

~~Weirdo.~~



It's Asperger

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*"Asperger is...*

*Asperger is thinking differently, not being insensitive. Asperger isn't not want to talk to you, it is not understand how to do it or what to say. It is to be honest, simple and direct even if it makes people uncomfortable.*

*Asperger is being euphoric inside without showing it outside, but being happy after all.*

*Asperger, in silence, lets me think and create, believe and grown... In a silence that, even though you don't believe me, I'd love to tell you.*

*Asperger is more than knowing the capitals, making lines of cars, calculations or strict routines.*

*It is being unique, but equal even if you are Asperger."*

*Leonardo Caracol Farfán*

# 1. INTRODUCTION

Imagine someone takes you to a place you have never been to before, a place whose language is unknown to you. Well, now you're a step closer to understanding how this person feels.

Asperger Syndrome is the main topic of this project.

The first time I heard about this syndrome was in a film, but I could not remember which one (I have been looking for it but it has been impossible for me to find it).

Since then, I have been interested in autism and Asperger Syndrome. And that was when I decided to become a psychologist.

I also help a kid, Pol (who I have interviewed in this project), with English and a couple months before deciding on the topic of the project, her mother came to me to tell me he suffers from Asperger. After that I got shocked.

Actually, I did notice he did not understand the sarcasm or some jokes. He also loves physics obsessively and he always talks about it, but I did not notice much more so I thought it all was because I was obsessed with Asperger.

That is when I decided to do this project, because it would also help me to understand him a little bit better but in my high school, the Department of Psychology rejected the topic I chose and it was there when I decided to do it in English.

What I want is to get to know this syndrome through people who suffers from it, their relatives who have to deal with their behaviour and of course, a specialist.

# 2. ALL ABOUT ASPERGER'S SYNDROME

## 2.1 What is Asperger's syndrome

The AS (Asperger's Syndrome) is a set of mental and behavioral conditions. AS is considered as a part of the spectrum of autistic disorders.

This disorder has a proportion of people who suffer from it between 2'6% and 4'8% of every 1000 newborns. AS is more usual in boys than girls.

This syndrome is recently known by the scientist as a part of the spectrum of autistic disorders so we do not know much about it and it's not known by the population or professional people.

The scientific community considers that AS is underdiagnosed (to diagnose a condition or disease less often than it is actually present).

It is a severe developmental disorder that involves a neurological alteration determined in the information processing.

Asperger's people have a normal appearance and a normal intelligence or even better than the average so this disease is not evident.

Being intellectually gifted is not a characteristic of this syndrome but most of them are intellectually gifted and are interested and has special skills in restricted but absorbing areas, usually in science subjects like Mathematics, Physics or Chemistry.

Asperger people think in a different way. They have a logic, specific and realist thought.

They have several difficulties in social interactions, in the communications area and the imaginative sphere affecting that way the interests and their playing.

Their tone of voice is characteristic and they use a really specific language and vocabulary in the topics they like. They like reading although they usually don't understand the jokes or the sarcasm of the book or the magazine they're reading.

They have a specific routine and a really structured timetable because they have some difficulties to organize their time and activities on the spot.

They love being praised and applauded, winning and be the first but it's impossible for them to stand when they are beaten, criticized or something is not perfect according to them.

Just as a curiosity, people with Asperger's syndrome can be called "Aspies".

## 2.2 History



**Figure 1. Hans Asperger working with a kid.**

Source: Google Images

Asperger Syndrome is named like this because of Hans Asperger.

Hans Asperger (Austria-Hungary, February 18, 1906 – Austria, October 21, 1980) he was born on a farm in the outskirts of Vienna. He had some difficulties to make friends and he was considered as a lonely boy. During his childhood he had some of the symptoms of AS. He admired an Austrian poet called Franz Grillparzer. He also liked to quote himself and often referred to himself from a third-person

perspective.

He studied Medicine at the University of Vienna (*Universität Wien*). He graduated in 1931 and became director of the special education section of the university children's clinic in Vienna in 1932.

Hans Asperger identified in four boys (Fritz, Harro, Ernst y Hellmuth) the same behaviour and abilities that included "a lack of empathy, little ability to form friendships, one-sided conversations, intense absorption in a special interest, and clumsy movements". Asperger found out that many of those children were identified as autistic.

In 1944 he publicized a theory about these four children and he used "Autistic psychopathy" to explain what he considered a mental disorder. Unfortunately, this theory was ignored all around the world for about 30 years. Despite that, he continued investigating and treating children with autistic psychopathy.



He died in 1980, a few months before AS was internationally recognized thanks to Lorna Wing.

Lorna Wing (7 October 1928 – 6 June 2014) was an English psychiatrist and physician. She advanced understanding of autism worldwide and introduced Asperger's Syndrome thanks to Hans Asperger's theory. He founded the National Autistic Society (NAS) in the UK with other parents of autistic children help.

