

*They say I am rational
That I should express my emotions
But they want me
To look there where I am blind*

Martin

*I am made of so much glass
That each harsh voice
Is a stone and a crack*

Gerrit Achterberg

Dedicated to all those people who showed me the strange special world of autism, especially J.B, S.D., J.v.E, F.H, J.K, P.M, L.S, P.v.O and B.S

Short list of contents

FOREWORD 15

PART I WHAT IS IT? 17

- 1 Introduction 19
- 2 Predisposition or environment 33
- 3 Differences between men and women 53
- 4 Autistic development 81
- 5 The diversity of autistic behaviour model 101
- 6 The Socioscheme and the MAS1P 109

PART II WHAT CAN YOU DO ABOUT IT? 169

- 7 Before and after diagnosis 171
- 8 The base of education and help, joining the MAS1P 181
- 9 Stimulating the me-otherdifferentiation and empathy 193
- 10 Social skills 219
- 11 Forming friendships and relationships 255
- 12 Resistance to change 279
- 13 Coping with anxiety and obsessions 307
- 14 Coping with aggression 341
- 15 Acquired social anxiety 357
- 16 Epilogue 369

REFERENCES 371

LIST OF OUTLINES 401

LIST OF FIGURES 403

LIST OF EXAMPLE NAMES 405

NAME INDEX 407

SUBJECT INDEX 413

ABOUT THE AUTHOR 419

THE PICOWO SERIES 422

Extensive list of contents

FOREWORD 15

PART I WHAT IS IT? 17

1 INTRODUCTION 19

- The first researchers 19
- Autism or Autism Spectrum Disorders 21
- The structure of the book 22
- Predisposition or upbringing 24
- Diagnosis or label 27
- The strengths and the weaknesses 29
- The purpose of the book 30
- Focal points 31
- Focal points regarding attitude 31

2 PREDISPOSITION OR ENVIRONMENT 33

- Development from predisposition and environment 33
- Visible versus non-visible 38
- Maturation 40
- Common threads: basic signs of disorders and atypical development 46
- Focal points 49
- Focal points regarding attitude 50
- Summary 50

3 DIFFERENCES BETWEEN MEN AND WOMEN 53

- Man or woman, xy or xx 53
- The self 56
- Imagining what goes on in another person's mind 64
- Moral development 71
- Resistance to change 72
- Self-reflection 73
- Capacity for action and its relation to anxiety and aggression 75
- Gender differences and upbringing 77
- Schematic presentation 78
- Consequences for autism 78
- Focal points 79
- Focal points regarding attitude 80
- Summary 80

4	AUTISTIC DEVELOPMENT	81
	The transition from DSM-IV to DSM-5	82
	The different forms according to the DSM-IV	82
	Typification of children with autism	89
	Prevalence of autistic developments	90
	(Early) detection of Autism Spectrum Conditions	94
	Focal points	99
	Focal points regarding attitude	100
	Summary	100
5	THE DIVERSITY OF AUTISTIC BEHAVIOUR MODEL	101
	The autistic diversity model	101
	Relation between source and behaviour	103
	'Pure' autism versus autistic behaviour	104
	Focal points	107
	Focal points regarding attitude	107
	Summary	107
6	THE SOCIOSHEME AND THE MASIP	109
	Social interaction	109
	Unfeeling or being "stuck"	111
	Theories regarding autism	112
	The theory-of-mind (ToM)	113
	Central Coherence (CC)	116
	Planning and Executive function (EF)	117
	The Empathic Systemizing, balanced brain (ESB)	119
	The socioscheme in relation to other theories	120
	The Socioscheme	126
	The MASIP, a broad age spectrum	129
	The socioscheme and the me-otherdifferentiation	130
	The socioscheme and time and space	133
	Memory	136
	The socioscheme and identity	138
	The socioscheme and the theory-of-mind	140
	Eye for detail	143
	Sensory experiences	151
	Use of language and underdeveloped language	153
	Striking interests	159
	Obsessive behaviour and rituals	161
	Learning disorders and going to school	163
	Schematic representation	165
	Focal points	167
	Focal points regarding attitude	168
	Summary	168

PART II WHAT CAN YOU DO ABOUT IT? 169

- 7 BEFORE AND AFTER DIAGNOSIS 171**
The condition, but not the diagnosis 171
The diagnosis, but not the condition 175
Focal points 178
Focal points regarding attitude 179
Summary 179
- 8 THE BASE OF EDUCATION AND HELP, JOINING THE MAS1P 181**
The QAP 181
Internal statistics 182
The MAS1P 183
A structural social training 187
A 'disorderly' development 189
The difference between mental age and chronological age 189
Problems recognising a developmental phase because of the chronological age. 189
Trouble recognising behaviour because of the combination with being physically older often changes the appearance of the behaviour. 190
Trouble recognising the developmental phase because of prejudices 190
Trouble recognising because of one's own uncertainty 190
Trouble recognising behaviour by taking it literally 190
Difficulty identifying a delayed development 190
A key sentence 190
Focal points 191
Focus points on attitude 192
Summary 192
- 9 STIMULATING THE ME-OTHERDIFFERENTIATION AND EMPATHY 193**
Inadequate me-otherdifferentiation or symbiosis 194
Delayed development 196
A strange world 200
Sensing or learning the rules 202
Developmental tasks 204
A pre-schooler with the developmental task of a baby 205
Attachment 208
Strange and familiar 212
Strangers: good and bad 215
Social intercourse 216
Focal points 217
Focal points regarding attitude 218
Summary 218

