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Autism in women and girls: detection and diagnosis

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“How can you be yourself when you have never really been allowed to develop who you are because you had to become someone else for so long to survive?”

@unmaskedbyanna

“C’è una maschera per la famiglia, una per la società, una per il lavoro. E quando stai solo, resti nessuno.”

Luigi Pirandello

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Introduction

When we talk about ASD (autism spectrum disorder), few people may think about Asperger Syndrome. When we think about autistic people, the main common conception is that of a young boy, rocking, giving tantrums in public, and who can just calm down with his favourite objects: trains. This kind of stereotype is what blocks the broad image. This entrenched concept is the cause of not believing people who assert themselves to be autistic, especially when it is a woman who claims to have AS. Asperger Syndrome, like autism, displays differently and not everybody shows the same characteristics. As the American autistic professor Dr. Stephen Mark Shore once said: “When you meet one person with Autism, you’ve met one person with Autism”. The key, then, to a proper diagnosis, which requires understanding and acceptance of the people around us, is not to generalise. All we must do is just listen with no prejudice. Exclamations like “You don’t look autistic at all”, “We are all a bit autistic”, or “You cannot be autistic, you make eye contact!” are detrimental to the health of people seeking help. Usually, these responses are not given exclusively by relatives, friends, and colleagues, but by physicians as well. The main cause is related to a lack of up-to-date clinical tools which do not consider the variety of autistic traits, especially in adults and women. Since it is a developmental disability, and mostly young males were studied, girls and adults fall out of the radar or get a misdiagnosis. Spreading awareness is still needed nowadays, because, even if there are more neurodiverse authors, self-advocacy blogs, and communities, most people do not really grasp the difficulties autistic people have to face in a neurotypical-built society and world. The focus here is primarily on Asperger Syndrome, because it is even more subtle and challenging to detect, especially in females.

Throughout this dissertation, the characteristics of AS in females will be addressed, focusing on the differences between the male counterpart, and neurotypicals, alongside some important figures who contributed and are helping to spread recognition.

In Chapter 1 the terminology of neurodivergence will be addressed, exploring the paths of autistic people seeking their rights thanks to the rise of the Internet era. Furthermore, ASD (autism spectrum disorder) and AS (Asperger syndrome) will be discussed in detail (from their “birth” to the distinction with high-functioning autism).

In Chapter 2, diagnosis tools will be presented, as for relevant self-diagnosis tests, available also on the Internet. Moreover, some explanations for late diagnosis – and misdiagnosis – in women will be discussed, focusing on the differences between men and women with Asperger's and some distinctions with NT (neurotypical) women, too.

Chapter 3 will play a larger role in this dissertation since it lists all the possible complications and obstacles that an autistic person (and particularly a woman with AS) may face during his/her/their lifetime. Starting from a linguistic point of view, a vast span of everyday struggles that happen in life is addressed. Social interactions, such as with friends, lovers, and at work, are directly influenced by divergent wiring of the brain and thus by an apparent lack of empathy and misunderstanding of pragmatic rules. When there is stress (as a consequence of social interactions) and (or) confusion during sensory overload, cases of meltdown, shutdown, or burnout may manifest. To avoid these situations the most, it is vital to embrace stimming, as dedicating spare time to special interests. Before finishing the chapter, there are even less bearable facts that autistic women must deal with once or more during their lives: abuse situations such as bullying (mostly during school years), sexual assaults, addictions, depression, and suicide.

Chapter 4, the last one, will present emotions and life outcomes after the diagnosis and the reason to get an official one, plus all the available materials like books, blogs, and videos that lead to acceptance through families and social media. Last but not least, a case study about the work of Dr. Valentina Pasin, based here in the region of Veneto, is presented. Thanks to her career as a specialised clinician, many autistic people, both men and mostly women, are given the credit they finally deserve.

Chapter 1 – Explaining Autism

Even if two people share the same neurotype, it does not imply that they are similar. Since we talk about a spectrum, the severity of autism could be very mild, as very intense, and hence create more difficulties in many aspects of everyday life. In the past, autism was divided into three distinct categories: mild, moderate, and severe autism. Then, it was thought of more as a continuum, but its dichotomy High- and Low-Functioning (another way to indicate the opposite ends of the spectrum, with high-functioning also being called Asperger syndrome) is not frequent anymore since it was not sensitive towards people on the spectrum with more severe symptoms.

The choice of words is notably serious and imperative since they have a social impact and could hurt people's feelings in the autistic community. Another locution that most autistics decide to avoid is the label of Asperger Syndrome, due to the connection of Hans Asperger with Nazis (his participation in the eugenic experiments during the Third Reich will be analysed further in this chapter), and that is why many people diagnosed with AS decide to call themselves autistics, or people on the spectrum. Many individuals who received a former diagnosis or would have fallen into AS category, prefer the label Asperger, to voluntarily detach themselves from autistics with more severe impairments; in fact, they would feel bad implying they are the same because they are both on the spectrum, thus experiencing the same struggles and need for support. A similar debate on the importance of semantics has taken place in the last years, and it is about Identity-First Language. When the term autism first became of popular use, people described children as "suffering from autism", suggesting that it was a terrible situation, a severe disease that could not be cured, and alas, this misconception is still widespread. It is clear, thanks to self-advocate communities, that autism is not a disease and therefore there is nothing to be cured. Autism characterises a person, it is part of her/him/them and must be accepted, not just tolerated. Now, person-first language supporters are in favour of addressing autistics as autistic people, autistic individuals, or people with autism and never just as autistics: they proclaim the importance of a persona, since we are always talking about a human being with rights. The adjective autistic, then, must be always followed by the term person. "The theory behind person-first language is that it puts the person before the disability or the condition and emphasizes the value and worth of the individual by recognizing them as a person instead of a condition."¹ The locution "person with autism", though, does not satisfy all people on the spectrum, since with this expression

¹ Identity-First Language, an article by Lydia Brown <https://autisticadvocacy.org/about-asan/identity-first-language/>

they do not feel that autism is part of them, as a whole, but instead as a feature of their character, something that does not define them entirely, which they carry and can be separated to anytime. You do not have autism, you are autistic, because autism is part of who you are. Finally, the question of person-first language is essential and cannot be dismissed claiming that each person should use the terminology he/she/they prefer(s) and to ignore what other wants. But what everybody needs is respect and equity. Throughout this dissertation, then, the terms autistics, autistic people, individuals on the spectrum, Aspies, person with Asperger's etc. will be used interchangeably to indicate ASD community, also to avoid redundant lexicon, with the hope and will not to hurt or judge anybody.

In this chapter the historical background and the most relevant terms will be presented, as for the difference between Asperger Syndrome and Autism, even though they are not distinct anymore, according to the latest DSM – V (Diagnostic and Statistical Manual of mental disorders, APA 2013). In fact, Asperger syndrome was brought together under the autism spectrum disorder classification, though the International Classification of Diseases (ICD-1, by World Health Organization) still formally recognises it as a proper diagnosis. But the differences between these two diagnostics will be addressed more in detail in the next chapter.

Before moving on to the next paragraph, some thoughtful words which summarise the stigma about Autism are extrapolated from the book “Unmasking Autism: The Power of Embracing Our Hidden Neurodiversity” by Price Devon:

“Until fairly recently, most people believed Autism was rare, that only young boys had it, and that it was always easy to see. [...] This is how all of us were trained to view the disability: a horrible condition that renders you freakish and helpless, your life only as valuable as your savant-like skills are to other people. [...] Asperger's was stereotyped as a “higher functioning” flavor of Autism found in really smart, nerdy, usually rude men who worked in fields like tech. In both forms, Autism was associated with being awkward and uncaring (and male) with a penchant for numbers. People had little to no understanding of Autism's causes, what it felt like to be an Autistic person, or that a disability shares features with other disorders like epilepsy, Social Anxiety Disorder, Attention-Deficit-Hyperactive Disorder (ADHD), or Post-Traumatic Stress Disorder (PTSD).”²

² Price, D. (2022). *Unmasking Autism: The Power of Embracing Our Hidden Neurodiversity*. Octopus Publishing Group

1.1 Neurotypical; Neurodivergent; Neurodiverse

We refer to NTs, or Neurotypical people, when considering most of the world's population, with a common wiring and functioning of the brain. Starting from this group, another one is defined, for those people whose brains work differently, and it is called Neuroatypical. The term NT (neurologically typical) was introduced by the Autism Network International (founded by Jim Sinclair and Donna Williams in 1992) to refer to non-autistics. Less used in the academic field is the synonym Neurodivergent, often used to refer to people with autism spectrum disorder. Instead, Neurodiverse is a nonmedical neologism, whose etymology comprehend everyone who may have a brain, even neurotypical; in this sense it claims the rights and the respect for every brain functioning. But it is usually used interchangeably with neurodivergence (probably due to the identical acronym ND), usually to refer “to the wide spectrum of individuals whose thoughts, emotions, or behaviours have been stigmatised as unhealthy, abnormal, or dangerous.”³

An interesting perspective is given by autistic teen Siena Castellon, who expresses nicely the necessity of coexistence of NTs and NDs:

“The neurotypical brain is optimally designed to facilitate socialization. It allows neurotypicals to interact socially and communicate with ease. It gives neurotypicals the ability to read body language, understand facial expressions and subtle fluctuations in tone of voice, understand different points of view, hidden messages, innuendo, and other forms of communication. On the other hand, the autistic brain is optimally designed to focus on the physical world in much greater detail, to recognise patterns and shapes, to be logical, analytical, and focused, to develop areas of expertise and to focus on understanding the world around us. Although these two brains serve different purposes, they complement each other. Neither is better or worse.”⁴

The coin of the term “neurodiversity” is accredited to sociologist Judy Singer, who witnessed the emerging phenomenon called the Neurodiversity Movement (with her focusing mainly on Asperger Syndrome, because of the interest for her daughter and mother's traits), a group made up of people who never fitted in – or maybe they were not accepted? – and pointed out as *weirdos*, *nerds*, *geeks*, *eccentrics*, and *loners*, who created self-advocacy groups, support blogs etc.; people who were not

³ Price, D. (2022). *Unmasking Autism: The Power of Embracing Our Hidden Neurodiversity*. Octopus Publishing Group

⁴ Castellon, S. (2020). *The spectrum girl's survival guide. How to grow up awesome and autistic*. Published by Jessica Kingsley Publishers

considered “normal”, with the connotation it has gained during these last decades; when it entered the English language in the first half of 19th century, normal was an adjective for Ideal, a characteristic for deities, so not so easily reachable by common people.

Thanks to the rise of this movement and the gathering of neurodivergent people in support communities, autistics could finally feel a sense of acceptance by peers with similar characteristics and experiences, thus they could be more comfortable dropping off the masks and be who they were. Alienation and pain perpetrated by ableism stopped, eventually. Because of ableism and the “Medical Model” point of view, people were defined exclusively by their disabilities, and therefore considered inferior to non-disabled people.

The distinction, then, between deficit and handicap must be clarified. The former addresses the irreversible lack or deficiency of an individual (be it anatomical, mental, or psychological), while the latter is a social and cultural process, with political issues; hence it is called disability, given in a particular context. A person with a physical deficit is seen as disabled because of the situation, which is not adapted to his needs, but tailored for able people (expecting disabled people to be as able as others).

Disability and impairment were claimed by activists and theorists in the “Social Theory of Disability”, clearly in opposition to the “Medical Model”. This latter was one valid approach until 2001, when disability in the ICF (International Classification of Functioning, Disability and Health) was not conceived as a disease anymore, rather a consequence of a complex correlation between the health condition and the personal and environmental factors which represent the context in which the person lives. With this bio-psycho-social approach, the individual is seen in his whole background, not just as the medical deficiency.

Moreover, Michael Oliver, key advocate of the Social Theory of disability, stressed the interaction between the rise of capitalism and the societal change of people with disabilities, who were more integrated during feudal times, just to be excluded “from the industrial workforce with its demands for speed, efficiency and productivity”.⁵

The main desires for the Autistic movement were directly observed and reported by Judy Singer while participating in the Independent Living on the Autistic Spectrum, or InLv for short (an online support group for people with Autism, including Asperger Syndrome), and they comprised recognition of their neurodivergence, end to discrimination, civil rights alongside adequate disability services.

⁵ Singer, J. (2017). *Neurodiversity: the birth of an idea*. Published by Judy Singer

By the 1990s, public awareness was growing thanks to the advent of the internet, spreading the works of professionals, like Dr. Lorna Wing and Tony Atwood, and the autobiographical evidence by Donna Williams, Temple Grandin (just to name a few). Judy Singer was utterly persuaded that autism and Asperger Syndrome were nothing new, but she questioned herself about the reason for the Autism Spectrum emerging at the time. As she wrote in her honour's thesis and hence in her book:

“New disabilities do not simply emerge because certain bodily or mental configurations have never existed or been noticed before. Rather, they coalesce as new social formations render these configurations problematic.”⁶

According to Singer, the contribution of feminism, when mothers started to refuse in the '60s that they were the cause of their child's autism (“refrigerator mothers”, according to the Austrian psychologist Bruno Bettelheim), the failures of psychotherapy and the achievements of neurology, combined with the huge impact of the internet era (with autistics claiming that computers mirrored their mind functioning), were all factors that brought the Autistic Spectrum to emerge in the late 1980s-1990s. As autistic Prof. Temple Grandin suggests, the change in perspective about autism was in fact sociological, following the gay rights movement, that in 1972, “protested the DSM's classification of homosexuality as mental illness – as something that needed to be cured. They won that battle, raising the question of just how trustworthy *any* diagnosis in the DSM was.”⁷

1.2 Autism Spectrum Disorder (ASD)

Among the neurodevelopmental disorders, there are the so-called pervasive developmental disorders (PDD). The acronym PDD was used in the DSM-IV to indicate those neuropsychiatric pathologies that rise during the first years of life and among those we can find autism, Asperger syndrome, Heller syndrome, Rett syndrome, and the pervasive developmental disorder not otherwise specified (PDD-NOS). Now, with the updated version of DMS-V, all the disorders listed above are grouped in a single category, named Autism Spectrum Disorders. According to the latest version of ICD-11, Rett syndrome is excluded from the category of Autism spectrum disorder (code 6A02). They are all characterised by an impairment in three main areas: communication, reciprocal social interaction,

⁶ Singer, J. (2017). *Neurodiversity: the birth of an idea*. Published by Judy Singer

⁷ Grandin, T., Panek, R. (2014). *The autistic brain. Exploring the strength of a different kind of mind*. Published by River

repetitive behaviours, and restricted interests (deficit triad). It is ascertained that clinically, there lay more probabilities to have more co-existing neuroatypicities rather than single ones. Autism and Asperger may therefore present with ADHD, LSD (dyslexia, dyscalculia, dysorthography, dysgraphia), giftedness (in Italian called APC, Alto Potenziale Cognitivo, to indicate those who have an IQ higher than 120, or “Plusdotazione”, when the IQ is above 130), Tourette syndrome, dyspraxia, and other delays in speech acquisition.

“The quiet and distant child with intellectual disability” is the description given by the Austrian psychiatrist Chaskel Lieb “Leo” Kanner in 1943, who noticed some features of autism in children. He used the word autism (from Greek *autos*, reflexive pronoun “self”) in a different connotation from the first use of the word, which dates back in 1910. The Swiss psychiatrist Eugen Bleuler, indeed, coined it to describe schizophrenia. After that, the word autism has obtained the meaning that it has nowadays thanks to the concurrent studies brought on by Dr. Kanner and Dr. Asperger, who used it to describe similar behaviours detected in children almost during the same period, but in two different nations (U.S. the former and Austria the latter), without apparent communication between them. Leo Kanner (1894-1981) described eleven children (aged two to ten years) with early childhood autism, calling it *infantile autism*. In 1944, pediatrician Dr. Hans Asperger (1906-1980) described at Children’s Hospital in Wien, Austria, four children with autistic psychopathy and he detected that their speech was typically fluent by the age of five and that they showed average intelligence.

Between 1950 and 1970, autism was considered as a psychiatric disease, a behavioural psychosis, often confused with childish schizophrenia. In Chicago, during the ‘60s, Bruno Bettelheim (1906-1980), director of the university of Chicago's Orthogenic school for disturbed children, accused mothers to be the cause of their child’s autism, due to their cold and detached behaviours towards their progeny. His was a follow-up of Kanner’s popularised notion of the refrigerator mother, which saw children biologically predisposed towards autistic symptoms, which were latent until poor parenting came along. The turning point was the decade 1970-1980, when the first studies on language disorders and epidemiological research were made. Asperger syndrome as a term has been used for the first time after the death of Hans Asperger (1980), by English psychiatrist Dr. Lorna Wing, who, after Asperger’s death, recognised that the descriptions given by Leo Kanner, which were used until 1981 to diagnose autism in English speaking countries, did not define accurately the children and adults she treated during her career (over thirty-four cases). She was perplexed about the definition of autism used by clinicians at that time, because some of her patients showed classic characteristics of autism during infancy, but with growth they developed a normal behaviour, characterised by fluent language and a desire to socialise with others; hence they could no longer

meet the criteria based on Kanner's work, even though they still met difficulties in social situations and in conversations.

Indeed, though both Dr. Kanner and Dr. Asperger used the term autism, Asperger's work went unrecognised in anglophone countries till the '80s, when Dr. Wing made it known and the amount of people suspecting, or suspected, to have Asperger syndrome grew. Until then, the prevailing view of autism was that it was an incapacitating disability, with defected intelligence.

Following this, thorough research was made and in 1988 an international conference about Asperger syndrome was held in London, alongside the premises for the publication of one of the first criteria for diagnostics (Gillberg, 1989, 1991).

More awareness grew, as the number of diagnoses, which still today are notably increasing also in girls and women.

More than 30 epidemiological studies have been conducted starting from 1960s (4,4 every 10.000 between 1966-1991, and 12,7 every 10.000 between 1992-2001). In 1996 ASD had an incidence of almost 1 person every 100 (Wing, 1996). Therefore, it has been assessed that autism is not associated with a particular social class or geographic area (Wing & Potter, 2002). For decades, estimates of the prevalence of autism had remained stable, but that number had started to escalate in 1980s and 1990s, raising fears that a generation of children was affected by an epidemic of unknown origin. In "the Geek syndrome", published on *Wired* in 2001, the journalist Steve Silberman investigated the reasons behind the rising number of diagnoses in Silicon Valley, basing himself on the hypothesis of cognitive psychologist Simon Baron-Cohen, who in 1997 found a relationship between being autistics and becoming engineers. According to authors Grandin and Panek, the upturn of number of diagnoses of ASD is also due to a typographical error in the description of PDD-NOS in the DSM-IV: "a severe and pervasive impairment of reciprocal social interaction *or* [instead of *and*, indicating the necessity of meeting both the criteria not just either] verbal and nonverbal communication skills". The language was corrected in 2000 (DSM-IV-TR), but it cannot be known how many doctors assessed and continued giving diagnoses based on this huge error.⁸

According to a statistical study conducted by the centers of Disease Control and Prevention (Laio *et al.*, 2018) on the incidence of autism in U.S.A., between 2000 and 2014 there has been an increase of almost 150%. Though the rising numbers, the percentage of children with Asperger syndrome who

⁸ Grandin, T., Panek, R. (2014). *The autistic brain. Exploring the strength of a different kind of mind.* Published by River

are diagnosed is thought to be just 50% of the whole Aspie population. Children and adults with Asperger syndrome are indeed able to hide their difficulties, to show adaptive strategies and avoid to get diagnosed, confusing and directing the clinician towards other diagnosis (Moscone & Vagni, 2019, 49 in Vespe, 2021). Autism is esteemed to have – and these values would most probably keep rising – a ratio of 1:100 (Baron-Cohen, 2008), and a gender ratio of 4:1 (Werling & Geschwind, 2013) so the general belief is that it is a “male” disorder.⁹

But what do we know to this day? Autism has a complex aetiology, in which genetic factors play a central role, alongside an interaction with non-genetic factors. Neuropathology data (images about the structure and activity of the CNS, central nervous system) and neurochemistry highlight that autism is caused by different pathological condition. Some subgroups of ASD characterised by a prenatal defect in the development of the brain due to genetic basis (anatomical anomalies in the frontal lobes, which translates in fragilities with the executive functions; in the limbic area, which could be associated with sensory overload, and recognition of emotions; and in the cerebellum, with balance and coordination issues) and somatic mutations caused by infections (maternal pre/perinatal infections), toxins, and other environmental factors (association with increased relative risk are premature birth, perinatal hypoxia, maternal Vit. D deficiency, maternal obesity, and very low birth weight).¹⁰

People with autism display impairments with social interaction, verbal and nonverbal communication and activities (there is a preference for repetitive actions and a restricted number of interests). Due to the alteration of the intersubjectivity (the process of sharing mental activity between two subjects during any communicative act), autistics show poor ability to read nonverbal and confusion when there are many stimuli simultaneously. Autistic children lack the capacity to alternate the look from the object to the person and to pay attention on the same object. Furthermore, the alteration in interaction is explained by the deficit in understanding emotions and atypical strategies of face-processing; autistics present indeed an atypical functioning of mirror neurons (Gallese, 2006), thus a

⁹ Fisher Bullivant, F. (2018). *Working with Girls and Young Women with an Autism Spectrum Condition. A Practical Guide for Clinicians*. Published by Jessica Kingsley Publishers

¹⁰ slide n. 7 in What is autism and how do we make a diagnosis in the new era of DSM 5 and ICD 11, by Dr. Susannah Whitwell, Adult ADHD and ASD Service South London and Maudsley NHS Foundation Trust”

difficulty in elaborating emotional information and atypical body expressions and gestures for emotions. Finally, there are alterations in cognition, hence issues with attention, integration between the two hemispheres, perceptive integration (thinking in pictures, poor capacity of abstraction), which can explain the results of autistic children in the Theory of Mind experiment (ToM, Premack & Woodruff, 1978), because of deficits in the process of mentalisation (the intuitive comprehension of mental states) and easy socio-cognitive competences (such as the difference between *think* and *know*, *intensions* and *desires*).

However, autism is multiply determined, so it has no single cause, and still no gene appear to be associated directly. Premature delivering, among others, is considered a risk factor. “Based on epidemiological data, we know that one of the associations is advanced paternal age, that is, increasing age of the father at the time of conception. [...] Also, we know that exposure to certain agents can actually increase the risk of autism. In particular, there is a medication, valproic acid, which mothers with epilepsy sometimes take, we know can increase that risk of autism.”¹¹ Though, it is ascertained that there is no correlation between the onset of autism and vaccines,¹² despite the debates of these last decades. The original research study which suggested it was retracted from the journal *Lancet*, and the author (former Dr. Andrew Wakefield) had his medical license taken away. Furthermore, one of the ingredients in vaccines which was thought to be the cause of autism (thimerosal) was removed from vaccines in 1992, and it did not influence the increasing number of diagnoses of autism.

Both autism and other neuroatypicities (ADHD, SLD – Specific Learning Disorders, giftedness, dyspraxia, and Tourette Syndrome) are neurobiological conditions and people born with them. There is no “cure” since there is nothing that cause autism, or ADHD, during lifetime; people are just like this from birth. Among the criteria for diagnosis there is the clause that symptoms must be present from birth or early childhood, so, it is clear now that it is not a disease and it is not caused by poor diet, bad parenting, inoculations; moreover, it is not contagious, even though it could seem so when number of diagnoses started to upsurge, as the exclamation “There is an epidemic of autism in Silicon Valley. Something terrible is happening to our children” in Silberman’s book.¹³

¹¹ Ted Tak by Dr. Wendy Chung “Autism — what we know (and what we don't know yet)” (2014)

¹² Taylor LE, Swerdfeger AL, Eslick GD (2014). *Vaccines are not associated with autism: an evidence-based meta-analysis of case-control and cohort studies*. *Vaccine*. 32 (29): 3623–9. doi: 10.1016/j.vaccine.2014.04.085. PMID 24814559

¹³ Silberman, S. (2015). *Neurotribes. The legacy of autism and how to think smarter about people who think differently*. Published by Allen & Unwin

Autism spectrum disorder (ASD), also cited as autism spectrum condition (ASC), is more commonly diagnosed in boys than in girls, with a ratio of 4:1, according to the DSM-V. Females are at an elevated risk of going undiagnosed compared to males because their difficulties are frequently missed or misinterpreted (Lai & Baron-Cohen, 2015). Their behaviour, particularly in Level 1 Autism, is typically different from the description given in the DSM-V, which is presented in the following table:

| Severity Level for ASD | Social Communication | Restricted interests & repetitive behaviours |
|-------------------------------------------------------|-----------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------|------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------|
| Level 3 - 'Requiring very substantial support' | Severe deficits in verbal and nonverbal social communication skills cause severe impairments in functioning; very limited initiation of social interactions and minimal response to social overtures from others | Preoccupations, fixated rituals and/or repetitive behaviours markedly interfere with functioning in all spheres. Marked distress when rituals or routines are interrupted; very difficult to redirect from fixated interest or returns to it quickly. |
| Level 2 - 'Requiring substantial support' | Marked deficits in verbal and nonverbal social communication skills; social impairments apparent even with supports in place; limited initiation of social interactions and reduced or abnormal response to social overtures from others | RRBs and/or preoccupations or fixated interests appear frequently enough to be obvious to the casual observer and interfere with functioning in a variety of contexts. Distress or frustration is apparent when RRB's are interrupted; difficult to redirect from fixated interest |
| Level 1 - 'Requiring support' | Without supports in place, deficits in social communication cause noticeable impairments. Has difficulty initiating social interactions and demonstrates clear examples of atypical or unsuccessful responses to social overtures of others. May appear to have decreased interest in social interactions | Rituals and repetitive behaviours (RRB's) cause significant interference with functioning in one or more contexts. Resists attempts by others to interrupt RRB's or to be redirected from fixated interest. |

Table 1: "Chart 2 – Severity Levels of Autism Spectrum Disorder, DSM-5, APA, 60, 2013"

The criteria of DSM-V for an ASD diagnosis are listed below:

“A. Persistent deficits in social communication and social interaction across multiple contexts, as manifested by the following, currently or by history (examples are illustrative, not exhaustive, see text):

1. Deficits in social-emotional reciprocity, ranging, for example, from abnormal social approach and failure of normal back-and-forth conversation; to reduced sharing of interests, emotions, or affect; to failure to initiate or respond to social interactions.

2. Deficits in nonverbal communicative behavior used for social interaction, ranging, for example, from poorly integrated verbal and nonverbal communication; to abnormalities in eye contact and body language or deficits in understanding and use of gestures; to a total lack of facial expressions and nonverbal communication.
3. Deficits in developing, maintaining, and understanding relationships, ranging, for example, from difficulties adjusting behavior to suit various social contexts; to difficulties in sharing imaginative play or in making friends; to absence of interest in peers.