Nowadays it's recognized as a subgroup of autism and there are some cases in which it can be diagnosed to people who was never been qualified as autistic people.

We have to say that a year before (in 1943) Hans Asperger publicized his theory about AS, Leo Kanner publicized another theory about autism: "Autistic Disturbances of Affective Contact". So they both form the basis of the modern study of autism.

Leo Kanner (February 29, 1896 – April 3, 1981) was a psychiatrist from Austria-Hungary. He was the founder of the first academic child psychiatry department at Johns Hopkins University Hospital, His first textbook, *Child Psychiatry* in 1935, was the first English language textbook to focus on the topic. A few years later, in 1943 he wrote where he described autistic people with these words "Lack of contact with people, reverie and emotional loneliness".

The 18th of February is considered Asperger's Day and 2006 was declared as the International Asperger's Year because Hans Asperger had been born a century ago.

## 2.3 Symptoms

There are a lot of symptoms in this disorder but before describe any of them I want to make clear that people who suffer from AS have individual characteristics and a person with this disorder may not fit with some of these symptoms.

- The Aspies are usually obsessed with a subject and they ignore everything else. They want to know everything about it and they are always talking about it because it is something they control and they know about. There is never an ending to these topics for them. They can talk about it for hours and hours and never get tired and without notice that the person they are talking to has lost the interest and it is becoming annoying.

The interested areas can be really limited like obsession with the train timetable, telephone numbers, stamp collection or other kind of collection, physics, mathematics...

Almost all of them prefer enjoying these hobbies all alone. This disorder can make them want to be alone all the time searching information or reading about it than playing with other kids, stay with family or partner.



**Figure 2. Blaine in class.**

Source: Anna Ramírez

- The Aspies do not isolate themselves the way other autistic people do. They normally approach to other people but their problems with the language or the fact that they do not understand the jokes, sarcasm or metaphors

make them want to be apart so people do not bully them for their problems.

- Their body language (hand gestures, faces, visual contact...) is unusual. They speak in a monotonous tone and they do not usually react to other people emotions or comments. They do not understand that they need to change their tone in some situations.
- They do not show pleasure in other people's happiness.
- They are usually tagged as weirdos or freaks because they have problems with people of their age and sometimes from other ages too. They are not able to answer emotionally in normal social interactions.
- They are not flexible with their timetable and they always do the same. If you try to change this routine they get nervous and they upset.
- They are completely honest. They can't lie and that makes them have a lot of problems but they do not know why.
- They are grown later than usual or have unusual physical behaviours.
- They are not really good at sports or at doing something as easy as catching a ball, riding a bike or playing games. They are not good at running or even just walking.
- They have a lot of tics.
- They are usually really good at logic games or at playing chess.
- They are able to act because they are used to in their life. They have to act to let people know when they are happy, when they are sad, etc.
- They see and remember details that other people do not notice.
- They have an extraordinary visual, musical and numeric memory. That is why most of them become a mathematician, musician or other jobs where you need

these qualities.

- They are really good at remembering dates, rules, laws even though if they do not agree with them.
- They are better at writing than talking to people. They are really careful with the words they use. They always try to find the best word for what they want to say that is why they are always more expressive by the internet or a letter than face to face, because writing you do not need to use body language.
- Some of them usually have selective mutism.
- They do not meet the criteria for others pervasive developmental disorder or for Schizophrenia.

## 2.4 Causes

The exact cause of Asperger's syndrome is still unknown but we know that is a brain abnormality. That is why in 1944 Hans Asperger called AS an autistic disorder.

There is a strong relationship between autism and genetics. This disorder is usually hereditary.

In the first description of AS we could notice the similarity between Aspies and their parents. From that moment we knew that there was something related to genetics but we did not know the genetic character and we did not know if it was dominant or recessive.

Nowadays, we still do not know if it is a recessive or a dominant character.

In spite of the fact, they are all theories, scientists, because of all the information they have, are pretty sure that it is a polygenic condition in which the possession of the less favourable alleles of a group of genes functionally related would end to express this disorder.

There is a recent investigation where we can see the neuronal circuit is modified. The difference is located in the middle of the prefrontal cortex (one of the principal places for the social-emotional intelligence). The dorsolateral cortex is normal or sometimes even works more than usual, that's why they are usually more intelligent than the other people.

It is known that there is a reduction of the brain activity in the frontal lobe and abnormal specific protein levels related to those obsessive and repetitive behaviours.

Some scientist think it could be caused by an abnormal migration of the embryonic cells during the fetal development.