- 10 SOCIAL SKILLS 219**
- Social skills or “tricks” 219
 - Eye contact 223
 - Lack of contact orientation 228
 - Communication 233
 - The meaning of language 240
 - The meaning of jokes 244
 - Other people’s limits 247
 - The firm foothold of proper manners 248
 - Training programmes for social skills 250
 - Social knowledge > social insight > social skills 251
 - Focal points 252
 - Focal points regarding attitude 252
 - Summary 253
- 11 FORMING FRIENDSHIPS AND RELATIONSHIPS 255**
- From egocentric behaviour to partnership behaviour 256
 - Primary school 257
 - Bullying 261
 - Self-image 264
 - Developing friendships 265
 - Deepening friendships into relationships 270
 - On the threshold of sexuality 272
 - Isolation and depression 272
 - The combination: empathic with autistic 273
 - A relationship: learning from life itself 274
 - Focal points 277
 - Focal points regarding attitude 278
 - Summary 278
- 12 RESISTANCE TO CHANGE 279**
- Change and unpredictability 279
 - Force of habit 282
 - Resistance to different food 284
 - Resistance resulting from hypersensitivity 285
 - Terrorising or panicking 287
 - Ritualised programmes 288
 - Associative and magical thinking 290
 - Allergic to ‘must’ 291
 - Planning activities and keeping appointments 295
 - Punishment and reward 297
 - The burntout family 301
 - Dealing with resistance to change 303
 - Focal points 303
 - Focal points regarding attitude 305
 - Summary 305

13	COPING WITH ANXIETY AND OBSESSIONS	307
	Anxiety as a basic motive	307
	The detection of danger	308
	Reaction to danger	309
	The decisiveness of testosterone	312
	A bad balance	314
	Testosterone and aggression	315
	The 'missing link'	316
	The relation between a lack of testosterone and depression	317
	Female aggression	318
	Aggression versus depression	319
	Hyperactivity as a healthy outlet	320
	Differences between boys and girls	321
	Fight-or-flight versus nice-or-victim	322
	Signs of anxiety	323
	Preventing anxiety	324
	<i>Resistance to change</i>	324
	<i>Extreme attachment to the mother</i>	325
	<i>Resistance to strangers</i>	325
	<i>Avoiding social situations</i>	328
	<i>Self-hypnotic behaviour</i>	329
	<i>Adaptation</i>	330
	Forms of behaviour to reduce anxiety	331
	<i>Hyperactivity</i>	331
	<i>Obsession and compulsion</i>	332
	<i>Rituals</i>	334
	<i>Rational response, intellectual comprehension and argumentation</i>	336
	Feelings of inferiority, jealousy and depression	337
	Focal points	338
	Focal points regarding attitude	340
	Summary	340
14	COPING WITH AGGRESSION	341
	Aggression and sexuality	342
	Autistic sources of aggression	343
	Resistance to change	344
	Misunderstanding social interaction	348
	Normal aggression	350
	All alone in the world	351
	Asking for help	352
	Combination of autism and ADHD	353
	Focal points	354
	Focal points regarding attitude	355
	Summary	355

15 ACQUIRED SOCIAL ANXIETY	357
Labelling anxiety through cognitions	357
Medication or therapy	361
Behaviour therapy	362
Depression	365
The strength of the parent	366
Focal points	366
Focal points regarding attitude	367
Summary	367

16 EPILOGUE	369
--------------------	------------

REFERENCES	371
LIST OF OUTLINES	401
LIST OF FIGURES	403
LIST OF EXAMPLE NAMES	405
NAME INDEX	407
SUBJECT INDEX	413
ABOUT THE AUTHOR	419
THE PICOWO SERIES	422

Foreword

Foreword of Tony Attwood in the first English edition of *A Strange World*.

Martine Delfos has written a book for the intelligent reader, explaining the strange world of autism. She reviews each of the theoretical fields of study and then describes our current landscape of knowledge as though from an observation balloon to provide a single explanatory model for autism. The project has been remarkably ambitious but the author has an encyclopaedic knowledge of the academic literature and the various theoretical models, and extensive personal experience as a clinician. The author also has notable respect for those who have autism and Asperger's Syndrome and she is able to challenge and change attitudes as well as increase understanding.

The first part of the book explains the nature of autism from a theoretical perspective while the second part provides a framework for the practical application of our research knowledge. The author also includes quotations and descriptions of individuals with autism that bring life and reality to the text. The summaries at the end of each chapter ensure the reader can quickly access the key points, which will be of considerable value to students studying autism. I suspect that academics will now discuss and test the theoretical model proposed by Martine Delfos, and clinicians will use Part 2 for guidance in the design of remedial programs. Parents and teachers who want to explore the strange world of autism at a more intellectual level will appreciate the new perspective.

Tony Attwood in 2005

Author of *Asperger's Syndrome: A Guide for Parents and Professionals*

PART I

WHAT IS IT?