Specify current severity: Severity is based on social communication impairments and restricted repetitive patterns of behavior. (See table above)

B. Restricted, repetitive patterns of behavior, interests, or activities, as manifested by at least two of the following, currently or by history (examples are illustrative, not exhaustive; see text):

1. Stereotyped or repetitive motor movements, use of objects, or speech (e.g., simple motor stereotypies, lining up toys or flipping objects, echolalia, idiosyncratic phrases).
2. Insistence on sameness, inflexible adherence to routines, or ritualized patterns or verbal nonverbal behavior (e.g., extreme distress at small changes, difficulties with transitions, rigid thinking patterns, greeting rituals, need to take same route or eat food every day).
3. Highly restricted, fixated interests that are abnormal in intensity or focus (e.g, strong attachment to or preoccupation with unusual objects, excessively circumscribed or perseverative interest).
4. Hyper- or hyporeactivity to sensory input or unusual interests in sensory aspects of the environment (e.g., apparent indifference to pain/temperature, adverse response to specific sounds or textures, excessive smelling or touching of objects, visual fascination with lights or movement).

Specify current severity: Severity is based on social communication impairments and restricted, repetitive patterns of behavior. (See table above)

C. Symptoms must be present in the early developmental period (but may not become fully manifest until social demands exceed limited capacities or may be masked by learned strategies in later life).

D. Symptoms cause clinically significant impairment in social, occupational, or other important areas of current functioning.

E. These disturbances are not better explained by intellectual disability (intellectual developmental disorder) or global developmental delay. Intellectual disability and autism spectrum disorder frequently co-occur; to make comorbid diagnoses of autism spectrum disorder and intellectual disability, social communication should be below that expected for general developmental level.

Note: Individuals with a well-established DSM-IV diagnosis of autistic disorder, Asperger's disorder, or pervasive developmental disorder not otherwise specified should be given the diagnosis of autism spectrum disorder. Individuals who have marked deficits in social communication, but whose symptoms do not otherwise meet criteria for autism spectrum disorder, should be evaluated for social (pragmatic) communication disorder.

Specify if:

- **With or without accompanying intellectual impairment**
- **With or without accompanying language impairment**
 - (Coding note: Use additional code to identify the associated medical or genetic condition.)
- **Associated with another neurodevelopmental, mental, or behavioral disorder**
 - (Coding note: Use additional code[s] to identify the associated neurodevelopmental, mental, or behavioral disorder[s].)
- **With catatonia**
- **Associated with a known medical or genetic condition or environmental factor”¹⁴**

In order to get a clinical diagnosis of ASD, all three symptoms from criteria A, two from criteria B, and the conditions of both C and D must be determined.

¹⁴ The American Psychiatric Association's Diagnostic and Statistical Manual, Fifth Edition (DSM-V) <https://www.cdc.gov/ncbddd/autism/hcp-dsm.html>

1.3 Asperger Syndrome (AS)

The term was introduced for the first time in ICD-9 (1992) and later in the DSM-IV (1994). According to that edition of DSM, Asperger syndrome was not technically a form of autism, but it was one of the five disorders listed as PDD. Even if it is no longer in use, the criteria of the DSM-IV used to assess Asperger's disorder, give a clear description of the clinical characteristic of Aspies, therefore they are listed below:

“A. Qualitative impairment in social interaction, as manifested by at least two of the following:

1. marked impairments in the use of multiple nonverbal behaviors such as eye-to-eye gaze, facial expression, body postures, and gestures to regulate social interaction.
2. failure to develop peer relationships appropriate to developmental level.
3. a lack of spontaneous seeking to share enjoyment, interests, or achievements with other people (e.g. by a lack of showing, bringing, or pointing out objects of interest to other people).
4. lack of social or emotional reciprocity.

B. Restricted repetitive and stereotyped patterns of behavior, interests, and activities, as manifested by at least one of the following:

1. encompassing preoccupation with one or more stereotyped and restricted patterns of interest that is abnormal either in intensity or focus.
2. apparently inflexible adherence to specific, nonfunctional routines or rituals.
3. stereotyped and repetitive motor mannerisms (e.g., hand or finger flapping or twisting, or complex whole-body movements).
4. persistent preoccupation with parts of objects.

C. The disturbance causes clinically significant impairment in social, occupational, or other important areas of functioning.

D. There is no clinically significant general delay in language (e.g., single words used by age 2 years, communicative phrases used by age 3 years).

E. There is no 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 in childhood.

F. Criteria are not met for another specific Pervasive Developmental Disorder or Schizophrenia.”¹⁵

Focusing now on the historical background of autism, we may sum up as that Leo Kanner described children with a more severe form of autism, while Hans Asperger described children whose development was less compromised.

Dr. Asperger nicknamed his “autistic psychopaths” patients “little professors” because they could talk ceaselessly about their special interest, with a peculiar ability to recall dates and other information. While not the Nazis' main targets, autistic people were considered a threat to the Third Reich goal of the Aryan race. Labelling people with the term "Asperger syndrome", it reinforces the idea that autistic people have no value to society.

Dr. Asperger is often portrayed as a hero (that is what emerged also during a Ted talk speech by Steve Silberman in June 2015), who saved his patients from the Nazi killing programme, thanks to their intelligence. “However, it is now indisputable that Asperger collaborated in the murder of children with disabilities under the Third Reich”,¹⁶ and we know that thanks to the work and books by historians Edith Sheffer and Herwig Czech. Asperger Syndrome was brought into vogue again by Dr. Lorna Wing, but the official English translation of the 1944 “*Die autistischen Psychopathen im Kindesalter*” by Hans Asperger was cured by developmental psychologist Uta Frith in her book *Autism and Asperger Syndrome* (1991). Under National Socialist Germany regime, psychiatry played a major part in determining who would be pure, and therefore live, and who would be murdered in “euthanasia” killing programmes.

Hans Asperger published approving comments on race hygiene measures such as forced sterilisations,¹⁷ and, according to Alex Kasprak’s article “Is Asperger's Syndrome Named After a Nazi Enabler?” (published in May 2021 on *Snopes*) there are some documents in which disabled children assessed by Asperger were referred to the Am Spiegelgrund clinic (a known centre of “genetically inferior” child euthanasia and unit of Aktion T4, as it was called post-war, Hitler’s

¹⁵ American Psychiatric Association. (2000). Diagnostic and statistical manual of mental disorders (4th ed., rev.). Washington DC: Author. (Pg. 84)

¹⁶ Baron-Cohen, S. (2018). *The truth about Hans Asperger's Nazi collusion*. Nature 557, 305-306 (2018), Books and Arts

¹⁷ Czech, H. (2018). *Hans Asperger, National Socialism, and “race hygiene” in Nazi-era Vienna*. Molecular Autism 9, 29. <https://doi.org/10.1186/s13229-018-0208-6>

campaign of mass murder), where roughly 800 children were killed, some “starved, others given lethal injections. Their deaths were recorded as due to factors such as pneumonia.”¹⁸

Thus, as anticipated earlier, the choice of language is crucial, and some terms may produce enormous problems when misused or not fully understood. Those autistics who decide to label themselves as Asperger, are not to be judged, but it must be clarified the historical background, even though their identity and personality do not change simply because of historical revelations. According to Judy Singer, they “prefer to name their condition as AS, and themselves as autistics, ACs (autistics and cousins), and sometimes, comfortably, as “Aspies”, to distinguish themselves from those they have dubbed the “NT”s – NeuroTypicals”.¹⁹ Using a single term (ASD) to refer to more categories clarifies that a diagnosis for mental illnesses and disabilities is not an exact science and that ASD and AS concepts are continuously changing (Attwood, 2006).

With the current terminology, the German definition of “psychopathy”, as originally referred to autistic children, could be now translated it as “personality disorder”. In his studies, Asperger observed and described that in his patients, maturity and social reasoning were delayed and that some social abilities were unusual in every phase of development. They showed verbal and nonverbal difficulties in communication and social rules. For those children, it took more effort to build friendships and they were usually mocked by others. Their way of speaking was pedantic, showing an unusual prosody, voice timber, tone, and rhythm of the speech, while grammar and lexicon were relatively advanced. Some showed difficulties to maintain attention in class and some had specific learning disabilities. Asperger also noticed that they often needed assistance from the parent for organisation, self-care, and hygiene, more than expected from a child of that age. He described clumsiness in movements and coordination and he even noticed that some children were extremely sensitive to sounds, odours, particular textures and being touched. These characteristics could be detected at two or three years of age already, but they could become more evident later.

¹⁸ Baron-Cohen, S. (2018). *The truth about Hans Asperger’s Nazi collusion*. Nature 557, 305-306 (2018), Books and Arts

¹⁹ Singer, J. (2017). *Neurodiversity: the birth of an idea*. Published by Judy Singer

According to Tony Attwood's 1998 book, there are some typical AS behaviours, that could be summarised as follows:

- Naïve, one-sided interactions;
- Repetitive speech;
- Poor nonverbal communication skills;
- Special interests;
- Obsessive routines;
- Clumsiness, odd movements, and postures;
- Unusual tone of voice, prosody, accents.

In another volume ("The complete guide to Asperger's Syndrome", 2008), Dr. Attwood, one of the major experts about AS, who specialised in women, describes in more detail the distinctive traits and behaviours of adolescents and youngsters on the spectrum. Differently from peers with classic autism, children with Asperger's have tendency to monologue, without noticing whether others keep up the interest in the conversation; they struggle less to recognise primary emotions, they experience anger or desire of revenge towards some particular people. The sense of pride is pretty much developed, they feel shame (but this does not help to make social faux-pas), and compared to more severe forms of autism they show less difficulties in understanding facial expressions and in using communicative gestures; they show less evident motor stereotypy than other children on the spectrum, such as rocking (switching instead the weight on one foot and another when standing), fidgeting with hands and objects, and pure echolalia (preferring replicating quotes from books and movies). Some Aspies are highly creative and do have a quite good abstract thinking, though characterised by an accentuated inflexibility: they stick rigidly to routines, repetitive interests, and arguments; they need everything to be perfect etc. Though in both classic autism and in AS there is a strain and rejection towards changes, Aspies get bored pretty easily with the same tasks in the same field – unless in their area of interest – and ritualised actions are more commonly a form of OCD (Obsessive-Compulsive Disorder) rather than repetitiveness of ASD.

Usually, Asperger syndrome coincides with level 1 gravity (from the table n. 2 – Severity Levels of Autism Spectrum Disorder, DSM-V, APA, 60, 2013) and falls within the high functioning end of the spectrum, even though a neat distinction between the two terms is claimed.

A group of researchers at Yale University (Klin *et al.*, 1129, 1995) found out two different neuropsychological profiles, when analysing children with Asperger's and High Functioning Autism

(HFA). In clinical practice, though, these two terms are used interchangeably, but there will be a more detailed analysis in the next paragraph; clinicians must be aware and pay attention to the description in the diagnosis since Autism and Asperger syndrome have different scholastic support and services (allowances) depending on the country.

Subjects with classic autism tend to have a lower IQ, while in mild autism, they are typically in the normal to very superior range (above 85). Low functioning autism is characterised by a delay in language, but it might not be the case for Aspies, who may show less episodes of echolalia (a word from Greek meaning “to repeat speech/talk”. It is a subset of imitative behaviour, thus sounds and vocalisations made by another person are imitated automatically without explicit awareness; instead, we talk about *palilalia* when they are repeated by the same person, often in cases of Tourette syndrome. The more the frontal lobe matures, the less there are phenomena of echolalia and contagion.), but more episodes of monotone, robotic, or infantile voice, with frequent use of sentences and quotes from books and movies. Repetitive and stereotyped movements alongside sensory special interests are more common in low functioning autism, while people with mild forms may have passions about some scholastic subjects and specific interests in many fields (for women usually art, nature, animals, fiction etc.). Another main difference between Kanner’s autism and Asperger’s could be found even with comorbidities, with SLD, epilepsy, or mental retardation for people with classic autism, whilst conditions of anxiety disorder, ADHD, depression, or bipolar disorder for AS subjects (Soldateschi *et al.*, 2016, 47 in Vespe, 2021).

Nevertheless, there is an essential question concerning Aspies: how do they feel? There are some characteristics spread among autistics, which have been listed by teen Siena in her website “Quantum Leap - Peer Mentoring for Bright Kids with ASD and Learning Differences” and brought hereafter:

- Feeling different: the sensation of not fitting in the society, of not being understood by people, almost feeling like an alien;
- Social/Communication/Processing Difficulties: the feeling of being different is linked to the fact that Aspies do not understand social and communication norms, so their performance is often awkward, not being able to naturally hold eye contact, understand sarcasm etc. Plus, nonverbal communication is pretty tricky and easily misinterpreted (Aspies do not know how to decode facial expressions, body language and prosody, as it comes easily to NTs);
- Sensory Issues: triggers vary from person to person, some are more sensitive to sounds, others to lights or smells, tastes, textures, or temperatures. Aspies experience extreme sensitivity or

- insensitivity to these factors, and a sensory overload can lead to a shutdown, a meltdown or even a burnout; during these moments it is very demanding to process things;
- Motor Co-ordination Difficulties: coordination can be altered, resulting in being clumsy, with balance and stance issues, finding difficult to learn new complex movements, with driving being one of the most costing activities for the executive functions system;
 - Limited Facial Expression: Aspies are often accused not to be much expressive with facial features and tone of voice, letting think that they are emotionless, without empathy and just robots, even though it is not absolutely the case;
 - Speech and Language Difficulties: Aspies tend to speak in a flat, monotone manner, alternating whispering and almost screaming, not being adaptive to the situation (e.g. changing suddenly voice volume); furthermore, although AS is characterised by advanced language skills, Aspies have trouble with semantics (metaphors, figures of speech, idioms) and pragmatics, tending to interpret words literally;
 - Little Professor Syndrome: usually pointed out as know-it-all, even children correct others' speech, and speak in a way which is "overly precise, highly formal and too advanced for most of their peers to understand";²⁰
 - Organisational Issues: organising, initiating, analysing, prioritising, and completing tasks are some of the executive functions some Aspies may find themselves not so good at, or pretty good (looking at the result) but at a very high cost of energies;
 - Special Interests: Aspies are obsessive about their interests, which are intense (there could be many moments of hyperfocus) and narrow, and because of them people can find Aspies nerds, geeks etc.;
 - Vulnerability to Stress and Anxiety: many people with Asperger's are stressed and have severe anxiety, which can lead to psychological issues, including low self-esteem and depression;
 - Poor Cognitive Flexibility: reconnecting to the previous point, stress and anxiety may increase when (external) unexpected changes to routine take place, whereas familiar objects, settings, and routines offer reassurance and predictability.

²⁰ Siena Castellon's website: <https://www.qlmentoring.com/qlmentoring-about-aspergers>

1.4 HFA or AS?

As anticipated hitherto, debate has existed between researchers grouping AS and HFA (high-functioning autism) under a single label.

No papers published before 1981 referred explicitly to HFA; indeed, the first to use the term “high functioning autism” were DeMyer, Hingtgen, and Jackson (Gillberg & Ehlers, 1998). The term has been used to describe children with classic autism features who, growing up, possessed more intellectual skills, with better social, cognitive, and communicative competence than their peers with classic autism (DeMyer *et al.*, 1981). In the paper by Bibeau & Fossard (2010), the distinction between the two categories is explained. High-functioning autism is a recently new tag appeared after Asperger syndrome was still a diagnosis according to the DSM-IV. In fact, a normal IQ (thus the absence of mental retardation) is a common point of both, but some children could not be diagnosed AS because they showed a delay in language development and therefore not meeting the criterion D (APA, 2000), thus the scientific community named this new disorder HFA, differentiating from AS for the limits to communication maturity.

There are some studies about the difference of AS and HFA evaluated by linguistic and cognitive tasks, which have been analysed in the review “L’*autisme de haut-niveau ou le Syndrome d’Asperger: la question du langage*”.²¹ The authors have consulted over a hundred previous studies (published between 1991 and 2008, all in English) and selected 13, based on the criteria of comparison between Asperger’s and High-functioning autism and the presence or lack of a language delay in development. Of the 13 studies, only three reported significant language differences between the two groups, with a linguistic superiority in participants with AS. The others found subtle linguistic alterations between the two groups, not directly linked to a language delay. According to one of these studies, previous literature suggests that the differences in language shown by HFA and AS children tend to diminish over time (Howlin, 2003). Finally, several studies found no significant differences in language between participants in both groups, and this does not support the validity of the criterion to diagnose differently the disorders. The results, then, reflected the necessity to question the legitimacy and correctness of criterion D of DSM-IV (APA, 2000). After all, the revision of DSM-IV and the choice to group many syndromes under the “umbrella” of Autism Spectrum Disorder, might have been a

²¹ Bibeau, A., Fossard, M. (2010). *L’*autisme de haut-niveau ou le Syndrome d’Asperger : la question du langage**. *Revue canadienne d’orthophonie et d’audiologie (RCOA)* 34, n. 4, pp. 246-258

truthful adoption. Further reviews (Tsai, 2013) highlighted the lack of neat differences between the two categories, with the definition of high functioning autism being confusing and not diagnostically clear. In fact, as it was defined in the DSM-IV and ICD-10, AS is a form of HFA without language delay, but the boundaries are blurred.

In a recent study (De Giambattista *et al.*, 2018) discussed in Attwood's manual "The complete guide to Asperger's Syndrome", 80 Asperger and 70 high functioning autistics, previously diagnosed based on the DSM-IV-TR, had been compared on clinical and neurocognitive measures. The totality of AS fell in the Level 1 (mild) of severity, with the 56% of HFA, and the remaining 44% being diagnosed with a Level 2. In both groups clumsiness and trouble in calligraphy were frequent, with major problems in reading, mathematics, and writing for HFA, while Aspies disclosed more dull speech and a particular recovery of long-term memory, with a prevalence of comorbidities, principally anxiety disorders and depression (ADHD being common in both groups).

It is even harder to label children and people on the mild end of the spectrum because they could put in place schemes and therefore hide many aspects of their persona. Every child implements some compensation strategies, in order to fit in, and the tactic depends on the personality, on the experience and personal situation. There are those who internalise thoughts and sensations and have developed a sense of guilt and depression or who imagine and create a world where they feel accepted. There are some, instead, who externalise and may therefore seem arrogant, blame others for their own difficulties, or imitate peers.

Social skills and building strong friendships are abilities which are usually praised by peers and adults, and Aspies who are not good in these areas may internalise a lot, be too self-critical and excuse very often, developing clinical depression at the age at seven as well because of the "alien feeling" (they have the awareness of not fitting in, but they do not know how to change it).²² In cases of reactive depression, appetite and sleep may be altered, alongside a negative attitude towards every aspect of life, even thinking and attempting suicide. Another strategy may involve the creation of an alternative dimension, with imaginary friends who accept and love unconditionally the Aspie. In times of high stress or loneliness, imagination is a shelter, a safe place which may equate to reality for the person involved, leading to schizophrenia evaluations in more severe cases (Adamo, 2004).²³ Both aforementioned strategies were about internalisations, but when the child externalise negative

²² Attwood, T. (2015). *The complete guide to Asperger's Syndrome*. Published by Jessica Kingsley Publishers

²³ *Ibid.*

emotions, he may hyper compensate his “inadequate” feeling, denying the problem and developing a sense of arrogance, omnipotence, where he is above rules and blame is always on others. Last compensational mechanism is that of camouflaging; it is mostly put in place (consciously and unconsciously) by girls and women, and it is an adaptive strategy: the Aspie carefully observe the behaviour and characteristics of someone who is socially successful and imitate him/her. However, this final strategy will be analysed in much more detail in the next chapter.

Chapter 2 – Identifying Autism in Women

The diagnostic rate states that for every four males diagnosed with ASD, only one female is diagnosed (Fombonne, 2009). Small biases started from the study on small samples, like in those of Dr. Kanner (8 boys vs. 3 girls) and Dr. Asperger (4 boys vs. no girls). With a recent meta-analysis, the ratio is believed to be closer to three males to every female (Loomes *et al.*, 2017).

Though, there is a discrepancy between this ratio and the actual rate of ASD in gender and minorities as well. As autistic advocate Kate Kahle stated in her Ted Talk “Why autism is often missed in women and girls”: “The tests used to diagnose autism are still based on studies done on white autistic boys, which likely leads to lower and misdiagnosis in women. White children are 19% more likely than Black children and 65% more likely than Hispanic children to receive an autism diagnosis.”²⁴ Even the diagnosis takes place earlier for males who display similar mild symptoms to their feminine peers, with an average of two years earlier (Loomes *et al.* 2017). This is due to the nature of special interests – in females they are normally more socially accepted – but also to the skill called “masking”, which will be dealt further on. Camouflaging is the main cause of late and misdiagnoses, and, whether the person is really good at masking, there may never be a diagnosis at all.

The earlier the patient get a diagnosis, the earlier the access to treatments and specialised supports, which are of great help in everyday life. In many cases, however, specific services and clinicians do not have experience with females on the spectrum and often they do not know how to intervene and behave, especially in the public health services. “Missed diagnosis frequently creates further depression and despair for women who are seeking acknowledgment and validation of their social difficulties only to be told, that they cannot be autistic because they make good eye contact or communicate with gestures. This phenomenon appears to be a universal experience across the globe.”²⁵ Women who cannot afford or access a formal assessment, are left with the only option of self-diagnosis (may it be also a choice, not wanting a formal evaluation). That is why self-diagnosis must be respected and accepted exactly as an official one, at least by families and friends, who should

²⁴ Aylward, B. S., Gal-Szabo, D. E. , Taraman, S. MD. (2021). *Racial, Ethnic, and Sociodemographic Disparities in Diagnosis of Children with Autism Spectrum Disorder*. Journal of Developmental & Behavioral Pediatrics 42(8):p 682-689, October/November 2021. doi: 10.1097/DBP.0000000000000996

²⁵ Zener, D. (2018). *Journey to diagnosis for women with autism*. Advances in Autism, Vol. 5 n. 1, 2019, 2 – 13. Emerald Publishing Limited, ISSN 2056-3868. doi: 10.1108/aia.010.2018.0041

not discourage the person and discredit their statement. Yet even women on the spectrum who were not diagnosed until adulthood, would not define themselves completely autistic if they based on the criteria of males' behaviours (gender bias) and this is because autism display differently in women. As writes Annie Kotowicz in her book "What I mean when I say I'm Autistic. Unpuzzling a life on the Autism spectrum" (2022), learning how to camouflage makes you seem typical from the outside, but it does come at an energetic and emotional cost, not naturally (for instance, when suppressing stimming). Most of the times, girls are so able at masking that when they tell others about being on the spectrum, it emerges a sense of disbelief.

"What society expects of a grown woman is different than what they expect from a little boy, which is reasonable. But society also expects more of a little girl than a little boy. From a young age, girls are expected to have higher emotional intelligence and care more about their peers' emotions than boys. This is reinforced in almost every aspect of their life, from TV shows and toys to the words and actions of family and teachers. Women are better at masking because society expects more from us, and it doesn't make as many allowances for us."²⁶

As Siena Castellon notes down:

"In their eyes I don't exhibit the behaviours commonly associated with autism. I appear to make eye contact (I actually look at people's foreheads). I don't have meltdowns or hit myself or others, and I don't drone on and on about esoteric interests. [...] However, as you and I know, appearances can be deceiving. Despite outward appearances, inside we're very different. I've always known I was different - like an alien from a different planet."²⁷

To help other bright children with learning differences out, she created her website to mentor and support them. There, she debunks ten myths about girls with Asperger's, which are briefly summarised below:

- Asperger syndrome is not easy to diagnose in girls, in fact the data report that 1 in 42 boys and 1 in 189 girls is diagnosed with Autism (AutismSpeaks.org);
- Even though there is a higher number of boys diagnosed, this does not imply that Asperger's is less prevalent in girls;

²⁶ Kate Kahle speech available at the following website

https://www.ted.com/talks/kate_kahle_why_autism_is Often_missed_in_women_and_girls/comments/transcript

²⁷ Castellon, S. (2020). *The spectrum girl's survival guide. How to grow up awesome and autistic*. Published by Jessica Kingsley Publishers

- It is not true that Aspies lack empathy. Girls with AS usually have a great deal of empathy for people, animals, and nature, but probably it is not perceived fully because it is portrayed differently;
- Aspies (not just girls) find it hard to understand sarcasm because they take things literally. This does not mean that they do not have a sense of humour;
- Not making eye contact translated into being rude. Children on the spectrum are not capable of making proper eye contact, but avoiding the eyes of the interlocutor is socially unacceptable and seen as disrespectful, as they are not engaging in the conversation (even though it might not be the case);
- Just because Asperger's may be perceived as an invisible disorder, not showing physical and psychological difficulties and hiding them to fit in is extremely exhausting and most people are unaware of the challenges that autistics (even mild) have to face every day;
- It is not true that experts understand or even know AS in girls. There is still a lot to learn about autism, and, as already explained, no two people (even on the spectrum) are alike;
- Since there is no single cause to ASC, there does not exist an effective diagnosis tool for Aspergirls (a term coined by author Rudy Simone for her homonymous book published in 2010). The diagnostics tools available (such as surveys) are principally based on male traits (even though the work of prominent figures like Dr. Attwood, who developed a Screening Test for parents to support identification of girls with autism (2013), Marshall, who has developed a list of characteristics commonly found in Aspergirls, Hénault and others are gradually changing the situation);
- Having an Aspergirl as friend might turn out a pleasant experience, even if there is the misconception that girls with AS do not make good friends. On the contrary, they are extremely loyal, kind, honest, intelligent, and creative; but they must be accepted, respected and loved with their own quirks and peculiarities, like everybody else;
- People with AS are not like a movie or TV character with autism. What it is usually portrayed on the screen is stereotyped and does not correspond to reality. Even though awareness is arising (characters claimed by the autistic communities to be AS are: Nadine in the movie "The Edge of Seventeen", Lisbeth Salander in "The Girl With the Dragon Tattoo", Abby Sciuto in the TV series "NCIS", Dr. Temperance "Bones" Brennan in "Bones", Dr. Amy Farrah-Fowler in "The Big Bang Theory" etc.), most of the representation on screens is male and stereotypical (just think about the movie "Rainman" and how it is the first example that comes in mind when people think about autism).