## 2.5 Diagnosis

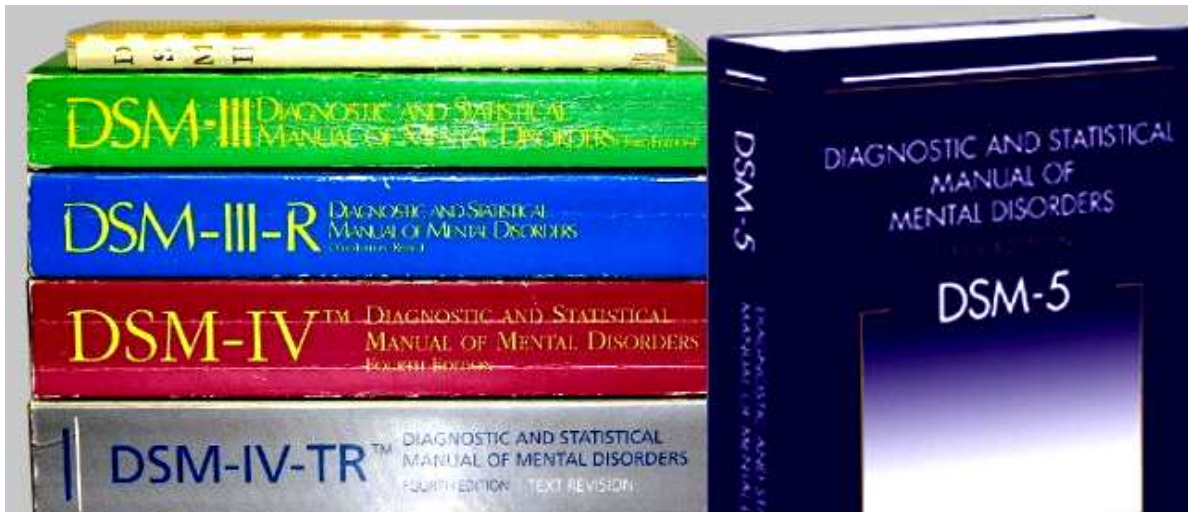


Figure 3. DSM

Source: Google Images

The most common age to diagnose is between 4-11 year old.

The diagnosis includes a neurological and genetic examination, the measure of cognition, verbal and non-verbal weaknesses and skills for independent life.

The diagnostic criteria to diagnose TEA combine:

- ADI-R test (Autism Diagnostic Interview-Revised): a semistructured interview for parents. It takes one and a half hour for 3-4 year old children and about three hours in teenagers and adults.
- ADOS test (Autism Diagnostic Observation Schedule): a conversation and a semistructured interview with the kid based on a game.

After doing these tests, is when DSM (Diagnostic and Statistical Manual of Mental Disorders), a guide that offers a common language and standard criteria for the classification of mental disorders, is used.

An Asperger screening tool must meet all six areas defined by the DSM-4 description that says:

### **299.80 Asperger's Disorder (or Asperger Syndrome)**

1. *Qualitative impairment in social interaction, as manifested by at least two of the*

*following:*

- *Marked impairments in the use of multiple nonverbal behaviors such as eye-to-eye gaze, facial expression, body posture, and gestures to regulate social interaction.*
- *Failure to develop peer relationships appropriate to developmental level.*
- *A lack of spontaneous seeking to share enjoyment, interest or achievements with other people, (e.g.. By a lack of showing, bringing, or pointing out objects of interest to other people).*
- *Lack of social or emotional reciprocity*

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

- *Encompassing preoccupation with one or more stereotyped and restricted patterns of interest that is abnormal either in intensity or focus.*
- *Apparently inflexible adherence to specific, nonfunctional routines or rituals.*
- *Stereotyped and repetitive motor mannerisms (e.g. Hand or finger flapping or twisting, or complex whole-body movements).*
- *Persistent preoccupation with parts of objects*

*3. The disturbance causes clinically significant impairments in social, occupational, or other important areas of functioning.*

*4. 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)*

*5. There is no clinically significant delay in cognitive development (memory, attention, perception, intelligence...) or in the development of age-appropriate self help skills, adaptive behavior (other than in social interaction) and curiosity about the environment in childhood.*

*6. Criteria are not met for another specific Pervasive Developmental Disorder or Schizophrenia.*

But DSM-4 stopped working when DSM-5 was published on 18th March, 2013.

In DSM-5, the term "Asperger Syndrome" disappear, just as "autism" and they are all called "TEA".

Even though it does not longer exist as a syndrome, many people who has already been diagnosed still refer themselves as people with AS.



## 2.6 Treatment

The AS treatment coordinates therapies that address the three main symptoms: a lack of communication skills, obsessive or repetitive routines and physical clumsiness.

There are some kind of programs to help them with these problems. They include:

- Group therapy to make them interactive
- Cognitive behavioural therapy , a type of " talk " to better manage their emotions and reduce obsessive interests and repetitive routines
- Medicine for depression and anxiety
- Physical or occupational therapy for people with sensory integration problems or poor motor coordination .
- Language therapy to help children who have problems with pragmatic discourse or even having a normal conversation.
- Parent training and support , to teach parents techniques behaviour to use at home .

It has no cure because the deficit stays in the brain, the only thing we can do is to make them easier and help them with the social integration.