1 Introduction

Does my child have autism or is my child mainly struggling with a lack of social skills? Is the child egoistic, does he or she show signs of a neglected upbringing, or does it have autistic characteristics? There are many labels for the various diagnoses surrounding autism, from autism in a 'pure form', up to and including related conditions such as PDD-NOS (Pervasive Developmental Disorder – Not Otherwise Specified) used in the DSM-IV (Diagnostic Statistical Manual of Mental Disorders, version IV, American Psychiatric Association, APA, 1994). But what is autism and how can one help the child, adolescent or adult? These are the questions that form the guidelines for this book. In this book we will talk about the *autistic spectrum*, the group of conditions where the core problem consists of having difficulty with (interpreting) social interaction, and the core talent is the cognitive capacity driven by the urge to want to understand.

Apart from interpreting social interaction there is much behaviour which can play a part with autistic developments and none of the theories have, up to now, been able to place all the aspects in one overall explanatory model. This book aims at doing just that, so that both behaviour like 'not understanding jokes' will become clear as well as the 'need to keep everything as it was and resistance to change', and the broad age spectrum within one person, the MAS1P (Mental Age Spectrum within 1 Person). The core concept of the model presented in this book is the *Socioscheme*. The theory / model is based on differences and similarities between men and women in the organisation of the brain and on a biological level deal with the influence of testosterone on the development of the foetus in the womb. For autism spectrum conditions the way the socioscheme works means the formation of a MAS1P; the broad age spectrum within one person.

The first researchers

The term 'autism' emerged for first time, independently from each other, at four different places in the world: Firstly in an article by Hans Asperger in 1938, and secondly by Chorus (Frye, 1968) in the annual reports (1937-1938; 1939-1940) of the Pedagogical Institute of Nijmegen, The Netherlands. Chorus used the term for children who were excessively withdrawn into themselves.

Two pioneers in the field of autism, the Austrians Leo Kanner (1894-1981) (Figure 1) and Hans Asperger (1906-1980) (Figure 2) used the term autism in order to describe children and adults who showed a specific pattern of behaviours. Bleuler (1908/1987; 1916/1979) used the Greek word 'autos' (self) and moulded it into 'autism', which means 'withdrawn into oneself', in order to describe people with schizophrenia being withdrawn into themselves, which is, however, a completely different problem. Kanner and Asperger

used this term for a problem that always existed but was never given a name. Autism can be recognised by a fixed pattern of behaviours throughout various countries and various cultures (Frith, 1989/2003).

It is amazing that both Kanner and Asperger used this term, working in different parts of the world (Leo Kanner emigrated to America at the age of 28) without knowing it from each other. They used the term to describe a specific pattern of behaviours that since that time has been given the name *autism*. The fact that they both used this term, is probably due to the fact that Asperger and Kanner both were originally German speaking and that they had their education in the same time period, where the work of Bleuler was prominent.



Figure 1: Hans Asperger (Frith, 1997)

Reproduced with permission from
Cambridge University Press.



Figure 2: Leo Kanner (Mottar, 1954)

Reproduced with permission from
John Hopkins Medical Institutions.

The very first article about the description of autism was written in 1938 by Hans Asperger. This makes him the true pioneer, and he describes it again in 1944. The very first time the term was used was by Hans Asperger was in 1934 in letters to his colleagues according to his daughter the psychiatrist Maria Asperger Felder (Asperger Felder, 2009). Kanner, however, wrote in English in 1943 causing his work to be spread internationally much faster. Asperger's 1944 article only became known about thirty years later thanks to Uta Frith's translation. The similarities between the two articles are striking but also the differences. The tone, however, is different. Asperger writes in warm and respectful terms about the people with an autistic development, emphasising the special aspects more than the deviating ones. This balanced and respectful way of looking at people with an autistic development matches very well with the fundamentally humanist scholar that Asperger was. He writes in more general terms than Kanner and his experience is principally based on youngsters (more than 200). Kanner describes in his first article eleven young children (eight boys and three girls) and pays a lot of attention to the description of the parents, of whom he states that the majority come across as 'cold'. It is probably because Kanner dealt a lot with very young children, two and three year old, that he speaks relatively often about feeding problems. In his article, Asperger is more oriented towards understanding what goes on in the children's minds; Kanner on the other hand is more oriented towards describing the children's behaviour. Asperger said about Kanner's ideas that they show some similarities with his ideas, but that what he (Asperger) was dealing with was totally different.

It struck Kanner and Asperger that the children and adults they described were extremely withdrawn into themselves and seemed to live in a different world. They displayed an amazing naïveté and a fundamental lack of knowledge about social interaction and insight into social behaviour. Kanner (1943) and Asperger (1944) show some similarities in their descriptions, but also many differences. The basis is, however, the same: a lack of social intercourse, a lack of social insight and social skills. Asperger however was clear about the two sides of their development. He spoke about their weaknesses and their strengths and said: 'It is two sides of the coin, one cannot exist without the other'. Asperger's view on the idea of autism was clearly broader than Kanner's.