In the appendix of this dissertation, Pictures 2 to 8 display some other characteristics of Aspies, illustrated by Mademoiselle Caroline in the Italian edition of Dachez, J. (2016) “La différence invisible”, while in Simone’s appendix there is also a table with a list of traits common to females with Asperger syndrome, which is reported here:²⁸

| Appearance/personal habits | Intellectual/giftedness/education/vocation | Emotional/physical | Social/relationships |
|-----------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------|------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------|------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------|--------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------|
| <p>Dresses comfortably due to sensory issues and practicality.</p> <p>Will not spend much time on grooming and hair. Hairstyles usually have to be “wash and wear.” Can be quite happy not grooming at all at times.</p> <p>Eccentric personality; may be reflected in appearance.</p> <p>Is youthful for her age, in looks, dress, behavior and tastes.</p> <p>Usually a little more expressive in face and gesture than male counterparts.</p> <p>May have many androgynous traits despite an outwardly feminine appearance.</p> <p>Thinks of herself as half-male/half-female (wellbalanced anima/animus).</p> <p>May not have a strong sense of identity, and can be very chameleon-like, especially before diagnosis.</p> <p>Enjoys reading and films as a retreat, often sci-fi, fantasy, children’s, can have favorites which are a refuge.</p> <p>Uses control as a stress management technique: rules, discipline, rigid in certain habits, which will contradict her seeming unconventionality.</p> <p>Usually happiest at home or in other controlled environment.</p> | <p>May have been diagnosed as autistic or Asperger’s when young, or may have been thought of as gifted, shy, sensitive, etc. May also have had obvious or severe learning deficits.</p> <p>Often musical, artistic.</p> <p>May have a strong interest in computers, games, science, graphic design, inventing, things of a technological and visual nature. More verbal thinkers may gravitate to writing, languages, cultural studies, psychology.</p> <p>May be a self-taught reader, have been hyperlexic as a child, and will possess a wide variety of other self-taught skills as well.</p> <p>May be highly educated but will have had to struggle with social aspects of college. May have one or many partial degrees.</p> <p>Can be very passionate about a course of study or job, and then change direction or go completely cold on it very quickly.</p> <p>Will often have trouble holding onto a job and may find employment daunting.</p> <p>Highly intelligent, yet sometimes can be slow to comprehend due to sensory and cognitive processing issues. Will not do well with verbal instruction—needs to write down or draw diagram.</p> <p>Will have obsessions but they are not as unusual as her male counterpart’s (less likely to be a “trainspotter”).</p> | <p>Emotionally immature and emotionally sensitive. Anxiety and fear are predominant emotions.</p> <p>More open to talking about feelings and emotional issues than males with AS.</p> <p>Strong sensory issues—sounds, sights, smells, touch, and prone to overload. (Less likely to have taste/food texture issues as males.)</p> <p>Moody and prone to bouts of depression. May have been diagnosed as bipolar or manic depressive (common comorbidities of autism/AS) while the AS diagnosis was missed.</p> <p>Probably given several different prescriptions to treat symptoms. Will be very sensitive to medications and anything else she puts in her body so may have had adverse reactions.</p> <p>Will have mild to severe gastrointestinal difficulties—e.g. ulcers, acid reflux, IBS, etc.</p> <p>Stims to soothe when sad or agitated: rocking, face-rubbing, humming, finger flicking, leg bouncing, finger or foot-tapping, etc.</p> <p>Similarly physical when happy: hand flapping, clapping, singing, jumping, running around, dancing, bouncing.</p> <p>Proned to temper or crying meltdowns, even in public, sometimes over seemingly small things due to sensory or emotional overload.</p> <p>Hates injustice and hates to be misunderstood; this can incite anger and rage.</p> <p>Proned to mutism when stressed or upset, esp. after a meltdown. Less likely to stutter than male counterparts but may have raspy voice, monotone at times, when stressed or sad.</p> | <p>Words and actions are often misunderstood by others.</p> <p>Perceived to be cold-natured and self-centered; unfriendly.</p> <p>Is very outspoken at times, may get very fired up when talking about passions/obsessive interests.</p> <p>Can be very shy or mute.</p> <p>Like her male counterpart, will shut down in social situations once overloaded, but is generally better at socializing in small doses.</p> <p>May even give the appearance of skilled, but it is a “performance.”</p> <p>Doesn’t go out much. Will prefer to go out with partner only or children if she has them.</p> <p>Will not have many girlfriends and will not do “girly” things like shopping with them or have gettogethers to “hang out.”</p> <p>Will have a close friend or friends in school, but not once adulthood is reached.</p> <p>May or may not want to have a relationship. If she is in a relationship, she probably takes it very seriously but she may choose to remain celibate or alone.</p> <p>Due to sensory issues, will either really enjoy sex or strongly dislike it.</p> <p>If she likes a male, she can be extremely, noticeably awkward in her attempts to let him know, e.g. she may stare when she sees him or call him repeatedly.</p> <p>This is because she fixates and doesn’t understand societal gender roles.</p> <p>This will change with maturity.</p> <p>Often prefers the company of animals but not always, due to sensory issues.</p> |
| <p>Will usually be very proud and protective of the gifts that Asperger’s/autism has bestowed, but would like to be more at ease in the world and suffer less.</p> | | | |

Table 2: “Simone, R. (2010) *Aspergirls. Empowering Females with Asperger Syndrome*. Published by Jessica Kingsley Publishers”

Autistic women considered themselves shy as young children (usually because being quiet does not cause any trouble, so it does not alert professionals), and this characteristic is also found in the literature (Giarelli *et al.*, 2010; Riley-Hall, 2012). Being passive and compliant at school can be misinterpreted as being good, the model pupil, sometimes turning out as the teacher’s pet. At home, then meltdowns can occur, showing a neat contrast between the behaviour in the two different (familiar and scholastic) environments. The distinction between shyness and autism is described in the ICD-11, under the voice “Boundary with Normality (Threshold) - Social interaction skills”, and

²⁸ Simone, R. (2010) *Aspergirls. Empowering Females with Asperger Syndrome*. Published by Jessica Kingsley Publishers

it states that “limited social interactions in shy or behaviourally inhibited children, adolescents, or adults are not indicative of Autism Spectrum Disorder. Shyness is differentiated from Autism Spectrum Disorder by evidence of adequate social communication behaviours in familiar situations.”²⁹ For some people the condition may be visible when growing up and not from birth and it may depend on the context. Sometimes the good behaviour may change during secondary school, with autistic girls seeming rude (even if there is no intention of being so) or lazy towards the professor. The typical characteristics of Aspies (this does not apply to level 2 and 3 of autism) may show in adulthood because the difficulties the person faces become more complex from a certain age (when we are children we might have a supporting team, made of family, teachers, who may compensate for our deficiencies). This does not mean that before there were no troubles, but they did not show or went unnoticed, also because of masking techniques. According to Aspie Rudy Simone, “these women start out as little psychologists and by adulthood can be masters at analysing social behaviour and emulating it. It must be noted that is usually not intuitive; it involves conscious awareness and effort 100 per cent of the time while in any social environment, which is draining.”³⁰

Finally, there can be a tendency to ignore family and self-reporting, and for clinicians to prioritise what they can see. But appearances, especially in Aspergirls, may be deceiving. Speaking of self-diagnosis, it is extremely uncommon to find a girl who is incorrect about herself; let us just consider that before approaching professionals for a diagnosis, self-diagnosed people have done their research and come to their conclusions sturdily. It may be argued that tests available online for self-diagnosis are not significant. Their reliability depends on the individual’s self-awareness (which is biased if the test is not administered by a clinician), and the lack or presence of comorbid conditions. So, if a self-administered test is above – or even below – the threshold, it might turn out as significant, so it is always desirable to consult a professional.

²⁹Autism spectrum disorder in ICD-11 <https://icd.who.int/browse11/l-m/en#/http%3A%2F%2Fid.who.int%2Ficd%2Fentity%2F437815624>

³⁰ Simone, R. (2010) *Aspergirls. Empowering Females with Asperger Syndrome*. Published by Jessica Kingsley Publishers

2.1 Clinical tools for AS diagnosis in Italy

In Italy the rate of autism is 1:77 (data collected from Istituto Superiore di Sanità, 2019), and the current diagnostic tools used are the aforementioned DSM and the ICD.

With the latest version of DMS-V, Asperger syndrome is no longer a diagnosis of its own, but is grouped among other syndromes under the Autism Spectrum Disorders. Another novelty about the new diagnostic manual may be found also on the shift from 3 to 2 diagnostic dimensions (in fact, social and communication were not unified under a single voice), alongside the chart of the Severity Levels of Autism Spectrum Disorder. However, the concept of gravity was already present in the previous edition. There had been new important introductions on the sensorial aspect (hyper and hypo reactivity to sensory input), qualitative variables with onset age, and specifications.

The current edition highlights how any disorder can be present in a mild form, leading, in the case of the autistic spectrum, to a risk of over-diagnosis because of the inclusion of even mild forms within the same diagnostic category (Vespe, 2021).

2.1.1 History and difference between DSM and ICD

The ICD is the official world classification, which records statistically the diagnoses of all psychiatric patients across the globe. By contrast, the DSM is the official classification in the U.S.A. for clinical diagnosis, but during the years it has gained influence worldwide.

In the U.S., the first attempt to develop a classification of mental disorders, for statistical purposes, is inserted in the 1840 census. By the 1880 some categories were distinguished (among them, mania, dementia, and epilepsy). In 1917, the American Medico-Psychological Association (which changed its name to the APA, American Psychological Association, in 1921), developed a system to gather health statistics across the nation. Instead, the first to try to classify diseases in Europe, were the French Guillard & Bertillon in 1853. They managed to call a conference in 1900, the first International Conference to revise the International List of Causes of Death, which held in Paris and became the known ICD. During WWII, a broader classification system was developed by the U.S. Army, while, during the same period, the WHO (World Health Organization) published the ICD-6 (including for the first time a section for mental disorders). The ICD has existed for more than a century (1900) and became a core function of the World Health Organization (WHO, and agency of the United Nations) in 1948, classifying most disorders in medicine. The DSM and ICD have shared collaborative agreements in their last editions, becoming more similar. In 1952 the first edition of DSM (a variant

of the ICD-6) was published. It was the first official manual of mental and behavioural disorders for clinical use. As research went on, revisions and new editions took place. The development of DSM-II and DSM-III (printed in 1980) went hand in hand with the development of the ICD. ICD-9 did not include diagnostic criteria because its main function was to outline categories for the collection of basic health statistics. In contrast, DSM-III and the following DSM-III-R (1987) was developed with the additional goal of providing precise definitions of mental disorders for clinicians and researchers. ICD-10 was published in 1992, whilst DSM-IV in 1994. The last version of DSM-V's work began in 2000, with the revision of the manual starting in 2007 and concluded in 2013, with its publication. The revised version of the DSM-V, called DSM-V-TR was published in March 2022, and it is, up to date, the latest DSM available.³¹ The ICD-11 is the latest version came into effect in January 2022.

A list of the differences between these two most used diagnostic tools was written in an article by APA, which is partially presented henceforth:

- “The ICD is produced by a global health agency with a constitutional public health mission, while the DSM is produced by a single national professional association.
- WHO's primary focus for the mental and behavioral disorders classification is to help countries to reduce the disease burden of mental disorders. ICD's development is global, multidisciplinary and multilingual; the primary constituency of the DSM is U.S. psychiatrists.
- The ICD is approved by the World Health Assembly, composed of the health ministers of all 193 WHO member countries; the DSM is approved by the assembly of the American Psychiatric Association, a group much like APA's Council of Representatives.
- The ICD is distributed as broadly as possible at a very low cost, with substantial discounts to low-income countries, and available free on the Internet; the DSM generates a very substantial portion of the American Psychiatric Association's revenue, not only from sales of the book itself, but also from related products and copyright permissions for books and scientific articles.”³²

³¹ For further information, visit the website

<https://www.psychiatry.org/psychiatrists/practice/dsm/about-dsm/history-of-the-dsm>

³² American Psychological Association. (2009, October 1). ICD vs. DSM. *Monitor on Psychology*, 40(9). <https://www.apa.org/monitor/2009/10/icd-dsm>

As for the codes for diagnosis, clinicians use the code 299.00 (DSM-V) or F84.0 (ICD-10) to indicate ASD. The other codes for PDD, Pervasive Developmental Disorders, listed in the ICD-10 are the ensuing:

- F84.0 Infantile autism
- F84.1 Atypical autism (PDD-NOS)
- F84.2 Rett syndrome
- F84.3 Childhood Disintegrative Disorder (aka Heller syndrome)
- F84.5 Asperger syndrome

With the latest edition of ICD-11, however, these codes have changed and there are six subtypes of autism spectrum disorder. These are divided into whether somebody has or does not have intellectual impairment, mild impairment of language, impaired functional language, or no language at all (either signed or verbal); see table 6.5.³³

Table 6.5 Diagnostic Codes for Autism Spectrum Disorder

| | with mild or no impairment of functional language | with impaired functional language | with complete, or almost complete, absence of functional language |
|----------------------------------------------|----------------------------------------------------------|------------------------------------------|--------------------------------------------------------------------------|
| without Disorder of Intellectual Development | 6A02.0 | 6A02.2 | — |
| with Disorder of Intellectual Development | 6A02.1 | 6A02.3 | 6A02.5 |

In ICD-11, the type of play that a child partakes in during childhood is not emphasised since it could vary depending on culture and country, as for eye contact (which may be avoided in some cultures, as a sign of respect). Instead, it focuses more on whether children impose strict rules when they play (Talk Mental Health by Dr Beth Colby).³⁴ The ICD-11 includes the same two categories of DSM-5: difficulty in interaction and social communication on the one hand, and limited interests and repetitive behavior on the other, thus eliminating the third feature about language problems, which could be

³³ Autism spectrum disorder in ICD-11 <https://icd.who.int/browse11/l-m/en#/http%3A%2F%2Fid.who.int%2Ficd%2Fentity%2F437815624>

³⁴ Autism Spectrum Disorder Diagnostic Criteria ICD-10 v ICD-11 v DSM-5 <https://youtu.be/uqppAvkylPI>

found in the previous edition of the ICD. ICD-11 classification provides detailed guidelines (with the possibility of regression in the clinical picture), and distinct codes, to distinguish between autism with and without an intellectual disability, whilst the DSM-V only states that autism and intellectual disability can occur simultaneously.

It is at the discretion of the clinicians to choose which one to use when it comes to diagnosis, and at the moment there are four available, two created by organisations (DSM and ICD) and two by psychologists, Peter Szatmari (Canada) and Christopher and Corina Gillberg (Sweden), respectively. “A good classification provides information about the causes of disorder, possible prevention, clinical characteristics, natural history (i.e. the course of the disorder without intervention), and a guide to treatment and outcome.”³⁵ Unlike DSM-V, which states that in order to meet the diagnostic threshold of autism all three symptoms from criteria A, two from criteria B, and the conditions of both C and D must be determined, ICD-11 does not stipulate that a person must have a specific number of characteristics to get diagnosed. Its flexibility allows professionals to make the cut-off based on clinical judgment and common sense.

Let us not forget that ASD cannot be diagnosed with tests or neuroanatomical and imaging studies, nor DNA tests, and the threshold for its diagnosis is up to the psychiatrists’ decisions, who decide the boundary between normalcy and disorder. Many clinicians do argue that DSM is more accurate, due to operational criteria and the higher funding (greater resource and effort) behind its making, compared to ICD. “DSM is mainly used by psychiatrists, although it is recognising that this is not entirely satisfactory and is promoting its use among psychologists and other mental health practitioners. ICD, on the other hand, has always had in mind the universal mental health practitioner”, as states professor Tyrer in his article “A comparison of DSM and ICD classifications of mental disorder.”³⁶

In the following table, taken from the presentation of Dr. Whitwell at a conference about ASD in 2021, the main features of each diagnostic manual are summarised.³⁷

³⁵ Tyrer, P. (2014). *A comparison of DSM and ICD classifications of mental disorder*. *Advances in psychiatric treatment*, vol. 20, 280–285 doi: 10.1192/apt.bp.113.011296

³⁶ *Ibidem*

³⁷ For further information, see

<https://www.google.com/url?sa=i&rct=j&q=&esrc=s&source=web&cd=&ved=0CAMQw7AJahcKEwjY6MzF6sn->

| ICD-10 | DSM-IV | DSM-5 | ICD-11 |
|--------------------------------------------------------------------------------------------------------------------------------|-------------------------------------------------------------------------------------------|------------------------------------------------------|------------------------------------------------------|
| Pervasive Developmental Disorders: Childhood autism Asperger syndrome Atypical autism PDD-other PDD-unspecified | Pervasive Developmental Disorders: Autistic disorder Asperger’s disorder PDD NOS | Autism spectrum disorder | Autism spectrum disorder |
| 3 symptom domains | 3 symptom domains | 2 symptom domains Including sensory sensitivities | 2 symptom domains Including sensory sensitivities |
| Onset by age 3 | Onset by age 3 | Removes age of onset | Removes age of onset |
| Atypical autism | PDD NOS | Social (pragmatic) communication disorder | Developmental language disorder |
| Comorbidity exclusions | Comorbidity exclusions | Allows co-occurring diagnoses | Allows co-occurring diagnoses |

Table 3: “slide n. 11 in What is autism and how do we make a diagnosis in the new era of DSM 5 and ICD 11, by Dr. Susannah Whitwell, Adult ADHD and ASD Service South London and Maudsley NHS Foundation Trust”

[AhUAAAAAHQAAAAAQAg&url=https%3A%2F%2Fwww.rcpsych.ac.uk%2Fdocs%2Fdefault-source%2Fevents%2F2021%2Fopen-events%2Fasd%2Fwhitwell-susie-powerpoint-slides-asd-conference-5-february-2021.pdf%3Fsfvrsn%3Ddf57271e_2&psig=AOvVaw31w9J6CziwbCfGBQYS-Dhd&ust=1682677015112244](https://www.rcpsych.ac.uk/docs/default-source/events/2021/open-events/asd/whitwell-susie-powerpoint-slides-asd-conference-5-february-2021.pdf?sfvrsn=3Ddf57271e_2&psig=AOvVaw31w9J6CziwbCfGBQYS-Dhd&ust=1682677015112244)

2.1.2 The diagnostic process

As Tony Attwood, one of the most prominent figures in the autistic field, summarises, there are several ways leading to a diagnosis of autism:³⁸

- Receiving a diagnosis of autism in childhood, then changing it in HFA or AS with growing (with the right therapy, a shift on the spectrum can happen);
- In elementary school teachers may recognise the traits typical of ASD and suggest a clinical assessment;
- Previous enquiries on other developmental disorders, linguistic and motor co-ordination disorders or delays, eating or mood disorders etc.;
- AS traits may become more evident during adolescence, when social and scholastic expectations get more complex to handle;
- Behavioural issues and conflicts with parents, teachers and authorities;
- When a relative (usually children for middle-aged women) gets a similar diagnosis or when some traits and characteristics are found in some members of our family, or in our partner;
- Exposure to autism in popular culture may lead to a self-analysis and research on the topic, which may become a special interest;
- Problems and conflicts in the workplace or finding an adequate job position.

The diagnostic process may start when a teacher observes that the child does not show evident characteristics associated with autism but is very peculiar in comprehending social situations, being considered immature handling emotions, and expressing sympathy for others. Learning style could be unusual, with vast knowledge in a particular area of personal interest, but at the same time there could be significant problems of learning and attention in other scholastic competencies. The teacher could mark motor coordination issues, for instance in handwriting, running, and catching a ball, and notice extreme sensory sensitivity. Another hint that a teacher could get is the raising anxiety showed by the child when routines are modified, or whether he cannot solve a problem. It is just clear that a child does not show intellectual disabilities, though it seems to have difficulties in the social interactions with peers. It is often a teacher who can detect qualitative differences in abilities and behaviours, since at home their profile does not seem unusual or evident, especially when the child has no siblings to interact with. (Attwood, 1998).

³⁸ Attwood, T. (2015). *The complete guide to Asperger's Syndrome*. Published by Jessica Kingsley Publishers

When social expectations begin to outweigh the person's ability to perform for neurotypical behaviours, that is usually when a process of diagnosis starts. The diagnostic process may also begin after a self-diagnosis, which usually follows many self-administered tests, also available online. Let us not forget that there are many scales and questionnaires out there, but they are not suitable for everyone. Some are specific for adults, others for children, some are designed for autistics with mild or no intellectual impairments, some are intended to be administered by a professional and therefore would not give meaningful results when self-assessed etc. An interesting website where many tests can be found is Neuroscapes (<https://www.neuroscapes.org/>). A renowned private Italian association for AS diagnosis based in Rome (CuoreMenteLab) relies on this website to examine the results got in each test and which are essential for the diagnosis. The registration and the compilation of tests is free, and it gives an insight on the possible autistic traits.

Another website where many of these tests can be taken is <https://psychology-tools.com>. There are many questionnaires (both self-report and administered by a professional) and some of the most notorious are listed below:

- The ASSQ (Autism Spectrum Screening Questionnaire) is a screening questionnaire for autism designed by Ehlers and Gillberg (in collaboration with Dr. Lorna Wing), developed to assess the prevalence of Asperger Syndrome and high-functioning ASD;
- The ASDAQ (Autism Spectrum Disorder in Adults Screening Questionnaire), a modified version of the former, but for adults;
- The ASBQ (Adults Social Behaviour Questionnaire) by Horwitz and colleagues (one of the most recent, 2016);
- The RAADS–R (Ritvo Autism Asperger Diagnostic Scale–Revised) and its shorter version RAADS – 14 are self-report questionnaires designed to identify adults who avoided the “ASD radar”;
- The AQ (Autism-Spectrum Quotient Test) is designed to measure the expression of Autism-Spectrum traits in an individual, as self-assessment. It was first published in 2001 by Simon Baron-Cohen and colleagues, alongside the EQ (Empathy Quotient) questionnaire (there are two versions, with 60 and 40 items, respectively) designed to measure empathy in adults. This latter is used to assess the level of social impairment by clinicians;
- The ADI-r (Autism Diagnostic Interview) is a standardised, semi-structured interview, undertaken with an informant who assess the presence/absence of behaviours associated with ASD, and the degree of impairment. The focus is on two different time frames: childhood (four/five years of age) and current behaviour;

- The ADOS (Autism Diagnostic Observation Schedule) is a semi-structured assessment, which provides opportunities to elicit spontaneous behaviours in standardised contexts. There are four modules, depending on language ability;
- The Q-ASC (Questionnaire for Autism Spectrum Conditions) was developed by Attwood, Garnett, and Rynkiewicz (2011) to identify behaviours and abilities consistent with the female presentation of autism, assessing parent/caregiver perceptions.

Some other tests, such as WAIS (Wechsler Adult Intelligence Scale), CELF (Clinical Evaluation of Language Fundamentals) and PPVT (Peabody Picture Vocabulary Test) are used for clinical assessment of language or intelligence impairments. It is crucial to administer these kinds of tests to identify the right diagnostic category.

Other questionnaires to identify specific characteristics in both children and adults, and which are listed, as follows, in Attwood (2015) are:

- “The EQ (Emotional Intelligence) assesses the empathy quotient (Baron-Cohen & Wheelwright, 2004);
- The SQ (Systemizing Quotient) is used to assess systemising cognitive styles (Baron-Cohen *et al.* 2003);
- The SPQ (Sensory perception quotient) is pretty recent (Tavassoli, Hoekstra and Baron-Cohen, 2014);
- FQ (Friendship questionnaire) is designed for adults with Asperger Syndrome or High Functioning Autism Baron-Cohen & Wheelwright, 2003).”³⁹

Another tool not to be underestimated is the DISCO (Diagnostic Interview for Social and Communication Disorders) a guide developed by Dr. Lorna Wing and Dr. Judith Gould, that enhances the gathering of detailed information on the development and actual history of children and adults in order to detect the conditions of the autism spectrum and developmental disorders. Moreover, the AAA (Adult Asperger Assessment) is a tool that combines the use of two diagnostic questionnaires: the AQ and the EQ and it was developed by Baron-Cohen and colleagues in 2005. Its diagnostic criteria coincided with those of DSM-IV-TR, with some additions.

Usually, during psychological sessions, prior the diagnosis, the recollection of episodes or particular behaviours is requested from parents, or close relatives, who may have a clear memory of their loved

³⁹ Attwood, T. (2015). *The complete guide to Asperger's Syndrome*. Published by Jessica Kingsley Publishers

one's childhood (it might also be considered the age of the parents, which may interfere with a correct recollection of memory due to aging).

2.1.3 Getting a diagnosis: regulations and support in Italy

It is arduous to get diagnosed as autistic if you are a young girl or woman with no visible impairment in Italy, as in other countries as well. Many physicians are not trained to the characteristics of autism in females or adults, or they do not know very much about ASC at all. In fact, clinicians usually focus just on children since they are dealing with a neurodevelopmental disorder, and therefore may not be able to recognise the traits in adults. So, it is unlikely that your family doctor may accept your idea about being on the spectrum, even on the high functioning side. There are then two other left possibilities: turn to the public or private institutions or make do with a self-diagnosis. In case the family doctor decided to give you a prescription for further analysis, you may look for a qualified doctor in public hospitals. It is not new, though, that clinicians working in public administration have studied on outdated manuals (based principally on males) and hence may not be willing to diagnose you on the spectrum even if you come to the visit prepared to argue your validation.⁴⁰ The choice to contact a specialised centre might not be accessible to many people since the cost for private associations is higher than the public institutes. There are greater possibilities, though, that a private clinician, who specialised on ASD (fewer are those specialised in Asperger syndrome in females, as Gruppo Empathie,⁴¹ but their work will be discussed at the end of this dissertation), may diagnose you correctly. It is vital to contact a professional in HFA and Asperger's because it could be detrimental to be diagnosed by a general psychiatrist or psychologist, who may not recognise the traits correctly and thus give a misdiagnosis (with a wrong psychotherapeutic path, or the wrong medications). Nevertheless, whether getting a diagnosis in a private centre might prove easier, their waiting lists are extremely long and sometimes temporarily suspended (being able to provide a first appointment for a diagnosis after months, even years), because there are few specialised centres and the demand is very high. So, in between, the only remaining option is to stand with a self-diagnosis, which is time consuming, but free. Often, researching and wanting to know everything about autism,

⁴⁰ There is a comic video about the difficulties about being diagnosed in Italy created by autistic Emanuela Masia "Come certa gente pensa funzioni la diagnosi" <https://www.instagram.com/reel/CpdCWSloFN0/?igshid=MDJmNzVkMjY=>

⁴¹ Coordinator and supervisor of this equipe is Dr. Valentina Pasin, a psychotherapist specialised in Asperger syndrome, both in men and women

sharing experiences on self-advocate communities and blogs, while trying to self-diagnose, becomes an absorbent interest, and turns out as a central key trait of being autistic.

As Rudy Simone recommends:

“if she’s self-diagnosed, accept it. If the information helps her, what harm could it possibly do? Most people I meet, do NOT use Asperger’s as an excuse but rather as an explanation.”⁴²

Among the hesitations, there is a suspicion about the objectivity and validity of the diagnosis given by specialised centres. Theoretically, professional ethics should always prevail, and therefore, there should not be diagnoses based on a personal/economical interest, rather based on tests and clinical judgment. There are some cases, though, when the Code of Conduct is violated; the specialised centre may have benefits from a diagnosis: for instance, when the psychotherapeutic sessions after diagnosis take place in the same centre or the wage of the professionals rises. It is not often the case, though. There is a higher risk of being misdiagnosed on purpose by a private single professional, not in a qualified centre; anyway, there always exists deontology. A list of some renowned centres and clinicians, specialised in diagnosing ASD in children or adults, is given in the following website, divided by region: <https://www.ilariaesimoneblog.it/professionisti-a-cui-rivolgersi-per-avere-una-diagnosi-di-autismo-per-bambini-o-adulti-in-italia>

Another topic that rises questions is the category of subclinical for those people who receive a late diagnosis. Subclinical means that there is no clinical relevance, and even if a person displays many traits, they are not sufficient for a formal diagnosis. We talk about subclinical autism when the person believes to have an autistic neurotype, but that is not detectable from all the tests, or when it is considered a synonym of Broad Autism Phenotype (a bunch of people with many traits, although not diagnosed with ASD, for example, relatives of autistics). However, being diagnosed in adulthood does not necessarily implies that a person is subclinical: there are many ascertained autistics that may fly under the radar for a number of reasons, but on the other hand, many people that are borderline between ASD and subclinical are diagnosed later.