# 3. ASPERGER'S SYNDROME ON TELEVISION AND LITERATURE

## 3.1 Through Me (Iñaki)

It's a documentary based on Iñaki Lemiechevsky's life.

*"Iñaki is a highly gifted 10 years old child with Asperger Syndrome (ASD) who lives in Badalona. For 2 years, he invites us to go deep into his mind's inner workings, which allows us to approach his complex way of seeing the world, his constant battle to adapt himself to a society that is different from him, and his brilliant vision of life. An inner journey between reality and dreams that gets us closer to one of the biggest mysteries of our time: autistic spectrum disorder, narrated by its own protagonist "*

This is the plot of the documentary THROUGH ME by Andrea Lamount.

THROUGH ME was first hatched in 22nd May, 2014 in Cosmo Caixa. I found it out



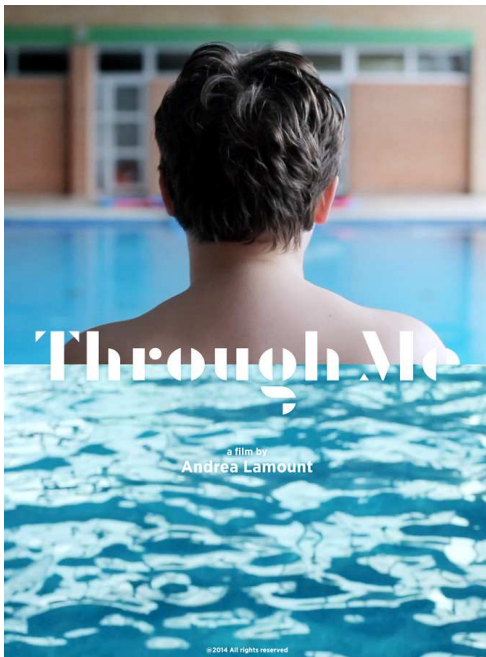
Figure 4. Karina, Andrea Lamount and Iñaki.

Source: Karina.

the same day when a friend of mine, Carla Cáceres, showed me an interview in 'Els Matins de TV3' where Iñaki, Andrea and Karina (Iñaki's mother) talked about this syndrome and the documentary. It was a 22 minute interview and it was very interesting but the best thing about it was the fact that someone phoned to the program and it was a mother with a kid (now he's about 24) with AS. Her name was Helena and at the

beginning she started talking and in the screen you could see "Helena (mother of an Asperger person) from Vilanova i la Geltrú" but when she found out that, she said: "Wait a minute, I'm not from Vilanova i la Getrú, I'm from Vilanova del Vallés. I've got some friends in Vilanova del Vallés so I decided asking them if they knew anything about this woman but they did not. I tried my best to find her but it was not possible.

I could not go to that one but I tried to contact with Andrea Lamount by Facebook, by gmail, by hotmail and some other ways. After a month of writing her, she finally answered me and told me she was showing THROUGH ME again in 4th September, 2014 in Casa Amèrica of Barcelona so I went to that one with my student Pol and his mother (*whom I interviewed*).



**Figure 5. Through Me cover.**

Source: Andrea Lamount's web.

It was not only watching the documentary but there was a debate and a question's session with Andrea Lamount, Francesc Cuxart (a consultor psychologist of Projecte Autisme La Garriga and a university professor at UAB), Iñaki's parents (Karina and Roberto) (*whom I interviewed*) and Iñaki.

I think that day (4th September) was the day where I really found what I wanted this project to be focused on. That was the day I also met Rosa del Hoyo (*who I interviewed too*) and she was a really important person for me to make that decision. It affected me so much what she said that day that I really wanted to focus on bullying.

The documentary was not as long as I thought it was going to be but I liked it because we could really see some of Iñaki's manias and what he thinks.

Two of my favourite quotes are:

*"I find it hard to understand the psychology of others. I just can't describe feelings."*

*"For me it's hard that people see with better eyes the fact that someone lies that the fact that someone farts in public."*

I really love those quotes because in the first one he admits one of the main symptoms of this syndrome. He does not say that he can't feel, that he has no feelings. He just says that it's hard for him to know what people or even what he feel.

The second one I think it could be my favourite one because it describes the fact that he can't understand why people have to lie. He does not understand the "social rules", he does not mind saying something wrong in front of other people or fart in public because actually, farting is something natural. He always says what he thinks and the fact that no one says that they really think it's something impossible for him to understand.

A funny curiosity was that after it all finished I went with Pol and Yolanda to ask Rosa and then Iñaki's parents to do an interview but Pol started acting in a strange way and when we asked him what was wrong, he told us there was a girl with an amputated hand that was making him feel uncomfortable so he had to leave the room and when we went out of the room after talking to Rosa and Iñaki's parents, we found him having a conversation with Iñaki but they were like 1 or 2 metres away from each other.

## 3.2 The Big Bang Theory (Sheldon)

Sheldon Cooper (Jim Parsons) is a fictional character on the television series The Big Bang Theory portrayed by Jim Parsons.