In the course of time it has been discovered that although some characteristics are essential for autism, others occur with the one but not with the other. In order to do justice to the different forms of autistic behaviour, Lorna Wing (1988) speaks of the *autistic spectrum*, also called the *a-spectrum*, within which there are various *autism spectrum conditions* (ASC). In this spectrum the behaviours vary from strong to weak in the fields of: social interaction; social communication in verbal and non-verbal behaviour; imaginary ability; repetitive characteristic of activities; language; response to sensory stimuli and specific skills (Wing, 2001). Wing, and the researchers around her, found three areas that are characteristic for autism, called the *triad*. Those are: problems in the field of *social contact, communication and imagination*.

In the course of the book we will describe the various forms and characteristics of autistic developments. We will show that the perspective of most researchers is Kanner-based and as such too narrow, neglecting one side of the coin. To that end we present a new, overall theoretical framework, in which the common theories have been jointly included and where all the various behaviours of people with autism prove to be pieces of a large puzzle. The core concept is, as we announced, the *socioscheme* with the concept of the *MASIP*. Without having to oppose common theories we discovered that it was possible to place these theories and the research in our *metatheory* in order to present an insightful image of autism. With this we hope to show what, for example, a lack of understanding of the concept of time has to do with badly interpreting social interaction; how anxiety, aggression and depression play a part; how obsessions function, what the role of the eye for detail is and how high intelligence can develop in the *plasticity* of the baby brain.

Autism or Autism Spectrum Disorders

In this book the diversity of Autism/ Autism Spectrum Disorders/ASD is discussed. When we speak of Autism Spectrum *Disorders* we refer to the terminology used in the handbooks on psychiatric problems (DSM and ICD-International Classifications of Diseases). Otherwise we will use the term Autism Spectrum *Conditions* to refer to a broader development than only a disorder. When we speak about autism we mean the genetic pattern underlying an *atypical development* instead of a disorder as we will see. We will explain that ASD is a container term and embraces many conditions that should not be qualified as autism.

The structure of the book

The book consists of two parts. In the first part, *What is it?*, we will describe the various autistic developments, sometimes called *contact disorders*. The explicit and extensive classification of autistic conditions was described in the DSM-IV, the diagnostic manual of mental disorders from 1994 (APA, 1994). This has been followed by the DSM-5 in 2013 (APA, 2013). In the DSM-IV subcategories are described like *Asperger's syndrome* and *PDD-NOS (Pervasive Developmental Disorder Not Otherwise Specified)*. This was designed to be about people with an autism condition without an intellectual disability and a normal or above average intelligence (called *Asperger's syndrome*) or those who are considered to have only a few autistic characteristics (PDD-NOS). In the DSM-5 these sub categories have disappeared. Only the overall category exists of *Autism Spectrum Disorders*. Autism is described in its core and through dimensions as seriousness or intelligence, and this is placed in the person as a whole. The perspective, however, is only one side of the coin, the social problem.

We will show that the combination of people with an autistic development and an intellectual disability is not about autism but is the result of specific problems.

The theory presented here applies to autism in general. The classification of autism has been placed in a context of dimensions like in the DSM-5 uses in 2013, from the first Dutch edition of this book in 2001 on.

We wanted to publish a book that could offer help to people with autism spectrum conditions, their immediate environment and their professional carers. The book is therefore both theoretical and practical. Progress in science is ultimately based on the harmonious relationship between theory and practice.

We will first explain the meaning of predisposition and maturation in general and to what extent upbringing plays a part in the child's development (chapter 2). Subsequently we will look at what is 'normal'. We will do this on the basis of the differences between men and women; because when we talk about making contact, there are many differences between people and certainly between men and women (chapter 3). Although in chapter 2 and 3 only indirect references are made to autism they are of vital importance in order to be able to place the following chapters. It requires some effort on the part of the reader to first read general lines about the development and differences between men and women, before we go into autism. Subsequently we will describe the various autistic conditions as conceived until now (chapter 4). In chapter 5 we present the new model on the *diversity of autistic behaviour* where we make the difference between autism itself and autistic behaviour based on different sources. We then describe the core of the problem and the core of the talent (chapter 6). In this chapter a new model, with the *Socioscheme* as a basic principle, will be presented.

In the second part of this book, *What can you do about it?*, we will discuss how one can deal with the various issues and how a child, and his or her parents, can be helped. The basic idea from the perspective of the autism theory of the Socioscheme is delayed and accelerated development at the same time. This means that help in the first place will be how to stimulate the development by joining the mental ages from the MASIP. From

coping better with changes, coping with anxiety and aggression to making friends. With each subject we will work out, as much as possible according to age, what the help could entail. We will focus both on the situation at home and at school. We will not, however, restrict ourselves to children but will also describe the problems of youngsters and adults with an autistic development. As autism is an atypical development, the chapters of the book follow the process of growing up from the *me-otherdifferentiation* to friendships and relationships. We will start with a chapter about the significance of the *diagnosis*, or the lack thereof, for children's growing up (chapter 7), and continue with the help which is needed. To understand the frame that is necessary to raise children with autism, educate and treat them, the *MASIP* will be presented (chapter 8).