Once obtained the diagnosis, the access to public support may start, but the services received vary depending on the diagnostic category, available also for autistics with mild impairment (Level 1), but with specific features. Obtaining the recognition of the handicap or civil invalidity status will be

⁴² Simone, R. (2012). *22 Things a Woman with Asperger's Syndrome Wants Her Partner to Know*. Published by Jessica Kingsley Publishers

complicated because of bureaucracy. The recognition of disability (art. 3 of Law 104/92) is subsequent to getting you a diagnosis in a public institution or recognised by the public system, if obtained in a private centre (it usually means undergo another assessment). Then, you must apply for a medical examination to INPS (Istituto nazionale della previdenza sociale, in English National Social Insurance Agency) and once you got the date of the medical examination (again, it could take some time to get an appointment), the Commission of medical examiner of the Local Health Office (ASL) will judge your situation and whether you will pass the examination of the Medical Commission at Medicina Legale of the ASL. You will have to wait for the examination result and in case of failure, it is possible to appeal in court against the INPS within 180 days of notification of the health report. Level 1 of ASD relies on the discretion of the Medical Commission (just to apply for art. 3 comma 1 of Law 104/92, and excluded for comma 3), while other levels do not need to prove that support is truly needed for the person, and therefore they can apply for art. 3 comma 3 of Law 104 as well. The main difference between the recognition of “comma 1” and “comma 3” stands in the idea of gravity, with comma 3 being more severe, hence people have the right to: work permits, special leave to assist the disabled person, pension benefits etc. If obtaining the disability “certificate” does not grant many benefits for autistics with Level 1, there are some limitations on the driving license (with the renewal every two years, a lower speed limit, and the ban to drive in highway). In other countries, take U.S.A. as example, private insurances usually do not cover medications or support for AS, or at a very high cost, if it appears in the medical records, you may not be eligible for some types of works (e.g., in the armed forces), up to being restricted to emigrate in other countries (Cook & Garnett, 2018). Before seeking a formal diagnosis, it is fundamental to weigh up the potential costs and pros, also considering the time that will pass before getting one.

2.2 Why do women and girls receive late diagnosis?

In children, the average age of being diagnosed with ASD Level 1 is 8 years old for boys, while for girls is 13.⁴³ Furthermore, girls were diagnosed with autism 1.8 years later than boys, according to a 2013 study.⁴⁴ But a more recent study (McCormick *et al.*, 2020) reported that this esteem was shorter,

⁴³ Cook, B., Garnett, M. (2018). *Spectrum Women: Walking to the Beat of Autism*. Published by Jessica Kingsley Publishers

⁴⁴ Begeer, S., Mandell, D., Wijnker-Holmes, B. *et al.* (2013). *Sex Differences in the Timing of Identification Among Children and Adults with Autism Spectrum Disorders*. *J Autism Dev Disord* 43, 1151–1156. doi.org/10.1007/s10803-012-1656-z

with boys being diagnosed 1.5 years earlier than girls. The main reason behind this discrepancy is that some Aspie can socialise very well, women in particular (even if it is at the cost of intellectual and emotional exhaustion), and this can confuse others because they see someone socially competent but needing social withdrawal and isolation at times. Female presentation of autism is qualitatively different to the typical male presentation (known as FAP, or female autism phenotype) in terms of behavioural expression of autism. FAP is a “female-specific manifestation of autistic strengths and difficulties, which fits imperfectly with current, male-based conceptualisations of ASC (APA 2013; Hiller *et al.*, 2014; Lai *et al.*, 2015; Mandy *et al.*, 2012).”⁴⁵

It needs to be noted, though, that not all women on the spectrum fall under the FAP subtype, and therefore they may not hide their stimming, have troubles socialising and often experience meltdowns and shutdowns.

Authors Cook and Garnett (2018) dedicated a chapter about this as well, listing the reasons why women are fewer than autistic males:

“We are more socially adept and less rigid than our male counterparts, and so we tend to fly under the radar. We are better at masking our challenges and blending in, perhaps because we are under more social pressure to do so. We may be perceived as simply shy. Our intense interests in childhood are more typical (albeit more intense) and therefore less noticeable – boy bands or ponies, for instance. We may also move on to new topics of interest more quickly than males.”⁴⁶

There is another theory behind the ratio which sees autism more commonly diagnosed in males than females, and it is called “female protective effect” (Robinson *et al.*, 2013) which hypothesises that feminine gender reduces the likelihood of developing autism, since it requires greater environmental and/or genetic risk than males to express the same degree of autistic characteristics; it is believed, then, that girls “are ‘protected’ from autistic characteristics relative to males with a comparable level

⁴⁵ Bargiela, S., Steward, R., and Mandy, W. (2016). *The Experiences of Late-diagnosed Women with Autism Spectrum Conditions: An Investigation of the Female Autism Phenotype*. *J. Autism Dev. Disabil.* 46, 3281–3294. doi: 10.1007/s10803-016-2872-8

⁴⁶ Cook, B., Garnett, M. (2018). *Spectrum Women: Walking to the Beat of Autism*. Published by Jessica Kingsley Publishers

of risk factors (Robinson *et al.*, 2013).⁴⁷ Girls would be more “protected” from autism, because of an extreme male brain (EMB) theory, with autism as prenatally influenced by testosterone (Baron-Cohen, 2002). It is not the most accredited, though. In fact, the level of impairment could be similar between males and females, but girls are found to show interests, behaviours, and communicative features that are more socially acceptable (Lai & Baron-Cohen, 2015). For instance, girls on the spectrum, then, tend to experience internalising problems, such as anxiety and depression, rather than externalise hyperactivity and conduct problems, as their male counterpart (May *et al.*, 2012; Oswald *et al.*, 2016), but the main differences between “Aspiemen” and “Aspergirls” will be discussed further on. However, there are many differences across genders and some researchers have already argued that diagnostic assessments of ASC should include female-typical behaviours (Kreiser & White, 2014). It has been established that comparing women with the male presentation will just not fit, and it happened also to autistic author Sarah Hendrickx, who was diagnosed at the age of 43; she compared herself to her autistic partner, even though she worked and studied many years in the autistic field, even writing five books about it and holding conferences, and she could not reflect in the same characteristics.

2.2.1 Camouflaging and Compensation

The term masking also appears in an accredited manual. In fact, DSM-V and ICD-11 differ on criterion D, relating to functional impairment. While both manuals consider it a sufficient criterion, ICD-11 specifies that in some people without intellectual disability (AS), this compromise may not be easily detectable thanks to incredible efforts of adaptation and masking. The ICD-11 specifies that in these cases it is still possible to make a diagnosis of ASD. But what is exactly “masking”? As the word suggests, it is the act of wearing a mask, which is used to disguise, hide (feelings, thoughts). Its meaning is tightly tied to the theatre, where centuries ago and from the Greek tragedies, masks were used to pretend and act. Curiously, many Aspergirls are perfect actresses, according to Dr. Attwood, because it comes naturally to get into the part, after many years of surviving the neurotypical world. Masking, also called camouflaging, is a mechanism, conscious or not, that make autistics behave as they are not on the spectrum, making them hide behaviours associated with their ASC. They

⁴⁷ Hull, L., Petrides, K. V., Mandy, W., (2020) *The Female Autism Phenotype and Camouflaging: a Narrative Review*. Journal of Autism and Developmental Disorders (2020) 7, 306–317. doi: 10.1007/s40489-020-00197-9

camouflage in order to appear normal and socially competent. This behaviour includes mimicking facial expressions of the interlocutor, forcing oneself to make eye contact, stop talking about an interest, or copying someone else's behaviour and facial expressions, but also suppressing physical characteristics such as hand flapping, giving scripted responses to questions and imitating others (Kreiser & White, 2014; Lai & Baron-Cohen, 2015; Mandy & Tchanturia, 2015).

Other social strategies have also been proposed, such as avoiding isolation (and thus standing out), staying with other girls (Gould & Ashton-Smith, 2011), or adapting to school environments not to arouse teachers' suspicion (Hiller *et al.*, 2014; Mandy *et al.*, 2012). Masking is not linked to insecurity or manipulation: autistic people hide their "symptoms" because they want to connect with others and achieve social and professional success. It is never easy to fit in for those who are out of the ordinary. Masking behaviours include forcing eye contact, mimicking others, or memorising scripts to survive small talk and conversations. Obviously, not all autistics or Aspies are good at masking. Those who are better at it do not have less problems; their autism affects them as much as other autistics who mask less well. Actually, the efforts put to mask are counterproductive, because they will exhaust the person a lot (it is grueling always checking the correct posture, facial expression, the right tone of voice and gesturing, an adequate eye contact etc.). For NTs all this comes naturally, without even thinking about it. As states Kate Kahle in her Talk:

"The difficulty of masking can often lead to secondary mental health challenges. Depression can stem from working so hard and still not being accepted, while anxiety can come from the stress of having to mask for a good portion of the day, every single day, for a good portion of your life, or risk being discriminated against and ostracized. These secondary mental health challenges are of particular issue for women and girls. 34 percent of women with autism have depression, and 36 percent have anxiety. All autistic people are born autistic, but from birth, girls are thrust into a more socially rigorous environment that increases the pressure to mask and the challenges an autistic person faces daily."⁴⁸

Young girls may rehearse with their dolls and toys those behaviours they copied from someone they value as successful. This role-play enables them to act the same scripts in the real-life conversations when they need it (Attwood *et al.*, 2006). Social mimicry is another strategy used in social situations and it is usually perceived as automatic, unconscious and a prime example could be the switching accent when talking to somebody. "Some young women had noticed that they would quickly pick up

⁴⁸ Why autism is often missed in women and girls by Kate Kahle https://www.ted.com/talks/kate_kahle_why_autism_is_often_missed_in_women_and_girls

accents from other people and suggested that this may have been an unconscious attempt to create an increased sense of familiarity when socialising with new people.”⁴⁹

Another term frequently used in the literature is compensation. A definition of it is given in the article by Hull *et al.* (2020) “The Female Autism Phenotype and Camouflaging: a Narrative Review”: it “describes the use of alternative cognitive strategies to overcome specific socio-cognitive or behavioural difficulties in autism. For instance, an autistic individual might compensate for theory of mind difficulties by using executive function strategies to learn to recognise different facial expressions.”⁵⁰ When camouflaging, the use of alternative cognitive strategies is not always involved. In the same paper, previous qualitative research about the experiences of camouflaging were summarised. There are some common themes, such as the uncertain nature of the social environment, the desire to make friends, and avoid bullying were the main motives for camouflaging attempts, using explicit techniques to mask autism-related difficulties (Tierney *et al.*, 2016), which have been shared also by late-diagnosed autistic women (Bargiela *et al.*, 2016). Furthermore, two main approaches have been distinguished: the Discrepancy Approach (in which camouflaging is evidenced by the discrepancy between the innate characteristics of autism and their external presentation) and the Observational/Reflective Approach (in which camouflaging is identified through observation and reflection of the (a)typical behaviours). Studies using the former approach have shown that discrepancy is higher in females than males, with “greater discrepancy between self-reported autistic traits and social cognitive abilities (Lai *et al.*, 2017). [...] This discrepancy was also associated with greater activation of the ventromedial prefrontal cortex in response to self-representation in females only (Lai *et al.*, 2019).”⁵¹ The latter approach, instead, quantifies camouflaging without measuring the internal autistic characteristics, focusing just on the behaviours and no significant difference on gender emerged from the studies based on this approach (CAT-Q and Q-ASC tests); parent-reported questionnaires, though reveal that girls on the spectrum mask more than boys (Ormond *et al.*, 2018). Anyway, the existence of a female autism phenotype is supported

⁴⁹ Bargiela, S., Steward, R., and Mandy, W. (2016). *The Experiences of Late-diagnosed Women with Autism Spectrum Conditions: An Investigation of the Female Autism Phenotype*. *J. Autism Dev. Disabil.* 46, 3281–3294. doi: 10.1007/s10803-016-2872-8

⁵⁰ Hull, L., Petrides, K. V., Mandy, W., (2020) *The Female Autism Phenotype and Camouflaging: a Narrative Review*. *Journal of Autism and Developmental Disorders* (2020) 7, 306–317. doi: 10.1007/s40489-020-00197-9

⁵¹ *Ibid.*

and future research on the topic should be addressed. Some papers have analysed, using qualitative approaches, the impact of FAP on the recognition of ASD; it is the case of paper by Bargiela *et al.* (2016) “The Experiences of Late-diagnosed Women with Autism Spectrum Conditions: An Investigation of the Female Autism Phenotype”, in which fourteen late-diagnosed Aspergirls were interviewed. Several shared experiences about pretending to be normal “thanks” to masking, seen more like an effort to learn and use social skills common for NTs. Camouflaging, indeed, has many cons: among them exhaustion, increased anxiety due to social rejection and confusion about one’s identity, leading to manipulations and abusive situation. “Participants described feeling pressure to play certain traditional feminine roles (the wife, the mother, the girlfriend), and finding this incompatible with how they wanted to live as a person with ASC.”⁵²

Interestingly, males may not report the same feelings about camouflaging. While the majority of females, across many studies, described masking as effective at times, but always draining and uncomfortable, in the article by Hull *et al.* (2017b), “60% of those who reported feeling positive or relieved after camouflaging were male (n = 9, compared to six females).”⁵³

In order to sum up the content of this paragraph, attention is drawn to illustration in the appendix (picture 11) in the abovementioned report by Hull *et al.* (2017b) “Putting on My Best Normal”: social Camouflaging in Adults with Autism Spectrum Condition, Fig. 1, which displays the two key motivations for camouflaging: assimilation and connection.

2.2.2 Comorbidities and misdiagnosis

In the 1960s and 1970s, treatments for autism ranged from psychedelic drugs (including LSD) to electric shock treatment and behavioral therapy, the latter based on the premise that it could be cured by encouraging patients to act normally – with a reward for good behaviour and punishment for a bad

⁵² Bargiela, S., Steward, R., and Mandy, W. (2016). *The Experiences of Late-diagnosed Women with Autism Spectrum Conditions: An Investigation of the Female Autism Phenotype*. *J. Autism Dev. Disabil.* 46, 3281–3294. doi: 10.1007/s10803-016-2872-8

⁵³ Hull, L., Petrides, K. V., Allison, C., Smith, P., Baron-Cohen, S., Lai, M., *et al.* (2017b). “*Putting on My Best Normal*”: social Camouflaging in Adults with Autism Spectrum Condition. *J. Autism Dev. Disord.* 47, 2519–2534. doi: 10.1007/s10803-017-3166-5

one. If those were the conditions of autistic people at the time, no wonder why many autistics avoided psychiatric treatment at all costs, leading to nowadays high prevalence of undiagnosed adults.

These days, awareness and acceptance is still growing, and more women decide to seek help or answers to their situation of their own free will. For those suspecting ASD, there is higher probability than males to get diagnosed incorrectly. In fact, women with ASD were “diagnosed more often than men with anxiety (36.3% vs. 26.5%) and depression (34.1% vs. 22.7%).”⁵⁴ Both anxiety Disorder and Depression are comorbidities, namely they are conditions often co-occurring with a primary condition (ASD in this case). Although, most of the times, physicians who are not specialised in autism (and in autistic females), may recognise just the comorbidity as the primary condition, not as a concurrent disorder. They will try then to “cure” the comorbidity, usually worsening the “symptoms” (since autism is not a disease, “characteristics” is to be preferred) of the primary undetected condition. So, the importance of contacting a specialised professional or centre is stressed again.

Henceforward, the most known comorbidities to ASD will be briefly presented (for further information, see Attwood, T. (2015). *The complete guide to Asperger's Syndrome*. Published by Jessica Kingsley Publishers). Starting with ADHD (Attention Deficit Hyperactivity Disorder, a conduct disorder), the child may worry teachers and parents for issues with attention, impulsiveness, and hyperactivity. It must be noted, though, that hyperactivity may be a reaction to high levels of stress and anxiety, in particular with new social situations, or a problem related to lack of motivation. Furthermore, its characteristics are common in nursery school, due to the brain development, but if they persist while growing, they are probably due to ADHD (which may present even without hyperactivity, so ADD). ADHD, as ASD, has strong genetic familiarity, and consists in an imbalance on neurotransmitters which affect inattention (the child is not able to finish tasks, often loses things) and impulsivity (often related to inhibition of improper behaviours). Some comorbidities of ADHD are dyslexia (SLI) and mood disorders.

Then, there are the learning disabilities, which – commonly to Asperger's – are referred to as hidden disabilities, since the person seems very bright and intelligent, and there is no cure or way of fixing them.

⁵⁴ Croen, L. A., Zerbo, O., Qian, Y., Massolo, M. L., Rich, S., Sidney, S., & Kripke, C. (2015). The health status of adults on the autism spectrum. *Autism*, 19(7), 814–823. <https://doi.org/10.1177/1362361315577517>

Among Learning Disabilities (DSA in Italian), we find:

- SLI (specific language impairment) also called DLD (developmental language disorder) may manifest during the first years of life of the child with no hearing loss. A delay in the language development is usually diagnosed by a speech therapist;
- Dyscalculia is associated with weaknesses in learning numbers and maths;
- Dysgraphia affects a person's handwriting ability and fine motor skills, with difficulty in storing and retrieving letters and numerals (there is usually some complications with Executive Functions as well);
- Dyslexia impairs individuals with word recognition, decoding, and spelling, with difficulties in phonemic, phonological, and orthographic processing;
- Non-verbal learning disability is troublesome for people who might not interpret nonverbal cues like facial expressions or body language.

Motor coordination disorders onset from infancy, and they can involve impairments in balance as in fine coordination skills, such as tying the shoes, riding the bike, catching a ball on the fly etc. The expert in infantile psychomotricity will diagnose the delay or the disorder and therefore could realise there is a comorbidity with ASD. Some children with AS can make involuntary body movement or incontrollable vocalisations (dyskinesia), very similar to Tourette syndrome (another comorbidity with Asperger's). Another comorbidity which can be found also in Tourette's, is the OCD (Obsessive Compulsive Disorder, in which obsessions are intrusive thoughts or images, while compulsions are behaviours acted to get rid of the obsessions). An example of OCD behaviours could be checking many times whether you locked the car or the house door, going back home to check the stove, washing hands too often because of fear of germs etc. "OCD is twice as likely to occur in people with autism and if a parent has OCD, children have a higher risk of autism. In a cohort study in Denmark by Meier *et al.* (2015), individuals with OCD were four times as likely to go on and receive an autism diagnosis compared to individuals without."⁵⁵

Furthermore, eating disorders, which are also listed in the DSM-V, can overshadow autism, in particular the diagnostic category named ARFID (Avoidant/Restrictive Food Intake Disorder), which may explain the autistic trait to avoid certain types of food, based on sensory processing (not mixing foods together, not eating something for the consistency, taste or colour etc. might limit dietary

⁵⁵ Zener, D. (2018). *Journey to diagnosis for women with autism*. Advances in Autism, Vol. 5 n. 1, 2019, 2 – 13. Emerald Publishing Limited, ISSN 2056-3868. doi: 10.1108/aia.010.2018.0041

preferences), or the need for routine even with meals. Anorexia nervosa, Bulimia nervosa and Binge eating disorder may represent all risk factors of a comorbidity with ASD, especially anorexia: a study by Anckarsäter *et al.* (2012) found that up to 30% of anorexic girls could be diagnosed as autistics, showing the same rigidity, perfectionism, mood, and anxiety disorders (Oldershaw *et al.*, 2011). Furthermore, according to the study by Kinnaird *et al.* (2019), eating difficulties persist into adulthood continuing “to influence the eating behaviours of autistic adults”⁵⁶ and contributing to eating disorders and weight gain (usually associated with poor variety of meals, or emotional comfort eating); it must be considered that the sample of this study, though, is pretty small, counting 12 participants in total (8 women, 2 men, and 2 non-binary individuals). Many other sensory issues play a role associated with eating; it is not easy for some people on the spectrum to eat at a crowded restaurant, where the music is too high, or because the environment is not familiar.

Moreover, among mood disorders, anxiety plays a huge part. Anxiety disorder must not be confused with fear (which is specific) and may present in many ways: generalised anxiety (GAD), social phobia, specific phobias, PTSD, separation anxiety. School for children on the spectrum may equate to a source of stress and abuse, so, to compensate for anxiety, they may not want to go, not explicating the reasons against it, and therefore showing mutism (Wood & Gadow, 2010). Anxiety is the most pervasive mental health condition experienced by girls on the spectrum (Lieke *et al.*, 2018). Girls tend to internalise anxiety and stress because they do not want to draw attention to them being unable to cope with the situation. Sometimes high levels of distress can lead to selective mutism (which can also be diagnosed in NTs), in particular during interactions with individuals who are not familiar. “According to Bejerot *et al.* (2014), one in four adults with autism experiences social anxiety” while “depression is experienced by up to half of all autistic adults.”⁵⁷

PDA (Pathological or Extreme Demand Avoidance Syndrome) also is associated to high levels of anxiety driven by the need to control and avoid the demands and expectations of others. It is usually described as an atypical subtype of autism, but it is not listed in international manuals, hence it is not an accredited and recognised diagnosis [yet]. The term PDA was first coined by developmental psychologist Elizabeth Newson, in the 1980s in the UK, and it differs from typical autism in that the person shows the ability to read situations and manipulate them to avoid demands, thus being socially

⁵⁶ Kinnaird, E., Norton, C., Pimblett, C., Stewart, C., Tchanturia, K. (2019). *Eating as an autistic adult: An exploratory qualitative study*. PLoS One. Aug 29;14(8):e0221937. doi: 10.1371/journal.pone.0221937

⁵⁷ *Ibidem*

able, even though just superficially. In a recent study by O'Nions *et al.* (2016), the characteristics of individuals with PDA were analysed and they include: strategic avoidance of requests, obsessive need for control, apparent lack of responsibility or sensitivity to the distress of others, low social awareness, sudden changes in mood, occasional meltdowns etc.⁵⁸

Alongside traits of anxiety, depression can onset once the child acknowledges his social integration difficulties. The depressive reaction may be internalised (leading to auto-critics and suicidal thoughts) or externalised (leading to judgments on peers and others). A severe depressive episode may be diagnosed when a person recognises five out of the nine symptoms every day for at least two weeks:

- “Sadness, hopelessness and a sense of failure;
- Lack of interest or pleasure in almost all the activities;
- Huge weight loss without being on a diet, showing irregular appetite;
- Agitation or slowdown in motor and psychological skills;
- Exhaustion or loss of energies;
- Feeling helpless and valueless, with a sense of guilt;
- Difficulty in thinking and concentration;
- Recurrent thoughts of death and suicide.”⁵⁹

In Aspies, depression usually manifest with a change of special interest (sometimes towards morbid) or complete loss for the former special interest, but also with outbursts of anger, which generally guarantee isolation (Attwood & Garnett, 2016). Being a female, alongside having a higher IQ, is found to increase likelihood of depression more than in males (Hedley *et al.*, 2018). Some people with severe depressive episodes may show even hypomanic episodes. Mania lasts at least four days and individual has an excessively high mood, extrovert, energetic or irritable, with a sense of greatness, risky behaviours, physical and mental agitation, hallucinations etc. Indeed, the comorbidity of ASD may be also BPAD (Bipolar Affective Disorder) representing the 7% (Skokauskas & Frodl, 2015) and which it was called “manic depression”. “Borderline personality disorder (BPD) also has shared

⁵⁸ For further information, see the original article in Italian

https://www.gruppoempathie.com/post/_pda

⁵⁹ Attwood, T., Garnett, M. (2016). *Exploring depression and beating the blues*. Published by Jessica Kingsley Publishers

traits with autism and can lead to confusion over the correct diagnosis. Shared issues include interpersonal difficulties, challenges with affect regulation and self-harm.”⁶⁰

Sometimes, autistic people have moments of alexithymia, when they are not able to find the right words to express their thoughts, and hence identify and describe their emotions, but that does not mean that they do not feel them. Studies on alexithymic people found a reduced neural response in many areas of the limbic system, for instance, the amygdala, which is central to the identification of emotions.⁶¹ It is often argued that some people on the spectrum do not seem to show emotions with their facial expression or tone of voice, so traits of anxiety and depression may not be recognised, letting the person feeling even more alienated.

To conclude, the results of a research conducted in Italy (Milan) on this topic are presented, with an indicative percentage of comorbidities in a population sample. In this recent article by Gesi *et al.* (2021), 61 participants (diagnosed as autistic and tested with AQ and AdAs tests, with no deficits in language and intelligence, n. 22 females and n. 39 males aged 28.5 averagely) were tested and “75.4% received their ASD diagnosis average eight years later than the first evaluation by mental health services.”⁶² Comorbidities, then, delayed the recognition of the primary condition, ASD, and a detailed list is reported below:

- Psychotic spectrum disorder (n. 2 = 3.3%);
- Mood disorder (n.19 = 31.1%);
- Anxiety disorder (n.10 = 16.4%);
- Eating disorder (n.4 = 6.6%);
- ADHD (n. 3 = 4.9%);
- OCD (n. 5 = 8.2%);
- Trauma and stress/related disorder (n.16 = 26.2%);

⁶⁰ Zener, D. (2018). *Journey to diagnosis for women with autism*. Advances in Autism, Vol. 5 n. 1, 2019, 2 – 13. Emerald Publishing Limited, ISSN 2056-3868. doi: 10.1108/aia.010.2018.0041

⁶¹ Marzi, T., Righi, S., Attanà, A. (2021). *Capire le emozioni per vivere meglio*. Psicologia contemporanea n. 286, dicembre 2021- maggio 2022, pp. 18-23

⁶² Gesi, C., Migliarese, G., Torriero, S., Capellazzi, M., Omboni, A.C., Cerveri, G., Mencacci, C. (2021) *Gender Differences in Misdiagnosis and Delayed Diagnosis among Adults with Autism Spectrum Disorder with No Language or Intellectual Disability*. Brain Sci. 2021, 11, 912. <https://doi.org/10.3390/brainsci11070912>

- Other clinical issues, such as sleep and behavioural problems (n.12 = 19.7%).

Among the 61 participants, “seven subjects (11.5%) did not report any comorbid diagnosis, 30 (49.2%) reported one comorbid diagnosis, and 24 subjects (39.3%) also received a second comorbidity diagnosis.”⁶³ Female’s age was significantly higher than males (an average of ten years of lag) when referred with mental health services and for ASD diagnosis; though, the time-lag between the first evaluation and diagnosis was the same for both genders.

Finally, gastrointestinal problems in autistic individuals must not be underrated. A compromised digestive system might be one of the causes leading to autism, thus the toxins from the food eaten by the pregnant mother could get into the bloodstream and impact the development of the brain because of a lack of healthy flora, as a consequence of antibiotics, poor diet etc. (Gates, 2006; Campell-Mcbride 2004).⁶⁴ Chronic irritable bowel syndrome (IBS), heartburn, allergies, and other gastrointestinal (GI) problems affect most of ASD population. Many physical problems, although are a direct manifestation of stress, and therefore, the main issue should be treated (e.g. when constantly feeling cramps due to stress, there is no point in treating it with medications, rather the work should be done to decrease the tension).