Sheldon is a theoretical physicist with genius IQ level (187) but with an almost total lack of social skills, a difficulty in recognizing irony and sarcasm, a lack of humility and empathy...

That's why everyone relates Sheldon's problems with Asperger Syndrome and an obsessive-compulsive personality disorder but co-creator Bill Prady has repeatedly said that Sheldon's character was not made by any of these syndromes.

Here is an analysis I made of the character:

- **Lack of social skills:**

He does not get happy when one of his friends is happy.

He does not notice when a girl is interested in him.

He does not get when something is appropriate to say or not. He can insult someone without knowing that he is actually doing it, he does not do it on purpose, he just says what he thinks.

He gets very uncomfortable with giving and getting hugs or any physical contact.



**Figure 6. Sheldon Cooper.**

Source: Google Images.

He was and he still is bullied because of this.

- **Behaviour patterns, interests in restricted areas, strict routine...**

He always gets up at 6:15 and have the same breakfast and has meals for each day of the week.

He does the laundry every Saturday.

He has an specific sit on the couch where no one else can sit.

He knocks at the door 3 times and says the name of the person he wants to talk to.

He is interested in restricted areas like maths, physics...

- **He is gifted (187 IQ) and he has a photographic memory**

You can see he is a really smart boy and he knows a lot in a lot of areas. He is really good at almost everything. He has a very extensive vocabulary

He is a really vain person and he does not understand that showing people that he is better than them is not okay.

He has a photographic memory. When he and his friends play.

- **Inability to detect sarcasm and irony**

His friends usually have to tell him what is and and is not sarcasm with a little paper where is written "SARCASM".

- **Tics**

He usually has lots of tics but when he is nervous these tics increase.

- **Difficulty with reading facial expressions and body language**

He talks with her neighbour Penny about her sexual relationships or her period, the thing that makes her be uncomfortable and you can see it in her face but

he stills talks about it because he does not notice it.

- **Poor motor coordination**

He can't drive.

He walks and run in a particular way. He is really bad at sports.

### 3.3 Skins (JJ)

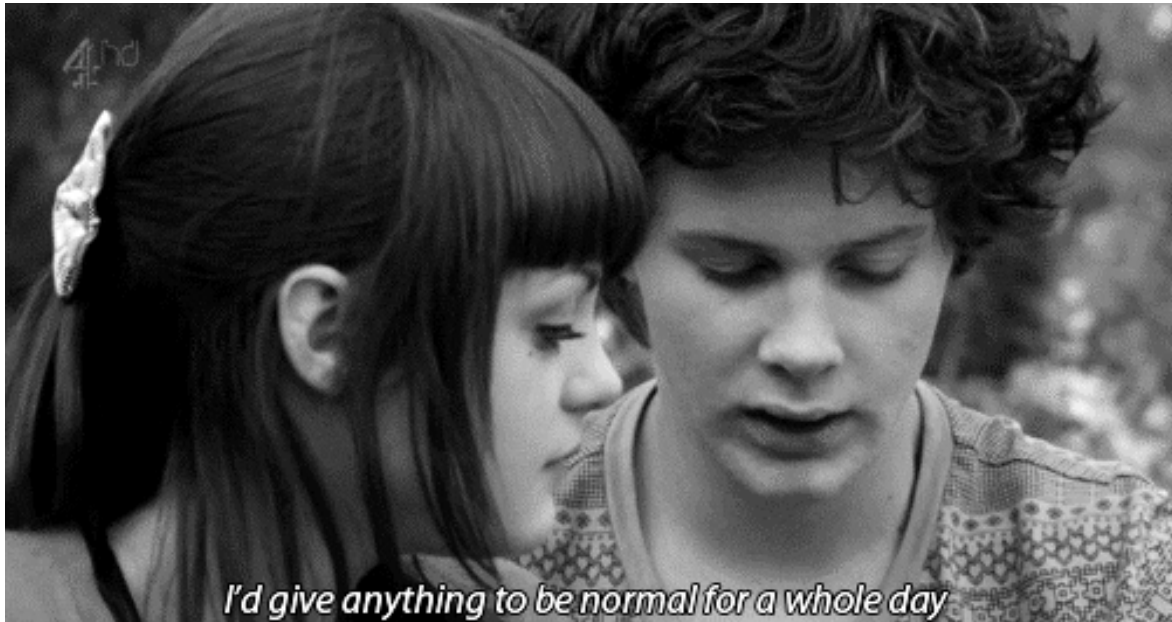


Figure 7. JJ and Emily (a friend) talking about JJ's feelings.

Source: Tumblr.

Skins, a famous British series, is divided in three different generations. Each generation has two seasons and each season has an episode for each character. So all this information is taken from two episodes.

In the second one we can see a shy boy, JJ (Ollie Barbieri), who acts a bit different from his friends. Yes, he has Asperger's syndrome.