One of the most important elements of contact problems, and this is characteristic for conditions from the autism spectrum, is the lack of ability to be able to put yourself 'into someone else's shoes' which is linked to an inadequate *me-otherdifferentiation*. It is therefore important to stimulate this as much as possible (chapter 9). The *me-otherdifferentiation* leads to *social insight* which is necessary to develop *social skills* (chapter 10). Children with contact problems struggle with poor social skills and it is therefore important to stimulate and develop these skills with them. Being able to put yourself in 'someone else's shoes' and developing social skills are of the utmost importance for striking up *friendships* and forming *loving relationships* (chapter 11).

A second important aspect with children who have contact problems is often their *resistance to change*. This aspect in particular is often very aggravating in normal daily life. How do you deal with the child's need to keep everything as it was, resistance to a new pair of pyjamas or a new teacher at school, but also his or her resistance to change (chapter 12). Contact disorders like autism often go hand in hand with intense *anxiety*, *obsessions* (chapter 13) and *aggression* (chapter 14). In the chapter about anxiety we will present the anxiety model in two schemes (Delfos, 2014a; 2004; 2010a) which gives insight into the workings of the body and mind with regards to anxiety, aggression and depression in humans. In addition we will also discuss the contact problems connected with anxiety and shyness, not to be confused with a lack of interpreting social interaction well, namely *social anxiety*. We will discuss the contact problem of social anxiety in order to explain the difference with the contact problem, which plays a part with autistic development. Apart from that, children within the autistic spectrum can suffer a lot of anxiety in social contact due to their inadequate social functioning, and not being understood by other children who sometimes treat them badly, and on that basis children with autism will develop social anxiety in addition to their autistic development (chapter 15). Finally, in the epilogue (chapter 16) we pay attention to the significance of disorders for our society.

Each chapter ends with *focal points*, in which central points are formulated regarding the nature of the problem and the appropriate help. Each chapter has focal points with regard to *attitude*. Before anything else an understanding, respectful attitude is necessary in order to help people with an autistic development and their environment. This attitude is partly given and can partly be achieved by a better understanding of the problem. However, one could question if giving help is possible without this attitude. In order

to promote the readability, we will end each chapter, except the introduction and the epilogue, with a summary.

Real-life examples have been included in the book in order to make the subject matter clearer and more expressive but the names used are fictitious. We systematically used the same fictitious name, so that an image can be formed of what the problem is like, for example, for 'Alec', 'Martin', or 'Sam'. It also means that we can show some of the development in the process of growing up and ageing and how the various subjects play within one person. In the back (p. 405) a list has been included of the names of the people used in the example so that various aspects of the condition can be checked per person.

The examples are mainly from the therapy practice of the author concerning both children, youngsters and adults with Asperger's syndrome or PDD-NOS (DSM-IV, APA, 1994) and some examples from autobiographies of people with autism. Sometimes, in order to clarify, examples are used of people with *autism-traits* that mean some characteristics of autism without it being a question of the full pattern so that it is not the full-blown condition. The advantage of an example is that it clarifies the subject matter, and illustrates it; the disadvantage is that recognition in one example can sometimes lead to the presumption that someone who we are dealing with has the condition, while this is not the case. Be prepared therefore that when a child shows the same behaviour as stated in one of the examples, this does not mean that the child has an autistic development. We all have traits which to a greater or lesser degree are linked to autism.

This is not a book about how you can 'cure' a contact problem, because that is in principle not possible, but it is about how you learn to cope with it and how you can give a child, a youngster or an adult the chance of happiness as much as possible and how you can learn from him or her. It is about how you can find the delayed elements and foster development where possible. How you can see both sides, strong and weak, and use their interaction.

Predisposition or upbringing

During the past years more and more scientific research has been carried out in the field of autistic development. It has become clear that this condition develops from the *predisposition* of the child (autism) but autistic behaviour can also manifest itself as a result of a *traumatic experience* or a *medical condition*, and that autism is not, as has been thought for a long time, caused by the child's *upbringing* (by the mother). Whole generations were brought up with the idea that a dominant or (over-) concerned mother was the cause of autism. A cold, cool, intellectual or *over-concerned* mother would bring her child up to be someone who was hardly able to make contact and lived completely in a world of its own. This image was created by Bettelheim (1967). He did this, however, following the description that Leo Kanner gave of the parents of children with autism. Leo Kanner (1943) had genetic origin in mind and described the parents of children with autism as having autistic traits themselves. He described them as 'cold' and 'cool', not very interested in their children. Kanner was, however, shocked (Kanner, speech in 1969 quoted in Sullivan, 1994

and in Feinstein, 2010, p. 34-35) that his work was interpreted as if he was blaming the parents for the autism of their child. He therefore exclaimed emotionally in 1969 during a meeting of the American Psychiatrist Association: *Parents, I exonerate you!* He stated that from the beginning he took an *organic disorder* as the starting point and not an *upbringing defect*. He even wrote a book: *In defence of mothers: how to bring up children in spite of the more zealous psychologists*, Kanner, 1958). Given his description of the parents it is, however, not surprising that following on from his work, behaviour therapists like Lovaas (1974; 1987; 1996) embroidered the idea of learned behaviour through upbringing. Treatment was developed that was based on the behaviour therapy techniques of *punishment, reinforcement* and *extinction*.