2.3 Differences between men and women

There are some features that emerged from the previous paragraphs, which corroborate the empirical evidence that girls and women with ASC differ from autistic males. To take stock of the situation, a list of the main gender diversities is proposed hereinafter. Always compared to boys, autistic females show:

- Higher social motivation and a greater capacity for traditional friendships than do males with ASC (Head *et al.*, 2014; Sedgewick *et al.*, 2015);

⁶³ Gesi, C., Migliarese, G., Torriero, S., Capellazzi, M., Omboni, A.C., Cerveri, G., Mencacci, C. (2021) *Gender Differences in Misdiagnosis and Delayed Diagnosis among Adults with Autism Spectrum Disorder with No Language or Intellectual Disability*. *Brain Sci.* 2021, 11, 912. <https://doi.org/10.3390/brainsci11070912>

⁶⁴ For further information, see Simone, R. (2010) *Aspergirls. Empowering Females with Asperger Syndrome*. Published by Jessica Kingsley Publishers

- Less likeliness to have externalising behaviours, such as hyperactivity/impulsivity and conduct problems, and more likelihood to internalising problems, such as anxiety, depression and eating disorders (Mandy *et al.*, 2012; Huke *et al.*, 2013; Oswald *et al.*, 2016);
- Lower scores on measures of repetitive and stereotyped behaviour (Van Wjingaarden-Cremers *et al.*, 2014);
- Interests, behaviours, and communicative features that are more socially acceptable (Lai & Baron-Cohen, 2015);
- Earlier acquisition of first words (Bleses *et al.*, 2008);
- Better and earlier integration of gesture using language (Eriksson *et al.*, 2012);
- Earlier onset of social pleasantries vocabulary (e.g. “please”), and a greater use of articulated and complex forms of speech (Bouchard *et al.*, 2009);
- A different use of language and communication, more focused on person-centered topics (Newman *et al.*, 2008), commenting on others’ emotions (Rieffe *et al.*, 2021);
- Better processes of emotional memory recalling (Goddard *et al.*, 2014);
- Increased narration of the internal states of others (Kausche *et al.*, 2016; Conclon *et al.*, 2019);
- Fewer autistic behaviours while interacting, but they report more sensory issues and traits typical of ASD (Lai *et al.*, 2011);
- Extended use of camouflaging skills (Lai *et al.*, 2011; Dean *et al.*, 2016; Lai *et al.*, 2017);
- Fewer socio-communication symptoms on the ADOS questionnaire, but more sensory issues (Lai *et al.*, 2011);
- Less stereotyped behaviours (Knutsen *et al.*, 2019), and less repetitive interests in parts of mechanical objects (Hiller *et al.*, 2016) than their male counterpart without intelligence deficiencies (with an IQ lower than 80, more stereotyped rhythmic movements were observed according to a study by Goldman *et al.*, 2009).

Other female autistic authors decided to summarise the main characteristics of Aspergirls, just like Rudy Simone in her homonymous book.⁶⁵ In the last pages, she listed some differences between boys and girls on the spectrum, which are partially resumed henceforth:

- Usually a little more expressive in face and gestures;
- Better at mirroring, very chameleon-like because of a weak sense of identity;
- More open talking about emotions and feelings;

⁶⁵ Simone, R. (2010) *Aspergirls. Empowering Females with Asperger Syndrome*. Published by Jessica Kingsley Publishers

- More expressive physical gestures/behaviours when happy;
- More prone to temper and crying meltdowns, even in public, due to sensory or emotional overload, or when hungry. Adult males usually are not prone to crying;
- Like males, there is a preference for comfortable clothes (usually not wearing makeup or elaborated hairstyles);
- Less likely to stutter when stressed or upset, but with the same mutism;
- Girls generally appear more skilled at socialising, but will shut down in social situations when overloaded;
- Most likely to keep pets as emotional support.

A contemporary review about early signs of autism in little girls by Chellew *et al.*, (2022) inferred that during the first years of life there are more similarities across genders, rather than differences. Some neuroanatomical studies, however, found that males and females on the spectrum may present a distinct neurological and cognitive brain (Lai *et al.*, 2013). Though, there is another study (Craig *et al.*, 2007) in which the anatomy of autistic women's brain was compared to controls, using neuroimaging tools (volumetric MRI and VBM) and some differences from NTs were discovered. Autistic women "have a significantly reduced density bilaterally of grey matter within the fronto-temporal cortices and limbic system, and of white matter in the anterior temporal lobes. In contrast, they have increased white matter bilaterally in the fronto-parietal, posterior temporal lobes and the cerebellum."⁶⁶ This paper was a replication of previous studies conducted on autistic males and controls (Abell *et al.*, 1999; McAlonan *et al.*, 2002), and it found that the brain regions involved were similar in anatomy for genders on the spectrum.

2.4. Differences with Neurotypical women

Autistic women have a different wiring than neurotypicals, according to the study conducted by Craig *et al.*, 2007. Differences are found not just in brain anatomy, but also in behaviours and self-

⁶⁶ Craig, M. C., Zaman, S. H., Daly, E. M., Cutter, W. J., Robertson, D. M. W., Hallahan, B., Toal, F., Reed, S., Ambikapathy, A., Brammer, M., Murphy, C. M., Murphy, D. G. M. (2007). *Women with autistic-spectrum disorder: magnetic resonance imaging study of brain anatomy*. *British Journal of Psychiatry*. 191,224^228. doi:10.1192/bjp.bp.106.034603

perception. According to the latter, in fact, individuals on the spectrum have more probabilities to suffer gender dysphoria, not identifying with their assigned-at-birth gender (Strang *et al.*, 2014).

As for differences on behaviours, even basic hygiene can become struggling for people on the spectrum, and therefore, girls may not want to groom and wear make up as much as other peers, with this uncomfortable expectancy starting during adolescence. Women on the spectrum may sacrifice their appearance for feeling comfy in their clothes, not caring much about spending hours getting ready to go out (in social situations, which they may dislike).

Another milestone in the life of every girl is period. Menstrual cycle can be extremely intrusive and unwanted by an Aspergirl, who may perceive it as an unexpected change in her routine, plus cramps, backache, the complexity of tampons, blood stains in awkward social situations etc.

Society, indeed, expect women to be girly, since infancy, starting with the way of playing and with good manners. Many girls on the spectrum, however, describe themselves as tomboy, and usually preferred the company of males (more easily understandable and direct than females), but even neutral gender behaviour is mentioned.

Anyway, a difference between neurodivergents and neurotypicals may be perceived even socially. A study on first impressions made n. 205 NTs observe females and males (both NTs and people on the spectrum, 10 participants each) in a mock job interview with a short video clip. Individuals on the spectrum were overall evaluated less favourably than controls, with autistic females perceived more positively than autistic males (Cage *et al.*, 2019).

Chapter 3 – Everyday struggles

The main focus of this dissertation is about the efforts that females that would be considered Asperger's do face every day. The amount of stress and anxiety that social interactions and life challenges bring is bearable for common people, but being neurodivergent means learning to face these struggles from an early age, with their consequences and issues. Sometimes, people do not even realise the pain and exertion that women on the spectrum must endure to survive, and this chapter is aimed to list (not exhaustively though) all the aspects in life which could be tricky for a person with ASD, even on the high functioning end. Once we understand how hard it is, maybe we could be more helpful.

3.1 Linguistic and communicational difficulties

Pragmatics integrate linguistic content with social context and females do exceed males on tasks involving it (inference, semi-structured speech etc.), probably due to the difference in social attention and motivation, but they are always behind typically developing females (Sturrock *et al.*, 2021).

Language is laminated and compound, thus there are many layers involving it. A visual and useful representation of the complexity of language is displayed efficiently in Picture 12 in the appendix. Hence, the components of language, which linguists have identified across all languages, are briefly described in this section:

- Phonetics: it studies the properties of phones (speech sounds of language) and how humans produce and perceive sounds (also signs for Deaf people) and it divides in articulatory, acoustic, and auditory phonetics;
- Phonology: it studies phonemes, an abstract categorisation of phones, and how speech sounds are organised in the mind and used to convey meaning (sound patterns);
- Morphology: it studies the smallest units of meaning (also known as morphemes like prefixes, suffixes, and base words), thus the word structure;
- Syntax: it studies how individual words and morphemes combine to create larger units, such as phrases and sentences (sentence form);
- Semantics: it is the study of the meaning of words and sentences, explaining how sentences are understood by native speakers. It is concerned with the lexical meaning of an expression, and it divides in formal, conceptual, and lexical semantics;
- Pragmatics: it studies how context contributes to meaning and how human language is utilised in social interactions. Pragmatics focuses on interpretation and intuitions, thus in felicitous or

infelicitous sentences. Furthermore, discourse analysis studies the meaning of related sentences.

Speech is already complex itself. It consists of at least two speakers who share coded messages, which must be decoded to be understood. In this change of information (the channel could be oral, printed or signed), there could be a loss of perceived speech, due to the environmental context (such as the presence of noises which interfere with hearing) or to the prosody of the speaker (tone of voice too low, too fast at speaking etc.). The process that lays behind the comprehension of a sentence starts with lexical access (to parse sounds or letters into groups, then to their meanings), then to parsing (accessing syntactic information for words), next it passes through semantic interpretation and finally to discourse coherence. These online processes are field of study of psycholinguistics, a branch of linguistics which focuses also on mental representations.

Aspies usually have issues with pragmatic competence, which is the ability to understand another speaker's intended meaning (so in pragmatics), as with semantics (taking things too literally and often not getting figurative speech), always assuming there are no visible language or intelligence impairments. People on the spectrum with mild to severe language delays have other core areas that are compromised, but we will focus on Asperger syndrome and its common characteristics.

3.1.1 Grice's maxims

People on the spectrum who mask admirably well, may have learnt the processes behind social interactions, even studying them. Herbert Paul Grice was a British philosopher of language and is best known for his theory of implicatures and the cooperative principle. His Maxims of Conversation (1975) are really helpful to understand the principles of communication, and represent where Aspies lack; thus, they are presented concisely hereinafter:

- “Quantity: make your contribution as informative as is required for the current purposes of the exchange. Do not make your contribution more informative than is required;
- Quality: do not say what you believe to be false. Do not say that for which you lack adequate evidence [language reflects our ability to create false beliefs, thus, to believe and to know are different; unless we lie on purpose, the speaker must believe that the other interlocutor is right];
- Relation: be relevant;
- Manner: avoid obscurity of expression and ambiguity. Be orderly and brief [avoid unnecessary prolixity].”

Speakers may decide to observe these maxims, violate them (thus assuming that the other interlocutors do not realise it, i.e., telling a lie), flout them (violating a maxim, but in a way such that the speaker understands it and both speakers must intend for an additional meaning), or opt out of the maxims (people are not cooperative).

Here, individuals with AS may have troubles with some of these principles. Children on the spectrum might not always be relevant, responding to peers' questions with apparently not pertinent contents (i.e., changing suddenly the topic), and they tend to be too much informative and longwinded about their special interest (not respecting then the maxim of quantity and manner). There could be issues in the maxim of quality when the other speaker decides to violate it: while other NTs may be able to recognise it is a lie, most of the time autistics are not able to do so. In a study by Surian, Baron-Cohen & Van der Lely (1996) children with autism showed impairments at detecting pragmatic violations, compared to both normal children and children with SLI; among eight participants on the spectrum, three passed both the Pragmatics Task and the standard False Belief Task, suggesting a successful association between the two.⁶⁷

Research on children with AS has mainly focused on pragmatics because problems lie onto both language production and comprehension, despite the fluency of speech, plus on difficulties in understanding idioms, humour, irony, metaphors, and on interpreting utterances too literally (Saalasti *et al.*, 2008). In the same paper, children with AS were tested on language abilities and they performed overall worse than controls in the Phonological Processing subtest and in the Comprehension of Instructions test, which “requires, in addition to language skills, short-term memory, attention, motor planning and spatial perception”,⁶⁸ but similarly to them in “semantic and phonetic fluency, naming, speeded naming, non-word repetition and sentence repetition tasks.”⁶⁹

⁶⁷ Surian, L., Baron-Cohen, S., Van der Lely, H. (1996). *Are Children with Autism Deaf to Gricean Maxims?* Cognitive neuropsychiatry. 1. pp. 55-72. 10.1080/135468096396703

⁶⁸ Saalasti, S., Lepistö, T., Toppila, E., Kujala, T., Laakso, M., Nieminen-von Wendt, T., *et al.* (2008). *Language abilities of children with Asperger syndrome*. J. Autism Dev. Disord. 38, 1574–1580

⁶⁹ *Ibidem*

3.1.2 Executive Functions

Individuals with Asperger's might make more efforts with some executive functions, such as working memory, which was involved in the task of Comprehension of Instructions, but deficits in short-term memory alone cannot explain the poorer performance. Probably, this deficit in working memory was combined with the difficulty for Aspies with a tendency to focus on details (and get lost), to integrate linguistic information in a context (Jolliffe & Baron-Cohen 2000). Another study (Gold *et al.*, 2010) has found – using ERPs – that in addition to the pragmatic deficits, there is deficiency in linguistic information (semantic integration) processing of Aspies, which is linked to their difficulties in the comprehension of metaphors, both conventional and novel.

Both people on the spectrum and with ADHD have issues with executive functions, which have a huge impact in everyday life. They are a group of cognitive abilities that control, adjust, and manage our thoughts and actions daily. The correspondent neuroanatomical area is the frontal lobes, which is the latest region of the brain to develop (the lobes – temporal, parietal, occipital and frontal – begin to mature after 2 years of age, but they are not completely formed until puberty), is also the first to decay with aging. Executive functions have interactions among them, but they are separate so we may have a deficiency in a particular function and have a strength in another one. Usually, logical problem solving is a strong point of Aspies, while cognitive flexibility and adapting to novelty and contingencies is a weak spot. During a diagnostic process, it is often necessary an assessment of executive functions, always keeping in mind that if autistics experience a temporary worsening of their executive functions, a burnout, a shutdown, or a meltdown may take place soon. A list of these E.F. is given, alongside a concise description of each:⁷⁰

- Organisation: it involves the assessment of necessities and the evaluation of options in order to achieve a goal. People with difficulties in planning may find hard learning complex body movements, driving, cooking, personal hygiene etc.;
- Problem solving: it involves activities such as identifying obstacles, finding a strategy to overcome them and achieve a predetermined aim. Those who have a deficit in this E.F. might find hard changing a strategy when something unexpected happens, realising that there is a problem to be solved, trying different solutions;

⁷⁰ List taken by the lesson on Executive Functions (slides by Dr. Valentina Pasin) by Gruppo Empathie for the Group of CyberAspergirls

- Working memory: it is the ability to retain information for a short period of time, while completing a task. Being multitasking, reproducing a picture by heart, following complex verbal instructions are just some things that people with poor WM may struggle with;
- Focus: in Aspies it is usually easy to hyperfocus on special interests, forgetting about the time passing, even eating, or drinking. Focus is an intentional ability, and people with ADHD, usually strain when they must focus, especially during activities that are not interesting, when they must complete a task, focus on one thing at a time, block environmental distractions, and be on time;
- Inhibition: it is the ability to suppress, consciously and unconsciously, thoughts, environmental stimuli, and emotions. People with inhibitory issues cannot recall memories and words easily, may keep talking even when the other speaker is not listening anymore, express everything that comes in mind even if it is not appropriate (thus, becoming impulsive), cannot suppress stims, or echolalia, or spend the whole day doing something about his/her special interest even though there are other things to do;
- Verbal reasoning: it is usually a strong point for HFA and AS, since it enables comprehension, analysis, critical thinking about concepts presented verbally. Taking notes, answering written questions, so mathematical problems expressed in words etc. are some of the difficulties faced by people with a deficiency in this E.F.;
- Task initiation: it is the preparatory stage for every activity (we are not referring to doing something but initiating something). People with Asperger's are often perceived as lazy, while most of the time they may have issues with this particular executive function. It is hard to start projects, tasks (looking for a job, deciding what do during the day, keeping the house tidy and neat, cooking, laundering etc.) without a prompt;
- Goal directed persistence: also called monitoring, is the ability to constantly check for correctness during activities. Deficits in this area translate into difficulties in finding mistakes in our own works, completing correctly a familiar task in a new and unfamiliar context, doing things under pressure and stressed etc.;
- Cognitive flexibility: it enables us to shift our attention and thoughts as the situation changes. People with poor cognitive flexibility may stress and not be able to accept changes and transitions (moving, changing jobs, maternity), interrupt what they are doing to do something else, get along with new rules and situations etc. This executive function is deficient in those autistic people who need routine to survive;
- Prioritising: not to be confused with planning, this function involves the discrimination of activities based on their importance, thus on the ability to list them on priority. Having issues

prioritising leads to not being able to plan things well, and not being efficient on tasks, because of the inability to discriminate meaningful from less important stuff;

- Decision making: this function always takes place when there is a choice between two or more solutions. Deciding quickly what to do, for instance at the wheel or in a conversation, avoiding procrastination, and not being influenced by others when making a decision, are all weaknesses in a person with a defective ability in this E.F.

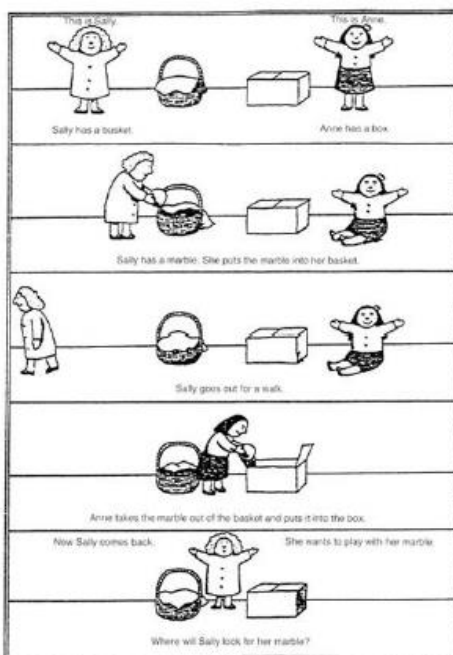
We must not forget that executive functions are blocked, or at least impaired, when there is an overload of sensory and social stimuli, as with emotions (too much anxiety). That is why yoga, meditation, and mindfulness as other relaxing activities are frequently suggested for people on the spectrum: they can bring the person in a quiet meditative state. In a neuroimaging study by Tang *et al.* (2015), participants who practiced mindfulness for at least 8 weeks showed an elicited and modulated neuroplasticity (i.e., the ability of the brain to grow and reorganise its neural networks), hence new neural connections were stimulated.⁷¹ As for ASD, there is no cure for deficits in E.F., but there are strategies that can help managing and improving them (e.g. specific apps help organisation or task initiation). Frontal lobes can be trained with exercises done regularly, as for a healthy routine can only improve the whole welfare (*mens sana in corpore sano*) of the individual.

3.1.3 Theory of Mind

Throughout this dissertation, the term ToM has already been used, but it will be explained more in detail in this section. The theory of mind refers to the cognitive capacity to attribute mental states to self and others, including the ability to infer other intentions, desires, and knowledge (Hamilton, 2009; Ahmed & Miller, 2011; Bradford *et al.*, 2015) and the term was coined by Premack & Woodruff (1978). It represents a fundamental social skill which typically develops in children between the age of 4 and 9 – earlier for bilinguals (Bialystok *et al.*, 2004; Costa *et al.*, 2008) – and is mainly tested through the Sally – Anne Task (Baron-Cohen *et al.*, 1985).

⁷¹ For further discussion, see Marzi, T., Righi, S., Attanà, A. (2021). *Capire le emozioni per vivere meglio*. Psicologia contemporanea n. 286, dicembre 2021- maggio 2022, pp. 18-23

Based on the False-Belief paradigm, it consists in presenting to the child a scene where an experimenter (or Sally) comes into a room and leaves an object (marble) into a box, then leaving the room. A second experimenter (Anne) comes into the room and changes the position of the object, moving it in another box. The child must indicate where the former experimenter (Sally) will look for the object, once returned. The first experimenter (Sally) is not aware that the object has been moved from its original position. ToM is successfully acquired when the child takes the perspective of the first experimenter (Sally) and therefore will think that he thinks that the object is in the first box and does not know it has been moved. Bilingual children and adults outperform their monolingual peers in this type of tasks, and it is generally interpreted as a result of their better inhibition (Rubio-Fernández, 2017). Autistic children, instead, generally do lack this ability, performing worse than normally developing children (Miller, 2012). There are many authors who sustain that ToM is flawed and misrepresents people on the spectrum (Leudar & Costall, 2009; Gigerenzer, 2018; Gernsbacher & Yergau, 2019), penalising autistic children with language impairment, whilst those with mild to no



Picture from Baron-Cohen, Leslie and Frith, 1985

delay in language development tend to pass (Gernsbacher & Frymiare, 2005). Theory of mind, though, can be taught and learned: before starting a psychotherapeutic path, psychoeducation is done, in order to give the child all the instruments needed to succeed in psychotherapy (thus, theory of mind, social and linguistic competence, and alexithymia are all aspects to train). Individuals with autism must learn consciously what others learn intuitively.

The False-Belief test presented here is not the only theory of mind that has been developed, but it is the most popular measure of theory of mind (Miller, 2012). As summarised by Matejko (2021):

“The three main frameworks in the area of theory of mind are theory-theory of mind, simulation theory and modular accounts of theory of mind (Miller, 2012: 37). Theory-theory postulates that the way in which we relate to others is indeed theory-like in nature. Simulation theory posits that we “simulate” what we would do in the place of others, based on our own perceptions and mental processes (Miller, 2012: 37). Modular theories focus on hypothesized cognitive mechanisms responsible for theory of mind, named *modules* after Jerry Fodor’s *Modularity of Mind* (1983). These innate, automatic brain

modules are proposed to be responsible for theory of mind in normally developing children, and which is absent or impaired in autistic children (e.g., Baron-Cohen *et al.*, 1985, Leslie, 1994).⁷²

Evaluating children on the False-Belief paradigm before the age of 4 is not suggested, since it based on the development of mental states. According to the studies by Henry Wellman (1991), at the age of 2 years the psychology of desire matures (the child describes emotions and desires with words, e.g., “I want ice-cream”), at the age of 3 arises the psychology of true beliefs (e.g., “He is bad! He broke my doll on purpose.”), which can be assessed by a test (Wellman, 1991), and at the age of 4 there is an ability to comprehend simple false beliefs (thus the ability being tested by an unexpected displacement test, such as Sally-Anne task). Theory of mind (Baron-Cohen *et al.*, 1985), weak central coherence theory (Frith, 1989), theory of deficits in executive functions (Ozonoff, 1995) are all theories on cognitive deficits, which suggest that the perceptive processes are intact in people on the spectrum, the atypicality concerns the interpretation of stimuli by the CNS (for further information, see Bogdashina, 2003).

3.2 Social interactions

As the diagnostic criteria elucidate, people on the spectrum have persistent deficits in sociality, both communication and interaction. Sometimes, it is even impossible to externalise feelings verbally (alexithymia), but it is even harder to understand others, to grasp the meaning of their verbal and nonverbal communication. The Mirror Neuron System (MNS) plays a crucial role in imitative behaviour and action perception, areas considered impaired in ASD (Khalil *et al.*, 2018). “The debate on the possible link between the MNS and autism has shifted the focus from higher level cognitive processes that are affected in autism (e.g., understanding of false beliefs) to foundational processes related to infant understanding and infant social learning.”⁷³ Below we analyse in more detail what mirror neurons are.

⁷² Matejko M. (2021). *Theory of mind, empathy and autism spectrum disorder*. Master’s thesis. Jagiellonian University of Kraków

⁷³ Vivanti, G., Rogers, S. J. (2014). *Autism and the mirror neuron system: insights from learning and teaching*. *Philos Trans R Soc Lond B Biol Sci*. 2014 Apr 28; 369(1644):20130184. doi: 10.1098/rstb.2013.0184

I Neuroni specchio were found by an Italian team at the University of Parma, supervised by G. Rizzolatti.⁷⁴ First discovered in the macaque monkeys, they activate both when an animal performs an action and when it sees the same action done by someone else. To activate the mirror neurons the action must not be a simple movement, but it must have a goal (reaching some fruit to eat, for example): this is the main critic factor for their activation. Even when we can see an action not completed because the last part of it is hidden to us (Umiltà *et al.*, 2001), the mirror neurons activate like as the observed action was finished, and this happens thanks to the anticipation of purpose's achievement. When in every-day conversations we unconsciously imitate the posture of our interlocutor (e.g. crossing the arms), our mirror neurons are activated.

Although deficits in social communication must be present in order to get a diagnosis of ASD, there could be also the interest in making friendships, and even being able to have some friends. Some girls on the spectrum may actually be overtly social and extrovert, yet be autistic (see the video by @paigelayle, who is an overly social autistic girl <https://www.facebook.com/BuzzFeed/videos/autism-in-girls/157580918736377/>). Differently from a neurotypical person, autistic individuals feel the fatigue after social interactions, thus they may need rest, isolation, sleep, and relaxing activities at the end of the day. Females may show fewer impairments in social relationships than males, due to their stronger desire to form friendships (Head *et al.*, 2014; Hiller *et al.*, 2014), but many times with no known tool to maintain them.

Aspies tend to be perceived as blunt and honest, but they can be frequently misunderstood, with their words and intentions being misread. That is the case for flirting, in situations where women on the spectrum just tried to be friendly, with no other subtle interest. Furthermore, it is extremely hard to maintain relationships, because – based on the experiences of many Aspergirls – when things do not work out, they tend to burn bridges, often as the result of depression and temper meltdowns. Deciding to be the one to burn that bridge (never dealing with that person or place again) is linked to a sense of power over the unpredictability of life. This behaviour is damaging when it leads to isolation of the individuals, who may therefore take refuge in their imaginary world. It is wrongly believed that children with autism do not engage in imaginary play (whose observation is part of the diagnostic assessment). Girls, who were perceived to be less creative in their games, create and “inhabit a rich fantasy world full of imaginary friends, animals, and creatures (Attwood, 2007; Holliday Willey,

⁷⁴ Rizzolatti *et al.*, 1996; Gallese, 2010. For further discussions, see Legrenzi P: 2014. *Fondamenti di psicologia generale*

2014).”⁷⁵ Relationships with peers could be of no interest in children on the spectrum, who may seek instead adult interactions (those of mothers and grandparents). Also, solo play is a more logical and less stressful choice for many Aspies, who prefer to not share personal possessions. Even if for many parents it may be hard to acknowledge that being alone is the best thing for their autistic child, they could see no point or functional benefits in attending a group play.

Furthermore, some autistics suffer from prosopagnosia (Grandin, 1996; Blackburn, 1999), thus they have difficulty recognising others’ faces; they are blind to faces that are not familiar. For those people that do not have the ability to read facial expressions due to their blindness to faces, nonverbal communication becomes extremely harsh, as for children and adults with a central auditory processing disorder, thus they cannot discriminate emotions from voices.

3.2.1 Friendships and Romantic Relationships

Having an Aspergirl as a friend or a partner means loyalty, trustworthiness, honesty, strong moral code, and many other positive factors that can emerge after you really get to know the person. Critics are detrimental; people on the spectrum need positive reinforcement more than others. Too often people stop at superficial acquaintances, and whether there have been episodes of bullying, these extremely nice qualities may never see the surface. The main issues in female friendships, where at least one friend is autistic, is the management of conflicts, finding gossip and competition very hard to cope with (that is why many girls on the spectrum preferred the company of males, more easily readable). Aspergirls may have neurotypical friends, though, but usually only a special one (who become a lifeline and help her to enter the social sphere). They usually crave exclusivity with that best friend, experiencing enormous distress when she/he decides to get along with others. For some women, their partner is the only person they need in their life.