- He has a very strict routine: he goes to work, come back home by car with his mom while they sing a rap song, when they arrive home his mom asks him questions about physics, chemistry, maths, history...
- His mind works in numbers, facts, and he has a wonderful memory. He goes to the doctor who ask him his weight and he says 11'3 stones but then the doctor immediatly asks for his metric weight and without thinking he answers 71'1kg. He does not need really much time to do calculations.
- He is also obsessed with science and space in general. He wants to learn



everything about it. His room is full of things related to the cosmos. He also loves magic.

- He also has a hard time reading people's body language and understanding social cues. He exhibits the social awkwardness. JJ does not have many friends and has little experience with girls.
- He has a really specific timetable. He also has a watch that alerts him when he has to do something.
- He is bullied by his friends even though they love him. Because he is different, they take advantage of him and do not listen to him.
- He has a date for the first time and someone gives him the advice to arrive a bit early so he arrives to the girl's house two hours before they had met.
- He also has something written in his hand that advise him how to act so he, for example, constantly touch her what makes it uncomfortable.

### 3.4 Frágiles (Lola)

Frágiles is a Spanish series about a physical therapist and his patients and one of them, Lola (Ruth Nuñez), suffers from AS. She is my favourite character.

Here are some of the symptoms she has:

- Her main symptom is that she cannot stand physical contact, what makes sense because the serie is based in problems that need to be treated with massages. When someone touches her, she gets upset and she has an anxiety attack.
- Her specific interest are fish and puzzles. She talks about it without caring if the other person gets bored or not.
- She interprets literally most of the things. One time, a boy asks for her phone and instead of giving him the number, she gives him her phone.
- When she is worried or has anxiety, she rubs her knuckles.
- She has a really good memory. She used to work in a library and know where all the books are.
- She always brings a notebook with her. There are some expression faces drawn in the notebook. She uses it to understand other people's feeling and to understand what she feels.
- She says all what she thinks without caring if she hurts someone.
- She cannot stand lies.
- She has no visual contact with the others.
- She has strict routines. She always has breakfast at the same place, in the same sit, at the same hour...

I personally think that this have done a great job with explaining this disease. They also chose a good actress, she could not have done it better.



**Figure 8. Lola.**

Source: Google Images.

### 3.5 My Name Is Khan (Khan)

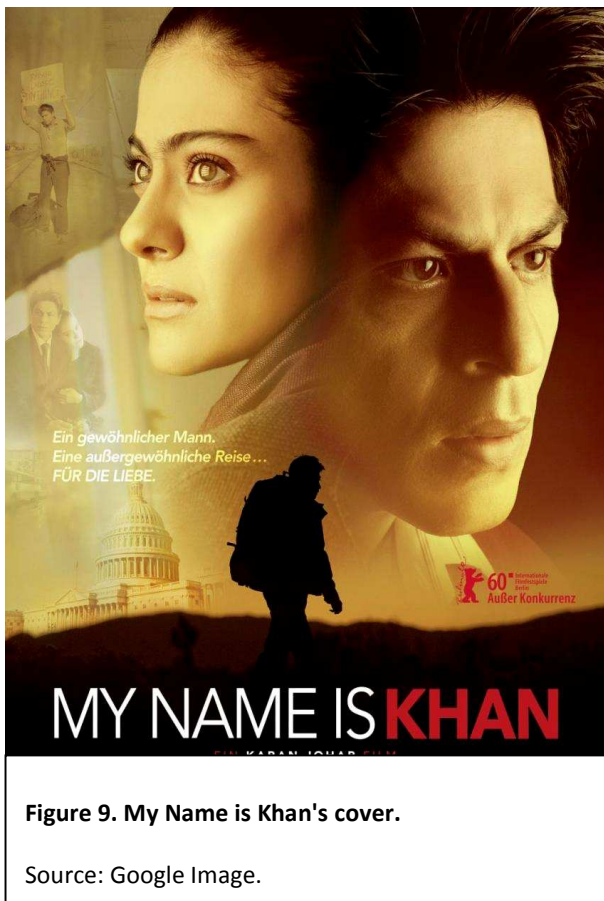


Figure 9. My Name is Khan's cover.

Source: Google Image.

A friend of mine recommended me to see this film when she knew I was doing the project about Asperger's Syndrome. She has always been good at criticizing films so I thought it would be a good film but it wasn't just a good film, it was an incredible one.

I really enjoyed it because it is not just about Asperger Syndrome but racism, bullying and love.

I think that Khan is a really lovely character and he loves Mandira so much that make the spectator love her too.

Khan has been really good embodied because he has most of the main

symptoms. He cannot stand loud noises, he has a really visual sensitivity, he does not get the sarcasm, etc.

The actors are really well chosen and I think it is a perfect film to understand this syndrome because it shows most of the symptoms and actually, the film is based on not understanding the sarcasm.