The behaviour of the children concerned has not changed substantially in the course of time, the characteristics of children with autism has remained, but the cause is being judged completely differently. Predisposition has started to play an increasingly more important part. Asperger (1944) already indicated that autism had to do with a predisposition factor, among other reasons, because the behaviour was very persistent through time. The behaviour of neglected children can sometimes be similar to that of autistic behaviour, but a different approach causes a neglected child to show different behaviour rather quickly (Wing, 2001). This is not the case with the child with autism. A different approach can, only with a lot of effort, insight and patience lead to different behaviour in a child with autism. In line with the leading theory of this book a difference is made between *autism* and *autistic behaviour*. Autism is the condition with an atypical development that is based on a gene pattern, and we will use the term ‘autism’ to refer to this specific genetic condition. On the other hand *autistic behaviour* can, but need not, be a reaction to traumatic experiences or a medical condition. In this book we will discuss how autistic behaviour can manifest itself, without a genetic disposition of autism. To explain this, we will use a term of Michael Rutter (Rutter et al., 1999): *Quasi Autistic Patter*, QAP.

Nowadays research into the genes, the bearers of the genetic characteristics that you are born with, shows that autism is connected to a deviation of the chromosomes 4, 7, 10, 16, 19, 22 and the X-chromosome, where chromosomes 2 and 7 are the most characteristic. Common alleles in risk for autism have been discovered and mutations have been given attention, and the relationship between genotype and phenotype of autism (International Molecular Genetic Study of Autism Consortium, 1998; Barrett, Beck and Bernier, 1999; Gillberg, 2000; Autism Genome Project Consortium, Lui et al., 2008; Anney et al., 2010; Holt et al., 2010; Bernier et al., 2014; Buxbaum et al., 2014; DeRubeis et al., 2014; Di Napoli et al., 2015). Gillberg (2000) indicates that with *Rett’s syndrome*, one of the syndromes which was classified under Pervasive Developmental Disorders in the DSM-IV, it was established that there is a chromosomal deviation. This is the reason why it does not figure in the DSM-5. Gillberg also indicates that the first man with Rett’s syndrome has been diagnosed, until recently only women with this autistic development were discovered. This immediately shows how important predisposition is. It is not the case that these conditions are brought on by the upbringing by the mother, but are already present at birth.

Research indicating that there is a relationship between the (overly) concerned mother and autism, has been misinterpreted. For a long time this finding was interpreted as being a causal relationship in the sense that the mother would cause the autism, which proves to be incorrect. In fact the causal relationship is the other way around: it is the child who 'makes' the mother's (overly) concerned behaviour. It is Scarr who showed that children generally create their own environment (Scarr & MacCartney, 1983). For instance a child that has trouble sleeping through the night, 'creates' parents who are tired during the day because of lack of sleep.

A mother usually senses very well that her child is 'strange', 'odd'. She feels that something is wrong with the child and that is the reason for her concern. She starts to protect the child more than she would another child. You can actually say that a child with autism *makes* a mother concerned, dominant, instead of stating that autism is caused by an over-concerned, dominant mother. It is the predisposition that is the foundation which determines the extent of the space the child has for growth and development. Because predisposition is so important, parents will also recognise characteristics of themselves and of family members in their child. Asperger (1944) indicated that he saw autistic traits in all the parents of children with autism he had been able to meet.

Disposition in the sense of genes proves to be an important factor in autism. The *genetic pattern* influences the way the central nervous system develops and matures. In chapter 2 we will go more profoundly into maturing. Autism can also occur in comorbidity with some specific conditions. The question with this comorbidity is whether the autism is caused by the illness or whether both have been caused by the same factor, indicating a genetic vulnerability. In chapter 4 and 5 we will go into this further.

Another problem is that historically, disorders were seen as distinctly different conditions. Disorders that concern a group of characteristics are called *syndromes*. Researchers are now more likely to speak of a continuum, a spectrum, a gradual scale of characteristics. 'Normal' (Typical Development, TD) characteristics can go together with 'abnormal'. This means that conditions can present themselves in mild and more serious forms, and that they can form different patterns, like a kaleidoscope, see Figure 3. In chapter 4 and 5 we explain further how disorders/conditions and normality relate to each other.

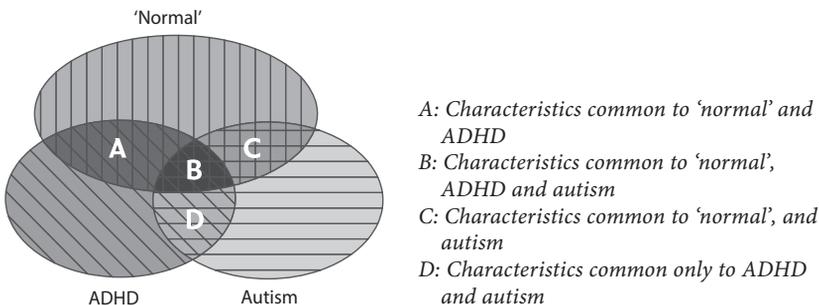


Figure 3: Conditions as a set of characteristics

In *autism spectrum conditions* some characteristics can occur in a mild form without causing serious problems and others may even be an advantage, such as a sharp *eye for detail*, related to a drive for precision. Other possible symptoms, like a deviant language development, are so important that they immediately constitute an indication of a serious problem. These are symptoms that impede the child's functioning to an important degree. This is also the case for the way in which a child makes contact with his or her environment, because this is a fundamental issue for all humans.