Several women found many “Aspies” friends using online media. Online platforms have made communication easier for people on the spectrum, preferring it to face-to-face conversations, because they are not invasive (you can decide when to withdraw from a conversation any time, how to dress etc.) and they do not cost money. Sometimes, though, the concept of “friend” on a social network may vary from the definition of “friend in real life”. For people on the spectrum, there is not a neat cut-off between friends, colleagues, acquaintances, which are roles sometimes complex to define; someone who would not consider them as friends, could be labeled as good friend by the Aspie.

⁷⁵ Simone, R. (2010) *Aspergirls. Empowering Females with Asperger Syndrome*. Published by Jessica Kingsley Publishers

Moreover, women on the spectrum may need a purpose (e.g., doing or talking about a special interest together) to meet: the idea of simply meeting to chat has no appeal, differently from NTs, who would choose socialising and companionship. As already discussed, for neurotypical people socialisation can be recharging; they do feel good when they have company. On the other hand, autistics may enjoy the time spent together, but it is always energetically draining.

As for love life, Aspergirls, differently from neurotypical girls, might be too direct with the person they like, generally making the first move. Traditionally, it should be the boy to ask the girl out, not vice versa. A guy asked out may feel intimidated, not expecting a girl to be so blunt and straightforward, since girls are expected to play hard to get and play games. But this could be perceived also as an invite to sex, even if it was not the initial intent. Sexual activity may not be enjoyed by many Aspergirls because it is strongly affected by sensory issues, hence being too painful or annoying. On the other hand, it can be extremely pleasurable, because of its intensity. However, studies have found that autistic women have a greater propensity to be asexual, gay, or bisexual, with a lower heterosexuality compared to males with ASD (Ingudomnukul *et al.*, 2007; Gilmour *et al.*, 2012).

When it comes to selecting a partner, practical considerations such as sharing interests and lifestyle are extremely important. During adolescence, though, Aspies may have a crush on someone just for a specific – and shallow – characteristic, as the hairstyle, the piercings, the tone of voice etc. Often, it occurs that two NDs end up together, suspecting some autistic traits in the partner whether he/she is not diagnosed (yet). Usually, romantic relationships between an NT and an ND are harder, but they could work anyway.

“Unconventional set-ups might be the answer for some: co-habiting might not work; sex might not be a requirement and separate rooms may be a necessity. Unconventional people require unconventional solutions to conventional arrangements.”⁷⁶

There is a TV-series currently distributed by Netflix which is titled “Love on the spectrum” (2019, Australian Edition, with two seasons, and 2022 for the U.S. Edition, with one season). It is a reality show that follows people on the autism spectrum as they explore the dating world, which received

⁷⁶ Simone, R. (2010) *Aspergirls. Empowering Females with Asperger Syndrome*. Published by Jessica Kingsley Publishers

positive critics, and which portrays the difficulties and aspects of dating life for neurodivergent people, giving an insight in the romantic life of autistic individuals in particular.

3.2.2 Workplace

Even though the person with Asperger may have excellent results in the academic field, in the workplace his/her social difficulties may interfere during interviews, or interactions with the team, not being able to keep their job eventually. It is often the case that people with Asperger's are unemployed or have a job that is not adequate to their qualification level, i.e., they get underpaid job positions despite their education (Allen & Coney, 2018). During interviews many Aspies mask their traits for fear of being rejected by the employer because of their diagnosis, and research confirmed that autistic individuals find it challenging to obtain employment (Engström *et al.*, 2003). There is still little awareness of the great benefits that people with Asperger's bring: they are a value added to the company.

In Italy, autistic people diagnosed with Level 1 (AS and HFA) cannot access to the employment lists provided for by the Law n. 68/99, which imposes an obligation on public and private employers to recruit disabled people according to the size of the company. Despite their difficulties, then, Aspies are not protected at all, and they are left on their own facing the struggles at work. The review by Zener (2018) lists some aspects of ASD that may interfere in the workplace, seeking to prompt a reflection on the changes in accessibility that should take place:

“Rigid rule following and policing others, and focusing on tasks while neglecting peer interactions can hinder relationship-building with colleagues. [...] Executive function challenges can interfere with work completion due to issues with organizing time, prioritizing tasks and planning and initiating work. Sensory overload from bright and noisy fluorescent lights, loud open workspaces, offensive smells and scratchy uniforms can easily overwhelm and distract an employee. After a history of workplace challenges, these women try to understand why their performance does not match their abilities and potential. [...] Admission of limitations equates to failure for many women with autism. Admitting vulnerability and asking for concessions or help is hard after a lifetime of masking.”⁷⁷

⁷⁷ Zener, D. (2018). *Journey to diagnosis for women with autism*. *Advances in Autism*, Vol. 5 n. 1, 2019, 2 – 13. Emerald Publishing Limited, ISSN 2056-3868. doi: 10.1108/aia.010.2018.0041

Sometimes Aspies can burn bridges even at work, leaving without giving notice. Such a behaviour will have an impact on the references and recommendations. Self-employment and smart working allow several Aspies to work from home at their pace, with their routines and spaces, and it turns out being the best choice for many, alongside part-time jobs (which enable autistics to dedicate more spare time to their special interests and relaxing activities). Neither earning large incomes, nor high status career positions are mentioned as priorities among Aspie community, rather preferring a healthy psycho-physical status, gained re-energising themselves and reducing anxiety levels. Research by Hendrickx (2009) found people on the spectrum gaining success in jobs where their strengths were needed and there was minimum exposure to the differences, correlating poor employment outcomes to initial negative first impressions during the interview.

3.3 Empathy

It is erroneously believed that autistic people lack empathy (Baron-Cohen, 2011). On the contrary, they show a marked sensitivity towards negative emotions experienced by others (Attwood & Garnett, 2014), even more than neurotypicals: “it is so strong that it can be overwhelming.”⁷⁸ They are extremely empathetic, and they cannot discern others’ suffering, witnessing it firsthand, thus becoming more depressed. Autistics must be educated to handle these emotions and increase their emotional awareness thanks to psychotherapeutic sessions of ACT (Acceptance and Commitment Therapy), CBT (Cognitive Behavioural Therapy) and Mindfulness. Individuals who may show less empathy, maybe decided to shut it off after traumatic and stressful periods (bullying, misunderstandings, critics, trauma etc.).

Two types of empathy are distinguished: cognitive (also called as perspective taking) and emotional (or affective) empathy. Autistic individuals have a great emotional empathy (empathic concern), showing difficulties with the cognitive one, which enables us to decide what to say and how to react in social interactions (inferring mental states). If individuals on the autism spectrum infer mental states incorrectly, they will react in a way that is not expected by NTs. People on the spectrum may find hard to put themselves in the shoes of neurotypicals, but the reverse is also true. We may describe the issue of autistics as a double empathy problem (Milton, 2012). The theory suggests that if people with different experiences of the world interact, they will struggle to empathise with each other; thus, autistic people seem not to lack empathy for other autistics.

⁷⁸ Simone, R. (2010) *Aspergirls. Empowering Females with Asperger Syndrome*. Published by Jessica Kingsley Publishers

“Autism spectrum conditions, along with other conditions such as psychopathy, have been described as “empathy disorders” (Gillberg 1992). Interestingly, few studies have formally assessed empathy in individuals with autistic conditions and those studies have generally focused on either the cognitive or emotional component alone or have not attempted to differentiate between the two components.”⁷⁹

Thanks to fMRI (Functional Magnetic Resonance Imaging), researchers have found that the regions of the brain playing an important role in empathy are the anterior cingulate cortex, the anterior insula, and the inferior frontal gyrus (IFG).⁸⁰ Other neuroimaging techniques like PET (Positron Emission Tomography), and non-invasive brain stimulation techniques such as TES (Transcranial Electrical Stimulation) and TMS (Transcranial Magnetic Stimulation) – the latter used as treatment for generalised anxiety – verified the localisation, in specific brain areas, of psychic functions whose alteration confirmed differences in pathological patients. An impairment of cerebral structures like amygdala and orbitofrontal cortex (OFC) compromises the regulation and processing of emotions (interpreting facial expressions falls into this brain structure). In autistic individuals, growth of amygdala is accelerated, and it is enlarged in two-year-old autistic children, compared to NTs. This study funded by the NIH (National Institutes of Health) found that that early therapies are crucial to reduce the symptoms of ASD; the earlier they begin (in the first year of life, “before the amygdala begins its accelerated growth”)⁸¹, the greatest chance of success they get.

⁷⁹ Dziobek, I., Rogers, K., Fleck, S., Bahnemann, M., Heekeren, H. R., Wolf, O. T. (2008) *Dissociation of Cognitive and Emotional Empathy in Adults with Asperger Syndrome Using the Multifaceted Empathy Test (MET)*. *J Autism Dev Disord* (2008) 38:464–473. doi: 10.1007/s10803-007-0486-x

⁸⁰ Shamay-Tsoory SG, Aharon-Peretz J, Perry D. [*Two systems for empathy: A double dissociation between emotional and cognitive empathy in inferior frontal gyrus versus ventromedial prefrontal lesions*](#). *Brain*. 2009;132(PT3): 617-627. doi:10.1093/brain/awn279 cited by <https://www.verywellmind.com/what-is-empathy-2795562>

⁸¹ Shen M. D., Swanson M. R., Wolf, J. J., et al. (2022). *Subcortical Brain Development in Autism and Fragile X Syndrome: Evidence for Dynamic, Age- and Disorder-Specific Trajectories in Infancy*. *The American Journal of Psychiatry*. doi: 10.1176/appi.ajp.21090896

Finally, the organisation of emotions is realised through the activation of the limbic system of which the hippocampus, the amygdala, the thalamus, and many other areas are part. An enlarged amygdala may explain the issues in sensory processing, which is analysed in the next paragraph.

3.4 Sensory Overload

High sensitivity is a typical neurological trait, present in 20-30% of the whole population, but the term “sensory processing sensitivity” and “environmental sensitivity” is proper of HSP (highly sensitive persons, PAS in Italian), of some people on the spectrum, and individuals with other neurodivergences (Acevedo, 2020). A sensory processing disorder is a syndrome per se, which is part of being autistic, each with a personal degree of severity (some are more sensitive to sounds, others to smells, touches, tastes, or sights). People often see autistics as impassive and hyposensitive (due to the monotone voice, the inexpressive face), while the truth is they feel everything that neurotypicals seem not to even notice. Autistic author Rudy Simone describes accurately the feelings and strategies to overcome sensory overload:

“Despite our legendary ability to focus, or perhaps because of it, we tend to need to address one noise at a time, so if we are on the phone, the television must be muted. If we are in conversation, the radio must be off. [...] Our sensitivity to sound as well as touch strongly affects our sleep habits and many of us can't catch 40 winks without earplugs and noiseless, heavy blankets. [...] some of us play in rock bands, or love heavy metal. But that means that we are prepared for it. We can handle an onslaught of sound for a time, but preferably a time, place and sound of our choosing.”⁸²

Many Aspies define their sensory processing problems more debilitating than their deficits in social communication. Sensory organs, or receptors, implement physical response to external stimuli transmitting signals to sensory nerves, and can be classified as exteroceptive and interoceptive receptors. The formers divide into sight, hearing, smell, taste, and touch, the latters operate internally (such as proprioceptors, which concern the proxemics and body movements, thermoreceptors that concern body temperature, hence the vasodilation and vasoconstriction, and nociceptors, nerves that concern pain). The vast majority of sensory information is processed in the thalamus, except for smell, which does not pass through the thalamus, but arrives directly in the limbic system (amygdala) up to the cortex. Differently from other senses, again, smell does not go to the opposite hemisphere, but it is processed by the same neurological side of each nostril.

⁸² Simone, R. (2010) *Aspergirls. Empowering Females with Asperger Syndrome*. Published by Jessica Kingsley Publishers

Another difference in sensory processing between autistics and neurotypicals is the Gestalt perception. Gestalt psychologists emphasise that NTs perceive entire patterns or configurations, not merely individual components, while people on the spectrum are not able to distinguish relevant from irrelevant stimuli, as foreground and background information. Autistics feel everything, not being able to select and filter (in 1974 Delacato found that some hypervisual autistic children were not deceived by optical illusions), hence in the whole image smallest details are usually remembered. Even if little elements change in a familiar setting, the whole scene (Gestalt) is perceived differently, thus becomes unfamiliar. Not knowing what to do in unfamiliar circumstances, and craving for routine, autistics may feel more stress and pressure, with a negative impact on the psycho-physical wellbeing. The perception of Gestalt may cause sensory overload; hence the individual adopts compensational strategies (conscious or not) to reduce it. “The sensory experiences more commonly shared by autistics are:

- Hypersensitivity and/or hyposensitivity (fluctuation between the two);
- Disorder derived from a specific stimulus or fascination for some stimuli;
- Distorted or delayed perception;
- Sensory agnosia (i.e., the inability to process sensory information);
- Sensory overload.”⁸³

In her book, author Olga Bogdashina (mother of an autistic child) also lists some perceptive styles which are influenced by compensatory and defensive strategies, and among these styles we find:

- “Monotropic (one channel of perception);
- Peripheral perception (avoiding direct perception, e.g., avoiding eye contact);
- Shutdown;
- Resonance (getting lost in stimuli, i.e., “feeling” colors or words, or identifying so strongly with animals, hence wishing themselves to be one);

⁸³ Bogdashina, O. (2003). *Sensory perceptual issues in Autism and Asperger syndrome*. Published by Jessica Kingsley Publishers. Edizione italiana: *Le percezioni sensoriali nell'autismo e nella sindrome di Asperger*. (2011). Uovonero edizioni

- Daydreams.”⁸⁴

Moreover, there is a moment in the life of many women, which is already destabilising per se: giving birth. The experience of delivering a baby is exceedingly overwhelming for women on the spectrum, who undergo a sensory overload, due to the lack of support for their autistic needs. Some may not behave typically, being too quiet and detached, while for others it can turn out as excruciating and exhausting. Awareness on the female profile in ASD is, for that reason, needed also in these fields, considering that autistics usually need and should take less than the recommended dose for medications, preferring herbal and homoeopathic treatments. Besides stimuli as light, taste, smell, there are many other factors that affect sensory processing of autistics, and are listed by Hendrickx (2015) in the following quote:

“Individuals with autism experience differences in tolerance for various stimuli. Traditionally, we recognise these to be related to external sensory stimuli such as light, sound or smell, but experience tells me that women with autism are affected by a much wider range of substances than that. Chemicals, medication, caffeine, fabric and other widely used substances cause physical reactions for many women. Air fresheners, fluorescent lighting, air conditioning, perfume, wool, aspartame, sucralose, sugar and washing powder are just a few triggers that are all around us and make life just that little bit more difficult for me personally (resulting in frequent migraines); as with physical health conditions, our reactions can make us appear to be fussy hypochondriacs, when, in fact, the sensitivity is very real.”⁸⁵

The main critic towards autistics behaving in a certain way (not accepted by social context), is why they cannot control themselves. It is not that easy to calm down when in overload, though. Electrophysiological and neuroimaging studies have shown that the conscious will to act appears after the onset of brain activity, thus before the individual is aware of his/her intention to act.⁸⁶ Decision making, then, is not a free willing choice, but it is already “dictated” by our brains. Therefore our

⁸⁴ Bogdashina, O. (2003). *Sensory perceptual issues in Autism and Asperger syndrome*. Published by Jessica Kingsley Publishers. Edizione italiana: *Le percezioni sensoriali nell'autismo e nella sindrome di Asperger*. (2011). Uovonero edizioni

⁸⁵ Hendrickx, S. (2015). *Women and Girls with Autism Spectrum Disorder. Understanding life experiences from early childhood to old age*. Published by Jessica Kingsley Publishers

⁸⁶ For further discussion, see Viggiano M. P. (2021). *Il rapporto tra mente e cervello: una ricerca continua*. *Psicologia contemporanea* n. 286, dicembre 2021- maggio 2022, pp. 6-11

actions are the result of unconscious processes that develop before awareness emerges (for further information, see Libet's clock paradigm).⁸⁷ According to the studies by Benjamin Libet (1983; 1985), which have been replicated many times, task initiation begins unconsciously, but it is always possible to exercise control consciously (in a limited time period, referred to as "veto" window) before executing the action; this "veto" window has been found to be shorter in people who define themselves impulsive,⁸⁸ as in pathological cases, such as psychogenic movement disorder, psychogenic tremors which are caused by anxiety, Tourette's syndrome, binge drinking, schizophrenia, and Parkinson (Cincotta, M., Giovannelli, F., 2021).

3.4.1 Shutdown, Meltdown, and Burnout

The symptoms of a meltdown can vary from stomach pain (accompanied by diarrhea, nausea, or vomiting), to headaches, dizziness, burning bridges, embarrassment etc. Two types of meltdowns can be distinguished: temper and depression meltdowns. The former types are usually over pretty quickly (in a few hours or a day), whilst the latter kinds can last for days, even weeks, and are very debilitating and intense (with negative thoughts, heavy crying), the recovery being pretty long, similarly to that of a mutism episode. Temper meltdown may manifest in public tears, yelling, or swearing, feeling an extreme tension due to witnessing injustice, false accusation, being ripped off, even hunger. Meltdowns in general can be triggered by touch, confusion, fear, and PMS (pre-menstrual syndrome) in girls, who become more susceptible during that time of the month.

A shutdown is a temporary and implosive response to a sensory overload and it leads to a withdrawal, not being able to speak and move, even struggling to think. Both are out of the control of the autistic individual. The difference between the two is described more in detail in the section "autism information resources" available on the website of Autism West Midlands charity:

"During a meltdown, a person may show extreme behaviours like shouting, self-harm, aggressive behaviour and repetitive behaviours. During meltdowns, there may be a risk of harm to the person themselves or to others. Meltdowns can be very distressing for the autistic person, as well as the people supporting them. During shutdown, a person may either partially or completely withdraw from the world around them. They may not respond to communication anymore, retreat to their room or lie down on the floor. They may also no longer be able to move from the situation they are in, no matter

⁸⁷ Cincotta, M., Giovannelli, F. (2021). *Quanto siamo consapevoli delle nostre intenzioni?* Psicologia contemporanea n. 286, dicembre 2021- maggio 2022, pp. 13-17

⁸⁸ For further discussion, see Intini, E. (2016). L'origine dell'impulsività. Focus. Published online at the following link <https://www.focus.it/comportamento/psicologia/lorigine-dellimpulsivita>

what it is (for example, a shopping centre or a classroom). Shutdowns tend to be more discreet than meltdowns, and may sometimes go unnoticed. However, like meltdowns, they are a person's response to reaching crisis point. Sometimes, meltdowns can turn into shutdowns. A person may show outward expressions of stress to begin with, then withdraw until their stress levels have reduced. In these cases, it is important to remember that the withdrawal itself isn't a sign that stress levels are reduced, but may be a necessary step for the autistic person to recover from the situation."⁸⁹

Both meltdowns and shutdowns are extreme reactions to everyday stimuli, a result of an accumulation of issues (stress, anxiety, depression etc.).

An autistic burnout on the other hand is not too dissimilar to a NT's burnout: it is caused by a long term exhaustion of emotional and executive overload, which may last even many months, similarly to depression. The definition of burnout in ASD is also given in the paper by Zener (2018):

“Autistic burnout is the emotional, physical and mental exhaustion caused by the cumulative effect of excessive and prolonged stress from having to consciously think through every life process. After years of performing at a high level, women can suddenly hit a wall. Feelings of inadequacy push them to work their hardest to prove their worth. They become profoundly drained and fatigued and can no longer function. This experience is often first identified as severe depression.”⁹⁰

Finally, in his book, Devon Price briefly summarises burnout as it follows:

“Autistic burnout is a state of chronic exhaustion where an autistic person's skills begin to degrade, and their tolerance to stress is greatly reduced.”⁹¹

⁸⁹ For further information, see

[https://www.google.com/url?sa=t&rct=j&q=&esrc=s&source=web&cd=&ved=2ahUKEwje0u24oL-AhWc_7sIHffjCMwQFnoECBQQAQ&url=https%3A%2F%2Fautismwestmidlands.org.uk%2Fwp-content%2Fuploads%2F2019%2F12%2FMeltdown and Shutdown Nov 2019.pdf&usg=AOvVaw1HXbgOmHTMckf5Grmc7LJV](https://www.google.com/url?sa=t&rct=j&q=&esrc=s&source=web&cd=&ved=2ahUKEwje0u24oL-AhWc_7sIHffjCMwQFnoECBQQAQ&url=https%3A%2F%2Fautismwestmidlands.org.uk%2Fwp-content%2Fuploads%2F2019%2F12%2FMeltdown%20and%20Shutdown%20Nov%202019.pdf&usg=AOvVaw1HXbgOmHTMckf5Grmc7LJV)

⁹⁰ Zener, D. (2018). *Journey to diagnosis for women with autism*. Advances in Autism, Vol. 5 n. 1, 2019, 2 – 13. Emerald Publishing Limited, ISSN 2056-3868. doi: 10.1108/aia.010.2018.0041

⁹¹ Price, D. (2022). *Unmasking Autism: The Power of Embracing Our Hidden Neurodiversity*. Octopus Publishing Group

3.4.3 What can lead to a meltdown or a shutdown?

There are many triggers, which also may seem trivial, but they usually are *the straw that broke the camel's back*. Autistic individuals experience high levels of stress, coming to a point they are no longer able to cope. Unexpected changes in routines, social overload, and sensory overload are all possible scenarios sparking off shutdowns or meltdowns.

Something that breaks the routine could seem silly and manageable from the majority of people; instead, people on the spectrum need routines and rituals as a way of controlling the unpredictability of the world. It can be linked to the executive function of cognitive flexibility, and it is not just about controlling issues. With the right therapy, time, and mindfulness, autistics can make compromises and reduce their need for routines, but it is a part of them and must be accepted (hence help them diminish confusion, e.g., putting objects always in their place; but rituals can also turn out irrational whether due to OCD).

In order to recover from a sensory overload or prevent a meltdown, some people have created special sensory rooms, with those smell, lights and sounds that relax and calm them down. Dark quiet rooms, hot baths, immersion in special interests, and social withdrawal are example of lessening overload. Another way to reduce stress and anxiety and hence prevent shutdowns and meltdowns are the stims.

3.5 Stimming

Stims are self-stimulant behaviours, involuntary strategies adopted by children to face hyper or hyposensitivity. These behavioural characteristics, although their usefulness in diagnosing ASD, do not provide explanations on the causes of such behaviours, nor how autistics experience the world. “Stimming behaviors typically include rocking, swaying, twirling, spinning (yourself or objects), humming, flapping, tapping, clapping, finger flaking, and so on.”⁹²

A more detailed list of stims is available below and at the link in the footnote (and they are valid also for adults, not just children):

- “hand and finger mannerisms – for example, finger-flicking and hand-flapping;
- unusual body movements – for example, rocking back and forth while sitting or standing;
- posturing – for example, holding hands or fingers out at an angle or arching the back while sitting;

⁹² Simone, R. (2010) *Aspergirls. Empowering Females with Asperger Syndrome*. Published by Jessica Kingsley Publishers

- visual stimulation – for example, looking at something sideways, watching an object spin or fluttering fingers near the eye;
- repetitive behaviour – for example, opening and closing doors or flicking switches;
- chewing or mouthing objects;
- listening to the same song or noise over and over.”⁹³

A series of toys, used by autistic people as stimming and fidgeting objects, is presented in the Appendix in Picture 13.

Suppressing the stims, in children is not useful; we should understand the reasons that trigger the behaviour and reduce them. Teens and adults, especially females, will start suppressing stims even if they are not told so, as a consequence of camouflaging: they recognise that these gestures, movements, echolalia moments are not shared by neurotypicals, hence they avoid them to disguise. Stims are soothing and shall they be suppressed when they are harmful for the person (e.g., head-banging or scratching.). They may help reduce negative feeling, as express joy and happiness, and everybody engages in stims to an extent (e.g., fidgeting with spinners or Pop it – Bubble toys), but the frequency and intensity are greater in autistic people, who stim from sensory issues, anxiety, social or emotional problems.

Autistic author Rudy Simone differentiate perseverations from stims, the former being “gestures, movements, or repetitive rituals we cannot stop ourselves from doing and so straddle that line between tic, stim, and ritual.”⁹⁴

Some autistic people may find ASMR (Autonomous Sensory Meridian Response) video soothing and beneficial, serving as audiovisual therapy. ASMR videos are described as “simulating sensory content such as whispering, crisp sounds, slow movements and personal attention. These varied media trigger the ASMR response in many, causing the person to relax, be comforted and even fall asleep”⁹⁵ and gives a sensation similar to goosebumps.

⁹³ For further information, visit website: <https://raisingchildren.net.au/autism/behaviour/common-concerns/stimming-asd>

⁹⁴ Simone, R. (2010) *Aspergirls. Empowering Females with Asperger Syndrome*. Published by Jessica Kingsley Publishers

⁹⁵ For further information, visit: <https://eu.usatoday.com/story/life/health-wellness/2022/10/06/what-asmr-videos-relaxation-sleep/10311995002/>

3.6 Special interests

“We have a marvelous ability to think about things in depth, continually, for long periods of time. In our hobbies, it's called *passion*. At work or school, it's called *focus*. But in our personal life, it's called *obsession*.”⁹⁶

Among the reasons why girls and women are diagnosed late in life, there is also the area of special interests, which is more socially accepted (Lai *et al.*, 2015) and results then in an underestimation of FAP. Females' special interest focus on animals, nature, soft toys, psychology, fiction, celebrities, historical characters etc. (Hull *et al.*, 2020) and differ enormously from males' interests (physics, computers, vehicles, trains, dinosaurs, space etc.). Every intense interest brings extensive knowledge – and a great amount of study – on a particular subject, which may become the favourite topic in every autistic conversation. Relatives, friends, and familiar people to the autistic person may perceive the discussions about these themes pedantic and more of a monologue – or lecture – given by their Aspie. Special interests are reassuring: “Knowing everything about a subject makes it known and provides a sanctuary from the anxiety and stress of a feeling of not knowing what's going to happen most of the time.”⁹⁷

3.7 Bullying and abusive situations

In order to feel accepted and fit in this social neurotypical world, autistic girls find themselves in passive roles, in risky situation, and toxic relationship, due to their ASC. Too many do experience victimisation, and passively, try to avoid conflict in every way, thus being forced to have sexual relations (not because they want to, but because “it is what it is expected by a girlfriend”). Girls on the spectrum are more likely to be sexually assaulted, compared to their neurotypical peers, and to be bullied (bullying victimisation is associated with increased levels of depression, anxiety, psychophysical health problems, low academic achievement, and behavioral difficulties) than autistic males (for further discussion, see Zener, 2018).

⁹⁶ Simone, R. (2010) *Aspergirls. Empowering Females with Asperger Syndrome*. Published by Jessica Kingsley Publishers

⁹⁷ Hendrickx, S. (2015). *Women and Girls with Autism Spectrum Disorder. Understanding life experiences from early childhood to old age*. Published by Jessica Kingsley Publishers

In a review by Bargiela *et al.* (2016), 9 out of 14 participants of their sample reported sexual abuse, at least half of them in a relationship, and three of them being raped by strangers. In the same paper, some reasons explaining how these young women had become entrapped in harmful situation were highlighted: the role of social mimicry, the difficulty in understanding others' real intentions and social rules, the feeling of isolation (and lack of space for discussion between peers), and the desperate desire for acceptance after being rejected many times. The diagnosis, for many of them, represented a tool to gain more confidence and becoming assertive, not passive anymore. Women and girls on the spectrum seemed compliant because of the fear of rejection, or just because they did not know they were allowed to say "no"; these mistakes are not related to any extent to intelligence, but purely with social understanding. Autistics believe what they are told and assume that others have good intentions, just as they do.