*"The protagonist in the film suffers from Asperger's Syndrome, a form of autism, while the film endeavours to depict the character as authentically and sensitively as possible, it is a work odd fiction and hence certain creative liberties have been taken in the portrayal of the condition."*

My Name Is Khan is an 2010 Indian film directed by Karan Johar and written by

Shibani Bathija. It was released on 12th February 2010 in Abu Dhabi, UAE.

It is about an Indian-Muslim boy called Rizwan Khan (I'm going to refer to him as Khan).

Khan is gifted, he has special abilities to repair mechanical things. He is a different boy and that makes his mother pay more attention in Khan and in his brother, what makes him get really jealous and when he grow up leaves the country to live in the United States of America.

After the mother's death, Khan has to leave the country too and go to live with his brother and his wife Haseena in San Francisco.

Haseena is the first one to diagnose Khan with Asperger Syndrome.

He starts working and he meets Mandira, a beautiful girl who has a son, Sameer (Sam).

After a long time, they finally get married and start living together when one day, everything changes. The September 11th, 2001. After that, Khan's family begins to be bullied for being Muslim. That affects Sam at school as much that one day a group of students hit him as much that he dies of a ruptured spleen. There's when Mandira loses his control and she breaks up with Khan and tells him that she wants him to leave and sarcastically tells him that he just can come back if he tells the president and the people of the United States that his name is Khan and that he is not a terrorist.

Khan does not get the sarcasm and he takes it seriously and starts looking for the president. He travels all around the United States to tell the president "My name is Khan and I'm not a terrorist".

### 3.6 The Curious Incident Of The Dog At The Midnight Time (Christopher)

*The Curious Incident of the Dog in the Night-Time* is a 2003 mystery novel by British writer Mark Haddon.

Mark Haddon and *The Curious Incident* have won a lot of prizes like the Whitbread Book Awards for Best Novel and Book of the Year.

The novel is narrated in the perspective by Christopher John Francis Boone, an Asperger 15-year-old boy who describes himself as "a mathematician with some behavioural difficulties".

Christopher lives with his father only because his mother, Judy, died two years ago.

He discovers the dead body of Wellington, the neighbour's dog. He decides to investigate the dog's death, despite his father's orders to stay out of other people's business. During his investigation, he records his experiences in a book: a "murder mystery novel".

One day he meets Mrs Alexander, who informs Christopher that his mother had an affair with Mr Shears and had been with him for a long time. He wants to talk to his father, Ed, who bans him to keep on with that investigation but Christopher keeps doing it behind his back.

But he finds the book out and confiscates it. While searching for the confiscated book,



**Figure 10. The Curious Incident Of The Dog At The Midnight Time in a theatre in London.**

Source: Anna Ramírez

Christopher uncovers a trove of letters which his mother wrote to him after her supposed death. Ed realizes that Christopher has read the letters and cleans him up. He then confesses that he had indeed lied about Judy's death and also that it was he who killed Wellington. He says it was all a mistake resulting from his anger after a heated argument with Mrs Shears.

Christopher loses all trust in his father and guided by his mother's address from letters, he goes to London to look for his mother, who turns to live with Mr Shears.

He finally finds his way to his mother and Mr Shears' home, and waits outside until they arrive. Judy is delighted that Christopher has come to her but she is angry that Ed told her she was dead.

But there are some problems, Mr Shears does not want Christopher living with them so his mother leaves Mr Shears, their relationship having broken down because of that and because Christopher wants to return to Swindon in order to take his mathematics A-level.

They go back to Swindon and Judy after an argument with Ed, agrees to let Ed meet Christopher for daily brief visits. However, Christopher remains terrified of his father and makes repeated attempts to prevent him from talking.

The story ends with Ed getting Christopher a Golden Retriever puppy and promising that he will rebuild trust with Christopher slowly, "no matter how long it takes".

In an interview, Mark Haddon said "If he were diagnosed, he would be diagnosed as having Asperger's syndrome. He can function on, you know, a day-to-day basis, in a kind of rudimentary way. But he has a serious difficulty with life in that he really doesn't empathize with other human beings. He can't read their faces. He can't put himself in their shoes. And he can't understand anything more than the literal meaning of whatever's said to him, he does not appreciate some metaphors and similes. Even though he presents all those symptoms, I'm very careful in the book not to actually use the word 'Asperger's' or 'autism.' because I don't want him to be labelled."

I personally loved that book because it was full of surprises, it is not a predictable book, you do not expect anything. I also think that this book reflects perfectly a person with asperger that si why I decided to include it in my project.

### 3.7 Mente, encuéntrame. Dos meses y medio en la vida de una Autista



Figure 11. Rosa del Hoyo and her book's cover.

Source: Rosa del Hoyo

Rosa del Hoyo, the girl I interview later, told me she was writing this book and I thought it would be excellent if I could write about it.

As you know, Rosa has AS and in his book she tells the story of her life when facing with real life.

She tells us about the different stages of her life: the different diagnosis, he got, how she reacted after knowing it was Asperger, how her family reacted...