A clear example of the idea that we are dealing with characteristics which can occur from a mild to a serious form and not necessarily problematic, is a statement by Hans Asperger (1944). He suggested that all men are a little autistic. What he was aiming at was that autistic characteristics are more connected to a male brain structure. This is expressed for example in the difference between men and women in the degree that they can put themselves in someone else's position. The male pattern of thinking and feeling occurs in the person with autism in an 'exaggerated' form as it were, according to Asperger. Simon Baron-Cohen (2003) took up this idea and published a book on the *extreme male brain*. The differences between men and women have their consequences in the way men and women are described. People sometimes say that every man is a little bit autistic but there could be a counterpart in the female condition. We could also say that all women are a little bit theatrical, without having to diagnose this as a disorder. We will see in chapter 3 why men are more prone to autistic characteristics and women more prone to theatrical traits.

The idea of a gradual scale of disorders/conditions means that it cannot always be clearly established whether someone is suffering from a certain disorder or that he or she has certain characteristics in a milder form which have been exaggerated in order to put one particular label on it.

Diagnosis or label

To what extent is it useful to make a diagnosis? When does a diagnosis become more than simply putting a label on someone, causing the person more harm than good? A diagnosis is actually only there in order to obtain understanding for certain behaviour and mainly to know how to deal with it, and to mobilise understanding and help. When the diagnosis only serves to put someone in a box and then actually discriminate against him or her, it is counterproductive and no more than a harmful label. Making a diagnosis can result in all behaviour, certainly the difficult behaviour, being placed under that label and for some behaviour being wrongly blamed on autism. Doing this we run the risk of harming someone. We can see this happen when using the term 'autist' instead of 'person with autism'. In the case of the label 'autist' the person is subordinate to the diagnosis, and so the risks increase that all of his or her behaviour is being classified under the term autism. It is not surprising then, that such a term can develop into an abusive word. Children, adolescents and adults with autism very often suffer from discrimination. Contrary to what people often think, they feel ashamed, embarrassed to have a condition that makes them so different from others, and children can feel how difficult it can be for their parents, and this is a heavy burden. They do not show this easily, but that does not mean it is not there.

Before we make a diagnosis, it is therefore wise to look at what can be gained from it. It seems that during the past years we have discovered the child and various diagnoses have increased substantially. (Delfos, 2002a). We are consciously choosing whether we want to have children and how many which leads to the concept of ‘helicopter parenting’ and ensuing high expectations. and that for the first time we really discover how they are. To our amazement children in general prove to be much more intelligent than we first thought, but the problem is also that we often expect more from our children and deviation from the average may be judged more severely than is necessary. The emancipation and self-development of men and women having as consequence that often both partners work is causing adults to have a busy life. It makes them less tolerant and may mean that they can deal less well with any deviant and disturbing behaviour of their children. When taking a closer look suddenly it seems that all children are deviant. A correct and balanced diagnosis is therefore even more important.

This book is not meant to further the making of diagnoses, that is to say to decide as a parent or teacher whether a child is suffering from some kind of disorder. When you see disorders being described it seems as though all of a sudden you know very many people who have that disorder, the same goes with diseases. When a disease comes up in the news it seems that suddenly there are a lot of people with that disease. That is because a layman often has difficulty in seeing exactly how a characteristic works and how strong its presence must be in order to speak of that certain disease or disorder and which other characteristics definitely have to occur, or on the contrary not, in order to really be that disease. Reading this book is not supposed to make people suffer from disorders they do not have and make people think that their children have an autistic development when they do not! This risk is certainly there because autistic traits are very common, certainly in men. We will easily think that we recognise the traits and think that our nephew, niece or husband has autism. Labelling someone with a disorder he or she does not have is detrimental and does not encourage mutual communication.

After this warning we want to say that parents are often experts regarding their children, although their fear and powerlessness sometimes causes them to be unable to access their expertise. That is where the skill of the professional carer comes in to validate the wisdom of the parent and to listen closely to the child and the parent, and communicate adequately (Delfos, 2000; 2014b; 2014c). The professional can then use this knowledge to make a correct diagnosis based on that information and ensure the right professional help. For professional carers this book hopes to give something extra to hold on to, because it puts the various diagnoses and their criteria together and offers handles for professional care.

For parents it is useful to know what information a diagnostician needs in order to make a correct diagnosis. To start with, we will deal in chapter 2 with the conditions for when the behavioural problem is more a matter of a disorder which is governed mainly by the predisposition or the maturation of the child, and when it mainly seems to be the environment within which the child is growing up, which governs the problematic behaviour.

The strengths and the weaknesses

Autism has always been an intriguing subject, the positive as well as the negative aspects. It is fascinating because basically it is an atypical condition of the true human nature (Happé, 1998). It touches humans in their very foundation: social interaction. The term autism stems from the Greek word ‘autos’ (self) and expresses the withdrawal into oneself. Autism is universal and timeless, and can be recognised in a distinct pattern of behaviour in different countries and in different cultures (Frith, 1989/2003; Happé, 1998). Social interaction is fundamental to the human being. Wing (1997) indicates that any degree of lack of social skills can have a large impact on the development of the child as a human being and on his or her chances of being able to function independently later.