3.8 Addiction and suicide

The percentage of Aspies experiencing depression is higher in adults than adolescents. Dr. Attwood and Dr. Garnett in their book *Exploring Depression and Beating the Blues* (2016) give some insights about the reasons that bring to depression, such as the devaluation from peers, exhaustion due to social interactions, recurrent thoughts on mistakes and negative experiences, history of family depression etc. Cases of ignored and untreated depression may lead to use and abuse of substances and attempts of suicide. Being autistic – and with average to high intelligence – increases the risk of addiction. Drugs and alcohol are seen as a way to cope with loneliness, stress, anxiety, and depression: the results of constant camouflaging. Zener (2018) reviewed previous literature about the topic and writes as follows:

“Suicide is the leading cause of premature death for autistic adults with average or above IQ (Hirvikoski *et al.*, 2016). In a clinical study of adults diagnosed later in life with Asperger's syndrome, 66 percent had contemplated suicide in their lifetime, with females being the most affected (Cassidy *et al.*, 2014). Rates of suicidal ideation were highest for women 35 – 64 years, ranging from 75 to 89 percent of the group studied. Loneliness, perceived burdensomeness and lacking a sense of belonging all contribute to suicidal thinking across the lifespan (Pelton and Cassidy, 2017).”⁹⁸

⁹⁸ Zener, D. (2018). *Journey to diagnosis for women with autism*. *Advances in Autism*, Vol. 5 n. 1, 2019, 2 – 13. Emerald Publishing Limited, ISSN 2056-3868. doi: 10.1108/aia.010.2018.0041

The participants interviewed by Rudy Simone in her book *Aspergirls* (2010), instead, report not having attempted suicide, just thought about it; they could have never been able to do it, due to the uncertainty of what happens after death and the consideration of loved ones.

Autistics may even decide to do drugs because that is what neurotypical peers do, in the hope to finally blend in. Pills, drinks, smoke do not enhance social skills, on the contrary, they reduce them (hence, episodes of mutism, among the others, might increase). A similar argument can be made for medications given by physicians. Usually, antidepressants and other meds are useful just temporary, if at all, useless or hampering, especially when the individual on the spectrum is given a misdiagnosis. Generally, depression is harder to cure with medications, while anxiety can be treated well. As already mentioned, the dose recommended by the doctor should be lowered, it would be effective anyway. The same goes for phytotherapy and homeopathy, whose effects must not be underestimated.

Chapter 4 – Towards acceptance

In this final chapter the reasons to get a diagnosis will be addressed, along with the aspects that could change in life after it; some interesting books, videos and other content on the topic will be presented, alongside a case study based on the work by Dr. Valentina Pasin as coordinator of Gruppo Empathie, with an insight into the changes they have been making in the region of Veneto, Italy.

In the next paragraph, there is a list of pros of getting a formal diagnosis of ASD. It is fundamental to evaluate the advantages and disadvantages when thinking about a huge life-altering decision as such. Many – NTs, most of the times – would wonder what is the point of getting a diagnosis in the middle of life, when you survived even without it. Of course, you could agree with them, thus deciding you do not need one. But according to the majority of autistic testimonies, women diagnosed in adulthood do not regret it, actually there are few cases in which they do not agree with the diagnosis of ASD (AS and HFA), unlike the diagnosis of comorbidities as primary conditions.

4.1 The reasons to get a diagnosis

Deciding to turn to a specialised clinician or centre is a turning point in the life of every autistic person. Faith in physician is increasing proportionally as people on the spectrum feel the right recognition and acceptance. There has been a remarkable shift from the vision of “refrigerator mothers” to the leveling out of the gender diagnostic ratio. The prevalence of ASD in women is far higher than once thought (and we will probably witness in future the gender gap to narrow), and it is usually diagnosed later.

Many self-advocate groups and autistic authors considered the pros and cons of getting a diagnosis, with the advantages being more than the disadvantages. Here, some reasons will be given, in order to try to help people suspecting ASD decide to begin the diagnostic process:

- Relief: the idea of finally getting to know there is a reason behind all those times in which you felt different, not accepted, not fitting in, almost like an alien etc. brings to a state of self-acceptance and self-love which was never experienced before. You will start to be less strict, self-critical, and harsh on yourself, because you know you better, realising that there is nothing wrong with you. The opposite is also true, the first times after the diagnosis you may experience the “imposter syndrome”, you may feel lost, rejected, bearing an illness that has no cure, helplessness, depression... all this will only last – hopefully – temporarily. In the end you will learn to accept your characteristics, your limits, your quirkiness and will start

showing and celebrating them with others, too. Once you learn to accept and love yourself, others will follow;

- Clarity: knowing exactly what you “have” gives a clear view of what you can do, what you want to achieve in life, what you need and who you do not. Those lifelong questions get an answer, and it is ASD, the missing puzzle to your identity quest. Sometimes it can be overwhelming and confusing, realising that you have masked and camouflaged for the majority of your life, to a point you are not even sure about who you truly are. Is the person you see in the mirror the true you, or is it a result of mimicking and copying to please others? A diagnosis will give you the chance to understand and discover what you really like (in job, love, hobbies etc.);
- Confidence: once you truly get to know you, you are more confident, gaining more self-esteem; also, you will seem more credible towards both NTs and NDs, your family, your social network etc. You could step up and explain to your friends and colleagues the reasons why you are autistic, educating and informing others, without the fear of being silenced by “the stigma”, because now you have a diagnosis validating what you have been self-assessing for so long. You will be more confident as a parent as well, knowing what you can offer to your neurodivergent child, or knowing how to adapt to your neurotypical baby, always trusting your inner instincts. Being more confident means being able to ask for accommodations or compromises which take into consideration your needs as a person (on the spectrum). Though, knowing you are autistic (in this case AS) will not fix the fear of change, the need for control, the depression, nor will make you automatically accepted socially: people you meet might not realise you are on the spectrum, because you look smart and normal, and still expect you to be multi-tasking, well-mannered, always dressed up and capable. As it emerges in Simone (2010), during the diagnostic process, some women may find their true self, almost experiencing more autistic traits;
- Community: when given a diagnosis, just remember that you are not alone. Whether you may feel depressed, alone, vulnerable, do not forget there are lot of autistic people out there who may have faced the same struggling situations or who may need your help and personal opinions. It is easier to get accepted to people who are similar to you, with the same interests, similar life experiences... people who know what being on the spectrum means, friends with whom you can take the mask off and relax, never feeling judged. You will find many wonderful individuals that you probably would have never met if you did not get a diagnosis in the first place;

- Physical benefits: when you get to know your limits, what triggers a meltdown or a shutdown, you will use the strategies that you learned to live a better quality of life. You will be able to identify the situations that cause you anxiety and stress and learn how to handle them properly. Try different approaches until you find the strategy that works for you. Try to mask less and be more yourself. You will then realise how much anxiety, depression, social phobia, illness have less impact on your existence, and how their symptoms diminish when other accept you as you are. Furthermore, a correct diagnosis leads to an effective therapy, with the comorbid symptoms mitigated;
- Anger and negative feelings: you may feel regretful and angry at having tried to behave well for all this time and hence being diagnosed later in life, at looking back on all your lost opportunities; knowing it earlier could have saved you a lot of social faux pas, risky situations, bullying, eating disorders etc. because you could have had support and intervention from an early age. Reaching an important milestone in your self-enquiry journey, such a diagnosis of ASD, may result in some downtime to process the change: it is the example of author Philip Wylie who had a mental breakdown, with economic and employment issues. But fortunately, this feeling of depression and helplessness is just temporary.

In this last part of the paragraph, two quotes from two different autistic authors are presented, in order to offer two diverse perspectives about the advantages of a diagnosis:

“Unmasking has the potential to radically improve on autistic person’s quality of life. [...] Refusing to perform neurotypicality is a revolutionary act of disability justice. It’s also a radical act of self-love.”⁹⁹

...

“The advantage of a late diagnostic assessment can be that it will explain many aspects of the person's developmental history from bullying and teasing to issues in relation to motion management and relationships. In general, those who have been diagnosed later in life have been very pleased to have that diagnosis as a means of explaining many aspects of their life. It can also be useful in terms of the future in focusing on strengths rather than trying to resolve weakness (Tony Attwood, personal correspondence, 16 October 2013).”¹⁰⁰

⁹⁹ Price, D. (2022). *Unmasking Autism: The Power of Embracing Our Hidden Neurodiversity*. Octopus Publishing Group

¹⁰⁰ Wylie, P. (2014). *Very Late Diagnosis of Asperger Syndrome (autism spectrum disorder). How Seeking a Diagnosis in Adulthood Can Change Your Life*. Published by Jessica Kingsley Publishers

4.2 After the diagnosis

Getting a diagnosis might not reveal as easy also because of gender barriers, so do expect your concerns to be dismissed by your family doctor and non-specialised physicians, as in the video by Italian autistic advocate Emanuela Masia “Come certa gente pensa funzioni la diagnosi”, available at the following link <https://www.instagram.com/reel/CpdCWSloFN0/?igshid=MDJmNzVkMjY%3D>. In her book “I think I might be autistic” (2013), Cynthia Kim shares the comments she received on the blog about the difficulties faced undergoing the mental health systems and writes:

“Adults who suspect they may be on the autism spectrum often need to become self-advocates, arming themselves with the information necessary to make their case to a series of medical professionals. [...] Thanks to my newly developed special interest in autism, I had a strong foundation of knowledge. Putting all of those things together, I began to develop a blog post about getting diagnosed with autism spectrum disorder as an adult.”¹⁰¹

Once you get a formal diagnosis and you decide to share the information, you could experience opposition and contrasts, due to the misconception linked to ASD. People could not believe you, get angry at you, even mock you. It is important to educate these people, even though it is not entirely up to you: just because they do not know what autism is and the various facets that it takes, it does not imply that you must be the one to disclose all the information. There is plenty of self-advocate groups, books, articles, interviews of other autistic people. If your partner, relatives, friends, and colleagues want to know something more about it, they should just make do, reaching you out for advice or personal opinion, but never feel obliged to educate others, if that is not what you want to. Also consider that for someone a diagnosis does not validate your situation: many could just discredit medicine and science or the professional who diagnosed you, just because “you can’t be autistic, you give eye-contact, are social, and don’t rock”: in this case you should not waste time convincing someone who is not willing to be open-minded. As Dr. Hendrickx wrote: “The perception that if the presentation isn't immediately visible then the autism isn't something requiring accommodation is a common, and in many cases incorrect, one.”¹⁰² Otherwise, you may opt not to share your diagnosis, for fear of not being understood, teased, and bullied. Whatever you choose is better for you, it will

¹⁰¹ Kim, C. (2013). *I think I might be autistic. A guide to autism spectrum disorder diagnosis and self-discovery for adult*. Published by Narrow Gauge

¹⁰² Hendrickx, S. (2015). *Women and Girls with Autism Spectrum Disorder. Understanding life experiences from early childhood to old age*. Published by Jessica Kingsley Publishers

work. When the diagnosis is about a child, teachers should pay attention to the Aspie's classmates, in case they (or their parents) might think autism is contagious, if they nickname – thus bullying – their autistic classmate (some of the most renowned monikers in Italian are “asparago, autista, sindrome di hamburger”)¹⁰³, and be extremely careful about the child's self-esteem not to sink.

In her book “The Spectrum Girl's Survival Guide: How to Grow Up Awesome and Autistic”, teen autistic Siena Castellon lists some benefits and drawbacks of telling others about your ASD diagnosis, and they may be resumed as follows:

- You will get help and support easily, feeling free to finally be yourself in front of others;
- Others will have the possibility to understand some behaviours of yours, getting to know more about autism;
- People may not understand or be interested in what being autistic means;
- You may lose some friends, also noticing that people treat you differently (alas, this can be true also with family, with some relatives being more close-minded and judgmental than strangers).

In the review by Zener (2018), the experiences of more than eighty late-diagnosed women were collected, analysing the feelings prior – usually confusion and overwhelm (Hendrickx, 2015) – and post diagnosis. The most common feelings may space from relief, pride, and validation (Gresley, 2000; Moscone & Vagni, 2013; Powell & Acker, 2016, in Attwood, 2015), especially when there was a previous self-diagnosis, to shock, shame, confusion, despair, and feeling internalised stigma. Some women who were diagnosed in adulthood, instead, are happy not having received a diagnosis in childhood because they surely would have lived very differently, probably “protected”, or caged, in a label that imposes many limits, thus impeding them to experience moments and opportunities fully, taking away the independence. These late-diagnosed women are more willing to talk about the process that made them want to seek professional advice, the motivations why they thought they were autistic and how the diagnosis affected their life, because it is something that changed everything,

¹⁰³ Attwood, T. (2015). *The complete guide to Asperger's Syndrome*. Published by Jessica Kingsley Publishers

differently from girls diagnosed from an early age, who got used to it and “don’t want to talk about it; they just get on with it.”¹⁰⁴

The testimonies of late-diagnosed autistic women are fundamental also to know what aging on the spectrum actually means. Knowing what the negative aspects are, we can act to minimise the effects. As in neurotypical population, some traits will be accentuated, making life harder getting older. Plus, though the number of late diagnoses is increasing, the life experiences are still not enough to draw conclusions about what aging on the spectrum actually means (always keeping in mind that every person is unique, so the traits and difficulties may vary). There are many people who still go undiagnosed at a late age; for instance, Dr. Hendrickx (2015) worked with some elderly people who were refused a formal diagnosis because they had no living relatives who could confirm and provide additional information about the childhood impacted by ASD. Furthermore, she inferred that diagnosed women tend to experience autism differently with aging, becoming more and more empowered, assertive, and accepting towards themselves. All the efforts they might have endeavoured to please others, are replaced by a sense of self-value. Sometimes, this could lead to age lonely, even though aloneness is enjoyed and not rejected.

4.3 Acceptance through social media, books, blogs, and families

The material available on the web about autism is huge; there can be found many users sharing information for free in blogs and communities, as there are books and contents for a fee. Much material has been studied and reported in this dissertation, so all the papers and sources reported in the bibliography are highly recommended. In this paragraph, some passages which are perceived as emotionally relevant are presented, alongside some funny videos and useful informational materials. In the book “The complete guide to Asperger’s Syndrome” by Dr. Tony Attwood (2015), a chapter is dedicated to the role of media in recognising the signs of autism and Asperger’s. Widespread informative content may truly make the difference in a person's life, changing the idea that one had about autism and discovering that he/she/they might be autistic, too. That is why, some biographies and experiences told by autistic people are listed below, to give the possibility for others to watch/read them as well. The intent here is to provide for a general overview of the most known authors, not expanding much the topic of their books or talks.

¹⁰⁴ Hendrickx, S. (2015). *Women and Girls with Autism Spectrum Disorder. Understanding life experiences from early childhood to old age*. Published by Jessica Kingsley Publishers

I personally came across this topic some years ago, when, scrolling down the phone on Facebook, I watched a video by @paigelayle which is available at the following link: <https://www.facebook.com/BuzzFeed/videos/autism-in-girls/157580918736377/> . This autistic teen posted a four-part series on TikTok platform to explain autism (focusing also on the terminology of HFA and LFA, the gender differences and misconception) and these videos were mentioned and published in a whole single video by BuzzFeed journal. In the article about her, she stated:

“The diagnosis has changed my life for the better. I can understand myself so much better, which is so beneficial for social situations, school/work life, and most importantly being alone. I can now function alone and understand my emotions better.”¹⁰⁵

When I watched it, I instantly realised the idea I had about autism was not at all what it truly is. I imagined how many other people are not aware of how it really works and affects people who are diagnosed with ASD, hence, I decided to read more about it. I found it an interesting topic, especially thinking about the differences between boys and girls on the spectrum. Talking to family members, and acquaintances, I could say that they really did not know anything about autism as well. Readings, blogs, and videos led me to take some of the aforementioned tests to have an insight whether I could be autistic myself. Then, I let this topic go for a while, coming back to it again months later. From that moment on, I kept focusing on it, always more convinced I am autistic as well. I contacted some centres to get a formal diagnosis, and that is how I met Dr. Valentina Pasin, whose work I will present in the last paragraph. I am on a waiting list to get my diagnosis, even though I already told my family about my self-assessment. In the meanwhile, ASD has become one of my special interests, and I keep learning about it, being part of an autistic community of Aspergirls (the CyberAspergirls, a project created by Dr. Pasin). Some of what I wrote in my dissertation is part of my personal experience, as well, which I have seen is shared by many others. This was the first video I watched about ASD, and it changed everything. The following materials did not have the same impact on me, but they have been crucial for the consolidation of my convictions.

Let us begin with “Thinking in Pictures” the biography written by Temple Grandin who is an autistic industrial designer and professor who also held many talks and interviews (the followings all for Ted: The world needs all kinds of minds, 2010; Educating different kinds of minds, 2020; The hidden gifts of visual thinking with Temple Grandin), with a movie made about her life, too (Temple Grandin, 2010). In 2010 she was among TIME Magazine’s “100 Most Influential People in the World”. She was also interviewed by another late-diagnosed woman, Dr. Luisa Di Biagio (“Donne in Blu.

¹⁰⁵ For further information, see <https://www.buzzfeed.com/daniellaemanuel/girl-tiktok-autism>

L'autismo al femminile", 2018).¹⁰⁶ Other authors, such as the deceased Donna Williams ("Nobody Nowhere", 1992, and her website auties.org, created in 2004), Rudy Simone ("Aspergirls", 2010) Liane Wiley Holliday ("Pretending to be Normal", 2014), Hendrickx Sarah ("Women and Girls with Autism Spectrum Disorder", 2015), Cynthia Kim ("I think I might be autistic", 2013) Michelle Garnett (who usually co-author books with Dr. Attwood), are all women who wrote about what it means being diagnosed with autism in adult age. Their experiences are extremely useful to "new" autistic women, they represent a lifeline which describes what to expect for those who just received their diagnosis and were not aware of what autism actually is, thus becoming mentors. Among these authors I recommend the books by Rudy Simone as a first reading because they are suitable for both parents and autistic girls, as for the partners of autistic women. She gives advice directly to young girls, encouraging them to cultivate their interests and talents, always being proud and happy to be an Aspie ("vulnerable and courageous" at the same time), and for parents and partners who may have some difficulties dealing with their loved-one. Dr. Bullivant, too, in her book "Working with Girls and Young Women with an Autism Spectrum Condition" (2018) collects the testimonies of many families, writing a guide for young Aspergirls and for clinicians who are not trained in the FPA (female autism phenotype). Some younger Aspergirls, such as autistic teen Siena Castellon (her book and website have already been cited throughout this dissertation), the Italian Eleonora Marocchini (@narraction), Ph.D. in Psycholinguistics, who spreads awareness about pragmatic issues, along her "DiverGente" and "NeuroKit" projects (among others),¹⁰⁷ the aforementioned Layla Page with her informative videos and Kate Kahle in her Ted Talk, the Italian artist Margherita Tercon (@la_panzer) who creates funny and informational videos with her autistic brother, and many others are willing to help other autistic peers and young adults and their contribution is equally welcomed and appreciated. It is imperative not to inform people just on occasions, though the World Autism Awareness Day – which is internationally recognised on April 2nd, with its colour being the blue, and it was adopted by the U.N. in December 2007– may represent a first step for awareness. There are other national and international events that spread knowledge about it, like conferences, and retreats accessible to autistic people, like Insar (International Society for Autism Research), Autreat, cited by Steve Silberman in his book "Neurotribes" (2015), which were autism-friendly retreats organised by A.N.I. (Autism Network International, the advocacy organisation founded by Jim Sinclair and Donna

¹⁰⁶ For further discussion about Luisa Di Biagio, see

https://www.facebook.com/freedamedia/videos/just-ask-luisa-di-biagio/2207806879300304/?locale=it_IT

¹⁰⁷ For further information, see <https://www.narraction.com/chi-sono>

Williams in 1992) with sensory inputs attenuated for the people on the spectrum to relax, availability of devices for augmenting communication and other characteristics conceived by autistic organisers for autistic participants, and they lasted from 1996 to 2013. Another conference by and for autistic individuals which has been held for many years running (the first dates to 2005) is the Autscope,¹⁰⁸ and many other international events, both future and past, are presented in the website World Autism Organisation (<https://worldautismorganisation.com/>).

4.4 Awareness raising in Italy. A case study

In Italy there are some public services specialised in adult diagnosis, for example the *équipe* coordinated by Dr. Roberto Keller of the ASL in Turin, Sant'Orsola hospital in Milan, Dr. Strizzolo and Dr. Sale at ULSS 8 Vicenza, the ASL in Rimini etc. Others may be found in the aforementioned link:<https://www.ilariaesimoneblog.it/professionisti-a-cui-rivolgersi-per-avere-una-diagnosi-di-autismo-per-bambini-o-adulti-in-italia>

In the region of Veneto there is also good public service for ASD diagnosis in adulthood (Vicenza), for example, as many professionals who work on their own. In this last paragraph, though, the attention is brought to the work of Gruppo Empathie, its *équipe* currently coordinated by Dr. Valentina Pasin, because of the quantitative – and qualitative – projects that they have developed to gather autistic people together.

Starting from the most recent conference, the 8th international convention “Autismi. Vite ad ampio spettro – Multidisciplinarietà e neurodivergenze” held in Rimini and online April 28th and 29th, in which Dr. Pasin had a speech on Autism in females and the history of Gruppo Empathie was exhibited.

Founded in 2015 by Dr. Maria Grazia Chilò, “Psychologist and Psychotherapist, former Head of the Child Neuropsychiatry Operating Unit of Thiene (VI) and former Head of the Outpatient Clinic for Autism Spectrum Disorders of the former ULSS n. 4 Alto Vicentino”,¹⁰⁹ the team was initially composed of three professionals and has expanded its network of clinical collaborations. In 2020, Dr. Chilò retired from clinical practice and the coordination of the team passed to her daughter Dr. Valentina Pasin, also Psychologist and Psychotherapist. Among the other titles, she also won the price in February 2023 “Donna dell’anno 2022 - under 35” the 5th edition of an Italian contest which presented fifteen out of the eighty-five applications received this year, thus appearing in many local

¹⁰⁸ For further information, visit the following page <http://www.autscope.org/>

¹⁰⁹ For further information, visit <https://en.gruppoempathie.com/equipeditiene-collaborazioni>

newspapers.¹¹⁰ The aim of the contest is to award the most influential professional woman, whose contribution in her own field is recognised by colleagues and citizens. The work that led her to win such a price includes a long academic path. Born in 1988, she graduated from high school, then she got her bachelor's degree in "Cognitive and Psychobiological Sciences" at the University of Padua (2010), and her master's degree in "Neuroscience and Neuropsychological Rehabilitation" at the University of Bologna (2014). Alongside the vocational trainings, conferences, and seminars, in 2015 she got the qualification to the profession of Psychologist at the Order of Psychologists of the Veneto Region (registration number: 9433). Moreover, Dr. Pasin specialised on autism in the female profile while training in Canada (2016-2017), obtaining the Canadian specialisation on ASD, the DESS-TED (*Diplôme d'Études Supérieures Spécialisées en Intervention Comportementale auprès des Personnes avec un Trouble Envahissant du Développement*) at the University of Québec in Montréal. There, she worked with Dr. Isabelle Hénault at the "Clinique Autisme et Asperger de Montreal", also publishing a diagnostic questionnaire for adult Aspergirs in "Le profil Asperger au féminin: Caractéristiques, récit et guide d'évaluation clinique" (2020, published by Chenelière Education). In 2022 she graduated from the SLOP (*Scuola Lombarda di Psicoterapia*), specialising in Cognitive and Neuropsychological Psychotherapy, and in the same year she also held a convention at Ca' Foscari University (May 25th), titled "Convegno internazionale: prospettive diacroniche sullo spettro autistico", with Prof. Tony Attwood and Dr. Isabelle Hénault as speakers.

Her academic career is a manifest symbol of her passion and professionalism towards the field of neurodivergences. Since her experience abroad in 2017, Dr. Pasin has started a clinical collaboration with internationally renowned experts, like Dr. Tony Attwood, Dr. Bruno Wicker, and Dr. Isabelle Hénault, who cooperate in another project offered by Gruppo Empathie: AUT-US. With this latest project (started in 2022), which has been successfully crowdfunded, Gruppo Empathie aims to create an Italian community of people – professionals and autistic individuals – offering a quality scientific training on autism and neurodivergence (hence, aligning clinicians with the latest methods, in order to create a national network up-to-date and able to support people on the spectrum), with monthly seminars with a two-year frequency, and simultaneous interpretation to overcome the linguistic barrier. Among the other implemented projects, the monthly appointments for the autistic community started in March 2018, with the first Aspergirs appointment in the previous office in Thiene (VI) with six participants, who became almost twenty in few months. In fact, Gruppo Empathie offers many services (from the diagnostic evaluation for Asperger's children, adolescents and adults, to

¹¹⁰ For further information, see <https://www.altovicentinonline.it/arte-e-cultura-2/fara-vicentino-valentina-pasin-e-la-donna-dellanno-under-35/>

psychoeducational training for children and adolescents, to adapted psychotherapy for adults, to neuropsychological evaluations and trainings based on age etc.) including group activities, which, at the moment, are divided into the following categories:

- Aspergirls: group activity made in person once a month, dedicated to Asperger girls and women aged 16 and over, but suspended temporarily due to COVID-19 restrictions;
- Aspergirls Baby: created in February 2023 for girls aged 8 to 10 and conducted by Dr. Francesca Vettore (alongside a monthly parent training meeting);
- Aspergirls young: starting in 2020 for girls aged 13 to 19 years, led by Dr. Alessia Gasparini, then splitting into two different groups in 2021 (dedicated to girls aged 11 to 15 and 16 to 20 years with online meetings, twice a month);
- Cyber Aspergirls: created in 2020 due to the pandemic of COVID-19, for adult Asperger women aged 20 and over, meeting online once a month;
- Aspiemen: exclusively for Asperger men aged 35 to 50, with monthly meetings, online;
- Sound Experiences: a collaboration which started in 2021 with musician and composer Carlo Garof, who teaches drums and percussions, alongside the history of modern music and propaedeutics to rhythm, to children, teenagers, and adults.

Previous meetings included two group activities with professional actor Loris Rampazzo (2018-2019): participants aged 11 to 16, with the involvement of speech therapist Dt. Anna Toniolo, focused on communicational aspects (tone of voice, rhythm, gestures etc.) and conversation; participants aged 17 to 22, a group conducted by Dr. Pasin and Dr. Lucia Pavin (Psychologist and Psychotherapist), concentrated on emotions (verbal and nonverbal expressiveness of primary emotions) and on the correct use of social network, with management of real and cyber-bullying. In general, however, there are various groups organised also for little ones, and also boys, when the minimum number of participants is exceeded. These meetings, regardless of age, offer a therapeutic space for the well-being of neurodivergent people, promoting sharing of experiences and worries, and they should always be complemented with individual paths. The themes addressed are obviously adjusted based on the age of the participants, but there are common topics throughout the groups: ASD diagnosis of Level 1, the female phenotype, interests and talents, strengths and weaknesses, management of anxiety and depression, sensory issues, relationships, sexuality, identity of gender, work and multipotentiality, executive functions, parenting and motherhood etc. In these groups, there shows a deep need to finally feel free and understood in a safe, non-judgmental space.

