Breznitz: *Handbook of Stress*. New York: The Free Press, 40-55.
- McKelvey, J.R., R. Lambert, L. Mottron, and M.I. Shevell 1995. Right-Hemisphere Dysfunction in Asperger's Syndrome. *Journal of Child Neurology* 10, 310-314.
- Miller, J.N. and S. Ozonoff 2000. The External Validity of Asperger Disorder: Lack of Evidence From the Domain of Neuropsychology. *Journal of Abnormal Psychology* 109, 227-238.
- Molloy, H. and L. Vasil 2002. The Social Construction of Asperger's syndrome: the pathologising of difference? *Disability & Society* 17, 659-669.
- Molloy, H. and L. Vasil 2004. *Asperger's syndrome, adolescence and identity: looking beyond the label*. London: Jessica Kingsley Publishers.
- Myles, B.S., Smith, T.D. Hilgenfeld, G.P. Barnhill, D.E. Griswold, T. Hagiwara, and R.L. Simpson 2002. Analysis of reading skills in individuals with Asperger Syndrome. *Focus on Autism and Other Developmental Disabilities* 17, 44-47.
- Nadler, A. 1990. Help-seeking Behavior as a Coping Resource. In M. Rosenbaum (ed.): *Learned Resourcefulness On Coping Skills, Self-Control, and Adaptive Behavior*. New York: Springer, 127-162.
- O'Leary, A. and L.S. Jemmott 2002. *Women and AIDS: Coping and Care*. Kluwer Academic Publishers [online]. (31 Jan 2006)

<http://site.ebrary.com/lib/jyvaskyla/>

Orona, C. J. 1997. Temporality and Identity Loss Due to Alzheimer's Disease. In A. Strauss and J. Corbin (eds.), *Grounded Theory in Practice*. London: Sage Publications, 171-196.

Pakenham, K.I., C. Samios, and K. Sofronoff 2005. Adjustment in mothers of children with Asperger syndrome: an application of the double ABCX model of family adjustment. *Autism* 9, 191-212.

Perlman, L. 2000. Adults with Asperger Disorder Misdiagnosed as Schizophrenics. *Professional Psychology: Research and Practice* 31, 221-225.

Ponnet, K.S., H. Roeyers, A. Buysse, A. De Clercq, and E. van der Heyden 2004. Advanced Mind-Reading in Adults with Asperger Syndrome. *Autism* 8, 249-266.

Portway, S. and B. Johnson 2003. Asperger Syndrome and the Children who 'Don't Quite Fit In'. *Early Child Development and Care* 173, 435-443.

Range, L.M. and T.A. Stringer 1996. Reasons for living and coping abilities among older adults. *The International Journal of Aging & Human Development* 43, 1-5.

Reimann, G. 1982. *On the Usability of Narratives for Discovering Biographical Structures among Psychiatric Patients*. Conference Paper.

Rice, K.G., M.A. Herman, and A.C. Petersen 1993. Coping with challenge in adolescence: a conceptual model and psycho-educational intervention. *Journal of Adolescence* 16, 235-251.

Richman, L. 1997. Peaceful coexistence Autism, Asperger's, Hyperlexia [online]. (31 Jan 2006)

[http://www.hyperlexia.org/aha\\_winter9697.html](http://www.hyperlexia.org/aha_winter9697.html)

Romanowski Bashe, P. and B. L. Kirby 2001. *The Oasis Guide to Asperger's syndrome*. New York: Crown Publishers.

Schlosser, M.B. 1985. *Stress, coping, hardiness, and health-protective behavior*. University of South Florida.

Schulman-Green, D. 2003. Coping mechanisms of physicians who routinely work with dying patients. *Omega: The Journal of Death and Dying* 47, 253-264.

Seiffge-Krenke, I. 2001. *Diabetic Adolescents and Their Families: Stress, Coping, and Adaptation*. New York: Cambridge University Press

Selye, H. 1993. History of the Stress Concept. In L. Goldberger and S. Breznitz (eds.): *Handbook of Stress*. New York: The Free Press, 7-17.



- Sirota, K.G. 2004. Positive politeness as discourse process: politeness practices of high-functioning children with autism and Asperger's syndrome. *Discourse Studies* 6, 229-251.
- Strauss, A. and J. Corbin 1990. *Basics of qualitative research. Grounded Theory Procedures and Techniques*. Newbury Park: Sage.
- Suutama, T. 1995. *Coping with life events in old age*. Jyväskylä: Jyväskylä Studies in Education, Psychology and Social Research.
- Tantam, D., Holmes, D. and C. Cordess 1993. Nonverbal expression in autism of Asperger type. *Journal of Autism and Developmental Disorders* 23, 111-133.
- Taylor, S.E. and L.G. Aspinwall 1993. Coping with Chronic Illness. In L. Goldberger, L. and S. Breznitz, *Handbook of Stress*. New York: The Free Press.
- Temoshok, L. and J.M. Moulton 1991. Dimensions of Biopsychosocial Research on HIV Disease: Perspectives from the UCSF Biopsychosocial AIDS Project. In P.M. McCabe, N. Schneiderman, T.M. Field and J.S. Skyler (eds.), *Stress, Coping and Disease*. Hillsdale: Lawrence Erlbaum Associates, 211-236.
- Watson, D. and P.C. Kendall 1983. Methodological Issues in Research on Coping with Chronic Disease. In T.G. Burish and L.A. Bradley, *Coping with Chronic Disease Research and Applications*. New York: Academic Press.
- Welchew, D.E., C. Ashwin, K. Berkouk, R. Salvador, J. Suckling, S. Baron-Cohen, and E. Bullmore 2005. Functional disconnectivity of the medial temporal lobe in Asperger's syndrome. *Biological Psychiatry* 57, 991-998.
- Wing, L. 2000. Past and Present of Research on Asperger Syndrome. In A. Klin, F. Volkmar and S.S. Sparrow, *Asperger syndrome*. New York: Guilford Press, 418-432.
- Volden, L. and C. Lord 1991. Neologisms and idiosyncratic language in autistic speakers. *Journal of Autism and Developmental Disorders* 21, 109-130.
- Volkmar, F.R. and D.J. Cohen 1985. The experience of infantile autism: a first-person account by Tony W. *Journal of Autism and Developmental Disorders* 15, 47-54.
- Volkmar, F.R., A. Klin, and D. Pauls 1998. Nosological and Genetic Aspects of Asperger Syndrome. *Journal of Autism and Developmental Disorders* 28, 457-463.
- World Health Organization 1993. *International Classification of Diseases, 10<sup>th</sup> revision*. World Health Organization.