Although we are talking about a disorder, we want to make it clear from the beginning that autism does not only contain negative characteristics. It distinguishes itself from an ‘average’ development, especially where having difficulty with *social interaction* is concerned. At the same time there are particularly valuable characteristics connected to the problem, the other side of the coin, as Hans Asperger put it. It would be a shame if we concentrate too much on the problematic characteristics and close our eyes to the special qualities. The sometimes staggering encyclopaedic knowledge and refined language and manners of people with autism, often puts people on the wrong track. They also expect the same intelligence and skills in the social field and that is where people with autism can have shortcomings. However their intelligence can make it possible for them to think things through and compensate for their shortcomings. With age social contact will develop if the conditions are favourable, and certainly when help is offered. People with autism can call forth their strengths to compensate for their shortcomings. We will see that it is more important is to realise that autism is an atypical development and that with the right educational help at the right moment, development can proceed. This is the background of the MASIP.

An essential, important positive aspect concerns norms and values. People with an *autistic development*, are generally more pure and communicate much more directly, without ulterior motives. It makes them very reliable, a quality which we consider very important in relationships. Birger Sellin (1995), a young man with autism who had not spoken since he was two and who started to communicate using language again with the help of the computer, wrote: *How often have I wanted to return to the muteness and peace of our valuable, non-deceitful world of people with autism.* Contact with people with autism can make you a better person. The beautiful phrase of Antoine de Saint Exupéry (1943) sums up very well the connection that can develop between people with and without autism: *Far from hurting me, you complete me when you differ from me.*

Their pureness also makes people with autism vulnerable. One of the mottos of the book (see the first page) is the first three lines of a poem by Dutch poet Gerrit Achterberg (1984). We believe the poem expresses the autistic vulnerability. The lack of interpretation of people’s behaviour means that they are able to experience everything more purely, without suspicion, and as a consequence they can experience acute injustice.

Without speaking about autism, Achterberg nevertheless voices the autistic pureness so well:

*I am made of so much glass
That every harsh voice
Is a stone and a crack*

The uncle of Joe, a small boy whom we will encounter more often in the course of the book, expressed himself as follows about Joe and his mother: 'They have no filter, they are pure, and the world enters them as it is.'

We can possibly help people with autism to use their qualities so that they are less troubled by their problematic characteristics and enjoy their positive characteristics more.

The purpose of the book

The most important purpose of this book is to make autistic developments more understandable, by means of theory and examples of the people themselves. We hope that with this book we can create *respect* and *understanding* both for people who struggle with such a condition, and for their environment. We hope that it will stimulate people to let go of their inner developed statistics of how people should be, and not to approach people with autism armed with those statistics and judge them on those grounds as being strange. This book gives advice and tips with the various subjects and situations that may occur in daily life. However, the book is not intended to be an exhaustive book of advice. Each person needs custom-made advice which is attuned to him or her. Something that may work for one parent may be impossible to carry out in a different family. But when the background of the behaviour is understood, people's own creativity can be awakened or people can explain to another person what is going on and ask whether they have an idea of how a certain problem can be dealt with. When parents have problems with a pre-schooler who has not slept through the night since he was born and thereby affects his own and his parent's night's rest, general advice will often be: let the child cry; while the parents feel that this is not possible. It will become very different when people become aware that the child also missing their (night's) rest and would love to sleep, but has enormous difficulties with learning the sleeping phases of *falling asleep* and *sleeping through*. Advice based on linking up to the predisposition, as we will see, is completely different and therefore more effective.

We want to offer a framework which makes people understand why the child becomes angry or cannot orientate itself in time, so that help can be offered which links up to the person with autism him- or herself. For people who struggle with autism it can, hopefully, help to read how they are regarded and also how fellow-sufferers looked for and found solutions.

Focal points

- ▶ Autism has always existed and exists in all cultures through all ages.
- ▶ Autism goes with a more ‘male’ brain structure.
- ▶ One can also have a few characteristics, ‘autistic traits’ or ‘Asperger-traits’, without having the condition as a whole.
- ▶ People can in principle not be ‘cured’ from autism, but can learn how to live with it, and how to develop instead of living with what is not a defect.
- ▶ Autism does not develop because of the upbringing, but is present due to predisposition. Autistic behaviour can result from many different causes.
- ▶ Sometimes it is not about autism (from predisposition) but autistic behaviour. Quasi Autistic Pattern can manifest itself due to life events or autistic behaviour can arise due to medical conditions.
- ▶ Parents (especially mothers) of children with autism are, out of necessity, very oriented towards their children.
- ▶ There are core characteristics and additional characteristics with autistic developments. Not all characteristics are always present and not all characteristics are always that strong.
- ▶ A diagnosis should have a function for the well-being of the person involved and his or her environment.

Focal points regarding attitude

- ▶ Autism is not a question of upbringing but of predisposition.
- ▶ Having respect for a person also means having respect for the limitations which predisposition puts to this person.
- ▶ People with autistic developments have qualities which are the other side of the coin of their problematic characteristics.