To access these groups Dr. Pasin has an interview with the person willing to join these activities – because they are intended and conceived just for neurodivergent people– considering the possibility of a future diagnosis. My individual meeting with her lasted more than half an hour, and I had sent her, prior to that meeting, my written consent for privacy and a self-reported, brief essay, about the reasons why I think I am autistic. She gave me the opportunity to join the Cyber Aspergirls group (with its support network via Telegram and Discord, two online social media platforms) even if I do not have a diagnosis of Asperger's yet, but she is pretty sure I will get one, already being able to label many traits and behaviours of my persona.

In the near future, Dr. Pasin and her equipe are willing to add to this list a group for LGBTQIA+, another target largely ignored by Italian professionals. This term includes various people: lesbian, gay, bisexual, trans, transsexual, transgender, questioning and exploring their sexuality, queer, intersex, asexual, with the plus sign (+) including people who support and rally the movement, such as agender, demisexual, genderfluid, gray-ace in general, non-binary and genderqueer, pansexual, sapiosexual, polyamorous, two-spirit (2S) etc. The priority, though, is currently given to the female Asperger profile, because it is still unknown to too many clinicians, who are not able to recognise the traits of ASD in women, most of times ending up giving a misdiagnosis. Alas, as for other specialised centres, the waiting list is long (with up to 12 months and up), so getting a diagnosis is practically impossible now. But the focus of AUT-US is exactly to form other professionals who could diagnose ASD in adult women as well, and to spread awareness on the topic (thus the supply and the demand could become even); the blog available at the following link <https://www.gruppoempathie.com/blog> provide informational content, accessible to non-professionals, too. The Group is constantly evolving and changing (implementing new collaborations and new projects), with the latest event being the opening on the 22nd of April 2023 of the new offices based in Vigonza (PD), which represent now the headquarter, and the previous offices in Thiene (VI) becoming the subsidiary. For the occasion, the mayor of the city attended, and the event was also reported in local newspapers. Soon, in this new head office, meetings and activities for the autistic community will return in presence, still maintaining the duality with online, a useful way to interact for all the participants who live in other regions and abroad. Indeed, methods of telematic intervention are effective as an alternative to those in presence. The pandemic had made possible to diagnose remotely, legally recognising the value of clinical work through online platforms, thus increasing the number of requests for diagnosis. Before the onset of COVID-19, the physical presence in the previous offices in Thiene (VI) was required, with limited requests from other Italian regions. Now, since Dr. Pasin speaks also French and English fluently, there is a high demand from north Europe as well. Finally, the centre counts among its

members over twenty both internal and external collaborators, with several national (Gruppo Asperger Veneto, FundAspie Italia, Fondazione Brunello Onlus, Holos) and international partners (Mind & Hearts Clinic, Attwood & Garnett Events, Clinique Autisme et Asperger de Montreal). We can expect great achievements and expanding projects from Gruppo Empathie. In this last paragraph a case study about this professional reality, and its clinicians, pride of the region of Veneto, was presented. Differently from other private professionals and public services, it is gaining more rewards over the years, consolidating in the national territory, and offering support to autistic and neurodivergent community as other institutions are not able to provide in such numbers and results. There is no such professional figure in the region of Veneto, specialised in autism in females both in Italy and Canada, working with the most prominent exponents of the field, and participating so extensively in the scientific divulgation, as Dr. Valentina Pasin, who undoubtedly deserves a praise for her pioneering career and unique approach towards her neurodivergent patients.

To conclude this chapter, one of the several pictures of Dr. Pasin with some international experts, but also collaborators and friends, is showed, with her (on the right) portrayed next to Dr. Tony Attwood, Dr. Isabelle Hénault, and Dr. Bruno Wicker (on the left).



Picture taken from the following link: <https://www.gruppoempathie.com/post/2018/11/19/il-nuovo-questionario-di-screening-per-le-donne-con-sindrome-di-asperger-gq-asc>

Conclusions

Throughout this dissertation, the main focus was given to Asperger syndrome, expressly maintaining the term to recognise the precise identity of people who have different functioning than those of classical autism, a thought shared by Gruppo Empathie and other experts as well. Officially, Asperger's as a diagnosis has been removed from the latest version of DSM, and it has been replaced by ASD type 1 (low need for support). When merging these two terms, though, the complexity of these worlds gets lost.

Terminology is essential, thus people on the spectrum do not “suffer from autism or Asperger's”. Coming out with a diagnosis should not be perceived as bad news. Others should not criticise for someone wanting to be “labelled”, even if late in life. Nobody should feel obliged to defend his/her/their own decisions to pursue diagnosis, as to have regrets putting it out. The reasons to seek professional advice have been extensively addressed. The common feeling of not fitting in unites most members of the autistic community. During her teenage years, autistic author Clare Sainsbury writes that she was depressed because she had always felt different without knowing why, and that this feeling is shared by many Aspies. Hereafter, a passage of her book “Martian in the Playground”:

“Some people fear that having a label is equivalent to stigmatize a child. But the social stigma is associated in every way with being disabled or different, not with the label itself (this process can be seen at work in the shift from “mental retardation” to “mental handicap” to “learning difficulties”, where each new expression is itself contaminated by the stigma). Sadly, those who are different will be marked, whether they have a label or not, and children with Asperger syndrome who avoid official labelling generally cannot evade the unofficial one. [...] The problem is the stigma associated with diversity, not the label. [...] Avoiding labels does not make the differences disappear, a person with undiagnosed Asperger syndrome still has Asperger syndrome. Sometimes parents, in particular, react as if it were the diagnosis itself that compromised their child; and if only it were possible to withdraw the diagnosis, their child's problems would disappear. But a proper tag is simply a way of describing someone by enabling people to better understand their differences. [...] A label can create problems, but it also provides the tools needed to understand such problems and begin to deal with them.”¹¹¹

¹¹¹ Sainsbury, C. (2009). *Martian in the Playground. Understanding the Schoolchild with Asperger's Syndrome*. Published by Sage. Edizione italiana: *Un'aliena nel cortile*. (2010). Uovonero edizioni. Alcune persone temono che avere un'etichetta equivalga a stigmatizzare un bambino. Ma lo stigma sociale è associato in ogni modo all'essere disabile o diverso, non all'etichetta in sé (questo processo può essere visto all'opera nello spostamento da “ritardo mentale” a “handicap mentale” a “difficoltà di apprendimento”, dove ogni nuova espressione viene a sua volta contaminata dallo stigma).

As for the situation in our country, nowadays in Italy, children progressively start to benefit from an early diagnosis and get the needed therapy, with methods of proven effectiveness (EBM, ABA, TEACCH). Among the laws and regulations about autism, there are “Linea Guida dell'Istituto Superiore della Sanità n. 21 *Il trattamento dei disturbi dello spettro autistico nei bambini e negli adolescenti* (2011)” and the following law n. “134/2015 *Disposizioni in materia di diagnosi, cura e abilitazione delle persone con disturbi dello spettro autistico e di assistenza alle famiglie* pubblicata nella G.U.”, but other reforms are needed to improve the quality of life of people on the spectrum.

Regulations and norms are constantly changing, but so is how autism is diagnosed. ASD has a highly heterogeneous presentation, besides screening and diagnostic tools are important, but more crucial is the clinical judgment. Teachers are fundamental in recognising autistic traits from an early age, which may manifest as behavioural problems. It is essential not to focus exclusively on these issues, which are just the top of the “iceberg”; it is important to understand the causes that underlie these behaviours, based on an analysis from the inside, and adapt some strategies. Teachers of Asperger’s children may sincerely appreciate and accept their characteristics, always been calm and concentrated, willing to learn, and tolerant (this also applies to support teachers, i.e., “insegnanti di sostegno” in Italian).

The majority of cases, when we deal with misdiagnosis or the lack of a diagnosis at all, is represented by adult girls and women. The core aim of this thesis was to consolidate the previous literature on the topic, focusing on this hidden disability, which seems to be ignored by this society when it involves girls. Special interests of little girls are more socially accepted than in boys, with females being better at masking. The need for a change and for a better understanding and acceptance of autistic women

Tristemente chi è diverso sarà marchiato, che abbia un'etichetta o no, e i bambini con sindrome di asperger che evitano un'etichettatura ufficiale generalmente non si sottraggono a quella non ufficiale [...]. Il problema è lo stigma associato alla diversità, non l'etichetta. [...]. Evitare le etichette non fa scomparire le differenze, una persona con sindrome di asperger non diagnosticata ha comunque la sindrome di asperger. A volte i genitori in particolare reagiscono come se fosse la diagnosi in sé ad aver compromesso il loro bambino; e, se solo fosse possibile ritirare la diagnosi, i problemi del loro bambino scomparirebbero. Ma una corretta etichetta è semplicemente un modo per descrivere qualcuno mettendo in grado le persone di capire meglio le sue differenze. [...]. Un'etichetta può creare problemi, ma fornisce anche gli strumenti necessari per capire e per incominciare ad affrontare tali problemi.” Page 46 [translated by me]

is possible just through spreading awareness about it. There are still too many misconceptions about what autism truly is. Looking for repetitive behaviours (like rocking or clapping hands), avoidance of eye-contact or meltdowns, are not the only manifestations of autistic traits (again, not symptoms, because autism cannot and must not be cured, just understood). All teachers, as clinicians, should get trained to look for common characteristics of both the male and female phenotype, with the hope that in a near future common people will know them, too.

To conclude, it is fundamental to remind ourselves that the aim, when dealing with people on the autism spectrum, is not to recover from ASD, but the improvement in their quality of life.

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Sitography

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- Autism in girls explained by @paigelayle
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- Siena Castellon and her website <https://www.qlmentoring.com/>
- DSM History <https://www.psychiatry.org/psychiatrists/practice/dsm/about-dsm/history-of-the-dsm>
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- Kati Morton, "Autism in females - How is it different"
<https://www.youtube.com/watch?v=gpJ6bJHEc-k>
- "The Autism Blogcast - Diagnosis and Prevalence of Females with Autism"
<https://www.youtube.com/watch?v=NWq0JcPTaus>

- Niamh McCann TEDTalk - "Copy & Paste"
<https://www.youtube.com/watch?v=QY2ctCuTWPw&t=96s>
- "The Chameleons: Women and Autism"
<https://www.youtube.com/watch?v=VJHa9xk16Hw&t=19s>

Appendix

Here are some charts and images, which are presented in this section because they would have occupied a lot of space in the chapters, making reading more difficult.

Pare che abbia
a che fare
con i vaccini!

In fondo
non siamo
tutti un po'
autistici?

Fatti prescrivere
dei farmaci.

Santo cielo, mi dispiace tanto,
è orribile.

Ma comunque
tu parli!

Oh merda.

Ma no, ma un autistico
è uno che sbava
e che sbatte la testa
sul muro!

Tu hai un'aria
così NORMALE!

Informati, credo
che sia curabile.

Sei solo
un po' timida.

Ah sì,
so cos'è, ho visto
la serie "MONK".

Vuole dire che
non ti piace
la gente?

È una
malattia?

Però non
è una scusa!

Picture 1: People's comment on being autistic in Dachez, J., illustrations by Mademoiselle Caroline.
Edizione italiana: *La differenza invisibile*. (2018) Edizioni Lswr.

ESSERE ASPERGER ("ASPIE" PER GLI AMICI) È...

Avere difficoltà a cogliere l'implicito, le metafore, i codici sociali.



la risposta non la so...
vado a naso!



Crescendo, la persona Asperger si costruisce un proprio repertorio di espressioni che arricchisce poco a poco, ma può continuare ad avere difficoltà con i doppi sensi, cosa che molto spesso la penalizza nella comprensione delle istruzioni a scuola e, più tardi, nella vita professionale.



Picture 2: What does it mean to be Asperger? in Dachez, J., illustrations by Mademoiselle Caroline. Edizione italiana: *La differenza invisibile*. (2018) Edizioni Lswr.

INTERESSI SPECIALI

Una persona Asperger di solito vive le sue passioni in modo così intenso che può dimenticarsi di bere e mangiare, e parlarne per ore.

Certi interessi sono socialmente accettabili...



... e altri meno.



Anche l'età è cruciale: un bambino aspie che parla per ore di dinosauri sarà sempre visto meglio di un adulto che fa la stessa cosa, ma non bisogna dimenticare che diventerà grande anche lui! La tolleranza delle persone che lo circondano non deve diminuire.

Picture 3: Special interests in Dachez, J., illustrations by Mademoiselle Caroline. Edizione italiana: *La differenza invisibile*. (2018) Edizioni Lswr.



Picture 4: Difficulties in social interactions in Dachez, J., illustrations by Mademoiselle Caroline. Edizione italiana: *La differenza invisibile*. (2018) Edizioni Lswr.



Picture 5: Ipersensitivity in Dachez, J., illustrations by Mademoiselle Caroline. Edizione italiana: *La differenza invisibile*. (2018) Edizioni Lswr.

ALTRE CARATTERISTICHE

The illustrations depict various characteristics of Asperger's syndrome. On the left, a person is shown in three different stereotyped movements labeled 'multifino', 'mezzogiorno', and 'senza'. In the center, a woman asks 'Hai visto il mio vestito nuovo?' and the person replies 'Carino eh?'. To the right, a person says 'Meh, non mi piace per niente.' and another person says 'oops!' while dropping a stack of papers.

Gli "aspie" possono compiere movimenti stereotipati.

Non sanno mentire

Spesso sono maldestri

E il sesso?

Sono comuni profili sessuali diversi da quelli delle persone non autistiche. Spesso gli aspie sono meno soggetti alle norme sociali, proprio come la loro identità di genere. La loro diversa concezione del mondo, infatti, spinge a una grande diversificazione sessuale. Una persona Asperger può essere eterosessuale, omosessuale, bisessuale, pansessuale, asessuale... Si osserva anche una comorbilità¹ con la disforia di genere² più elevata rispetto alla popolazione generale. Gli abusi sessuali sono molto frequenti, in particolare per le donne aspie, per il fatto che non sanno identificare i potenziali predatori e che spesso per loro il concetto di 'consenso' risulta incerto o poco chiaro. La goffaggine sociale può portare ad assumere comportamenti sessuali inadatti o perfino inappropriati, motivo per cui è essenziale parlare di sessualità con i bambini aspie fino dalla più tenera età.

Gli aspie sono attaccati ai loro rituali e routine, e gli imprevisti per loro sono molto spesso fonte di angoscia.

¹ Presenza simultanea di diversi disturbi, malattie o condizioni.
² "Disforia di genere" è un termine psichiatrico che descrive il disagio o la sofferenza, anche molto intensi e persistenti, di chi vive un'incongruenza tra il proprio genere sessuale alla nascita e quello in cui si riconosce, identifica, percepisce o a cui sente di appartenere.

Picture 6: Other characteristics in Dachez, J., illustrations by Mademoiselle Caroline. Edizione italiana: *La differenza invisibile*. (2018) Edizioni Lswr.



Picture 7: Adaptive strategies in Dachez, J., illustrations by Mademoiselle Caroline. Edizione italiana: *La differenza invisibile*. (2018) Edizioni Lswr.

I PUNTI FORTI DI UN ASPIE



Alcune aziende iniziano a rendersene conto e ad assumere persone autistiche o Asperger riconoscendo e apprezzando le loro competenze. Ma perché le cose funzionino è necessario tenere conto delle specificità del singolo individuo e proporre qualche adattamento, come per esempio:

- Un ufficio tranquillo.
- La possibilità di non trattenersi per tutta la riunione.
- La possibilità di lavorare in parte da casa, in telelavoro.
- Sostituire il più possibile i contatti telefonici con e-mail.
- Privilegiare le istruzioni scritte.
- Adeguare gli orari perché possa evitare le ore di punta sui mezzi di trasporto pubblico.
- Permettergli di portare tappi per le orecchie o una cuffia antirumore.
- Adattare l'illuminazione (niente neon, per esempio).

- **Ha un acuto senso dei dettagli. Molti, per esempio, si occupano della scrittura dei rigorosissimi codici dei programmi informatici.**

- **È molto onesto e rispetta le regole.**

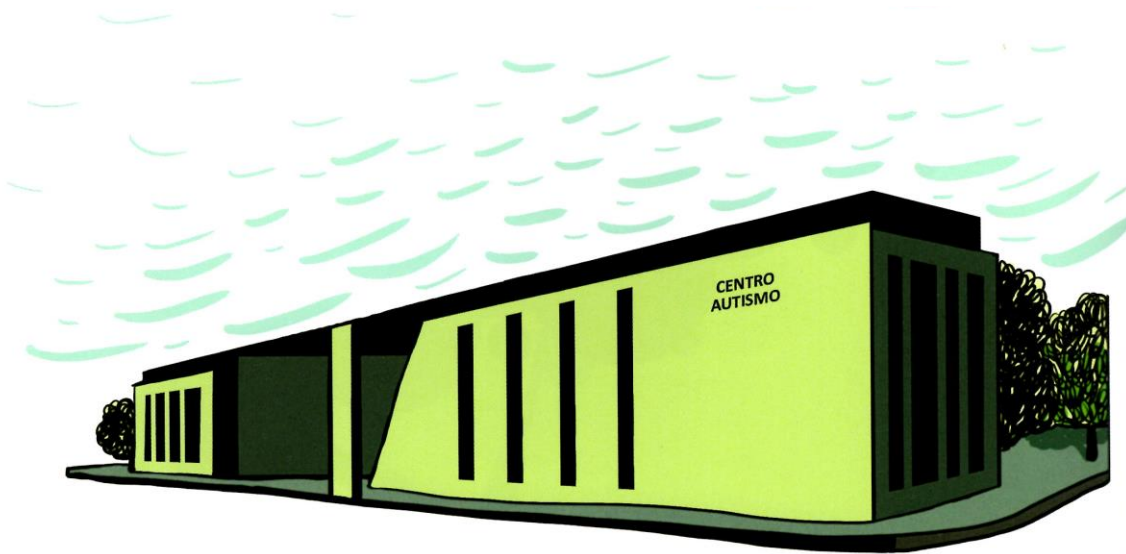
- **Tende a non farsi influenzare dall'opinione corrente, giudicando in modo indipendente.**

- **È capace di concentrare l'attenzione per ore su un argomento che gli piace.**

- Informare i colleghi delle particolarità di quello specifico individuo, in modo che non si formalizzino se non mangia insieme a loro o non si ferma a parlare alla macchina del caffè.
- Nominare un mentore volontario all'interno dell'azienda, che potrà dare indicazioni su quello che si fa e non si fa in base alla cultura di quell'azienda.



Picture 8: Strengths of Aspies in Dachez, J., illustrations by Mademoiselle Caroline. Edizione italiana: *La differenza invisibile*. (2018) Edizioni Lswr.



PER UN PAIO DI GIORNI MARGUERITE SI SOTTOPORRÀ A UNA SERIE DI TEST PER CONFERMARE (O MENO) LA DIAGNOSI DI AUTISMO.



*NOTA DELLA DISEGNATRICE E DELLA SCENEGGIATRICE

Picture 9: Tests for diagnosis part 1 in Dachez, J., illustrations by Mademoiselle Caroline. Edizione italiana: *La differenza invisibile*. (2018) Edizioni Lswr.



Picture 10: Tests for diagnosis part 2 in Dachez, J., illustrations by Mademoiselle Caroline. Edizione italiana: *La differenza invisibile*. (2018) Edizioni Lswr.

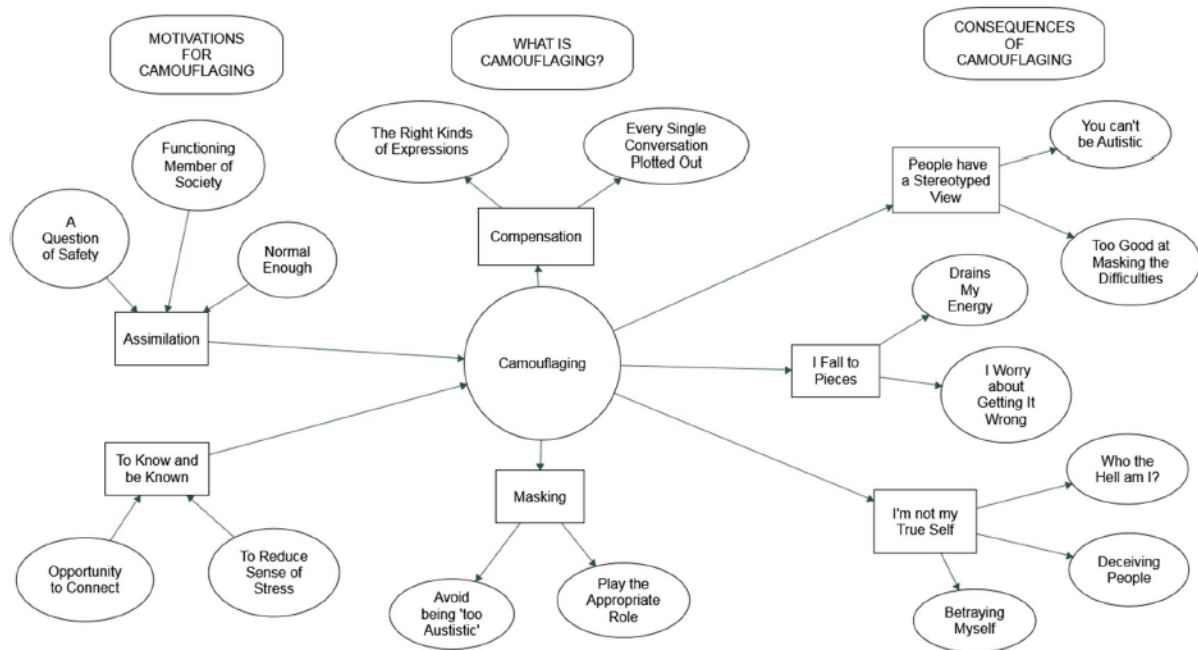
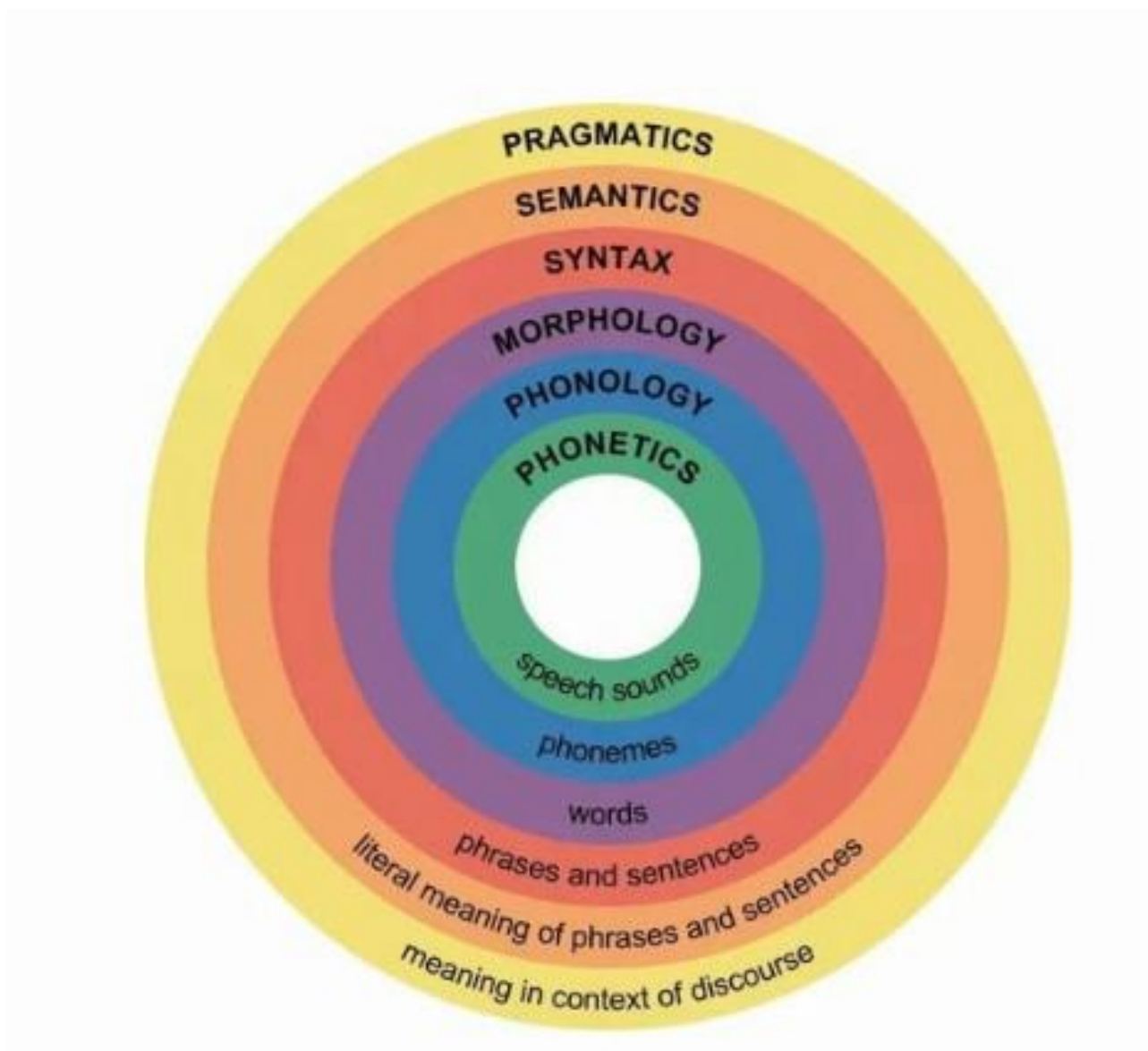


Fig. 1 Thematic map of the three stages (motivations, camouflaging, and consequences) of the camouflaging process. Themes are indicated by rectangles; subthemes by ovals

Picture 11: by Hull, L., Petrides, K. V., Allison, C., Smith, P., Baron-Cohen, S., Lai, M., *et al.* (2017b). *“Putting on My Best Normal”*: social Camouflaging in Adults with Autism Spectrum Condition. *J. Autism Dev. Disord.* 47, 2519–2534. doi: 10.1007/s10803-017-3166-5



Picture 12: Language in layers.



- Picture 13: an example of stim toys, precisely: 12-Sided Fidget Cube, Large Gyroscope Bubble Popper, Large Rainbow Bubble Popper Fidget, Mochi Squishy Fidgets, Key-Chain Bubble Popper, Spiky Ring, Squishy Noodle, Grip Pop Fidget, Stretchy Coil Bracelets, Video Controller Fidget Toy, Mesh Marble Fidgets, Caterpillar Squishy Fidget, Flippy Chain, Toolbox Pencil Toppers, Zipper Bracelet, Sequin Slap Bracelet, Pipe Popper. The ultimate fidget pack, available at the following link: <https://www.munchables.ca/products/the-ultimate-fidget-pack-ii>