She has been bullied several times in her High School, she did not isolate herself, the isolated her, they made fun of her, they received death threats for no reason...

For years, she thought it was all her fault, she thought she had something repulsive that made people hate her.

In this book, as she said in her presentation, she found herself and day by day you get to know all her problems.

She told us in the presentation that she started writing as a way of treating. She wanted to liberate all the bad feelings and thoughts inside her. But one day, she



found out she was writing to help other people in the same situation.

I also went to the presentation of the book, after the interview I made, we kept in touch and she has helped me a lot.

The presentation was the same day as the 22nd October demonstration so I spent the whole day out. I was nervous because I thought she was not going to remember me.

I arrived quite early and she came over to me and she seemed happy to see me, that relaxed me a lot.

She summarizes the book with these words:

*"I'm a woman with Asperger Syndrome. I've been through uncountable invisible battles against our society and I just enjoyed really few relaxing moments. I've been through hospitals, medication, psychiatrists and self-harms. Once I became an adult, all those battles became more present, more real. My mind could see all its dimension. But, even though it threatened to swallow me more and more, I develop a weapon: I wrote my life in a paper just to try to control all the chaos my life was. I did it. Now I feel I have to share my story, my emotions and my own reflections with all you."*

I enjoyed this book really really much. I think she explains everything to make you feel what she felt. You suffer as much as she (I guess she suffered more because she is the one who lived that) and once she finds herself, you are also relieved.

I cannot explain what I felt reading the book, I only can say that she is not just a great writer but a great person.

# 4. FAMOUS PEOPLE WITH ASPERGER'S SYNDROME

There are many famous people with this syndrome. Here is a list of some of them although there are ones that are not proved like Spielberg, Tim Burton...

What want to say with this part is prove that even f you have this syndrome, you can succeed in life.

## 4.1 Susan Boyle

Susan Magdalane Boyle (born 1 April 1961) is a Scottish singer who came to international attention when she appeared as a contestant on the TV programme Britain's Got Talent on 11 April 2009, singing "I Dreamed a Dream" from Les Misérables. Her first album was released in November 2009 and debuted as the number one best-selling album on charts around the globe.

## 4.2 Syd Barrett

Roger Keith "Syd" Barrett (6 January 1946 – 7 July 2006) was an English musician, composer, singer, songwriter and painter. A founder member of the band Pink Floyd. Barrett was the lead vocalist, guitarist and principal songwriter of the band. Barrett left Pink Floyd in April 1968 and was briefly hospitalized amid speculation of mental illness by drug use.

## 4.3 Daryl Hannah

Daryl Christine Hannah (born December 3, 1960) is an American film actress known for a lot of films but particularly for the Kill Bill films.

In September 2013, she revealed that she had been struggling with autism and social anxiety since childhood.

#### **4.4 Rafer Alston**

Rafer Jamel Alston (born July 24, 1976) is a retired American professional basketball player. He played for six NBA teams throughout his career.

He suffers from hyperactivity and Asperger's syndrome.

#### **4.5 Satoshi Tajiri**

Satoshi Tajiri (n. 28 de agosto de 1965) is a Japanese video game designer best known as the creator of Pokémon created in 1996, it's creator. He came up with the idea from his childhood hobby of collecting bugs.

The Pokemon game series has sold more than 200 million copies. Only the Super Mario game has sold more.

#### **4.6 Steven Spielberg**

Steven Allan Spielberg (born December 18, 1946) is an American film director, screenwriter, producer, and business magnate. Spielberg is consistently considered as one of the leading pioneers of the New Hollywood era.

#### **4.7 Tim Burton**

Timothy Walter "Tim" Burton (August 25, 1958) is an American film director, producer, artist, writer, and animator. He is married with Helena Boham Carter.

#### **4.8 Norm Ledgin**

Norm Ledgin (born 15 July 1928 in Passaic, New Jersey) is an American writer and

journalist.

He is known for two books dealing with autism, *Asperger's* and *Self-Esteem: Insight and Hope Through Famous Role Models* (2002) and *Diagnosing Jefferson: Evidence of a Condition that Guided His Beliefs, Behavior, and Personal Associations* (2000). The latter argues that Thomas Jefferson demonstrated traits of Asperger syndrome.

## **4.9 Bill Gates**

William Henry "Bill" Gates III (born 28 October 1955) is an American business magnate, philanthropist, investor, computer programmer, and inventor. Gates originally established his reputation as the co-founder of Microsoft with Paul Allen.

## **4.10 Vernon Smith**

Vernon Lomax Smith (born on January 1, 1927) is professor of economics at Chapman University's Argyros School of Business and Economics and School of Law in Orange.

In February 2005 Smith spoke out publicly about his Asperger syndrome.

## **4.11 Albert Einstein**

Albert Einstein (14 March 1879 – 18 April 1955) was a German-born theoretical physicist and philosopher of science.

He developed the general theory of relativity, one of the two pillars of modern physics.

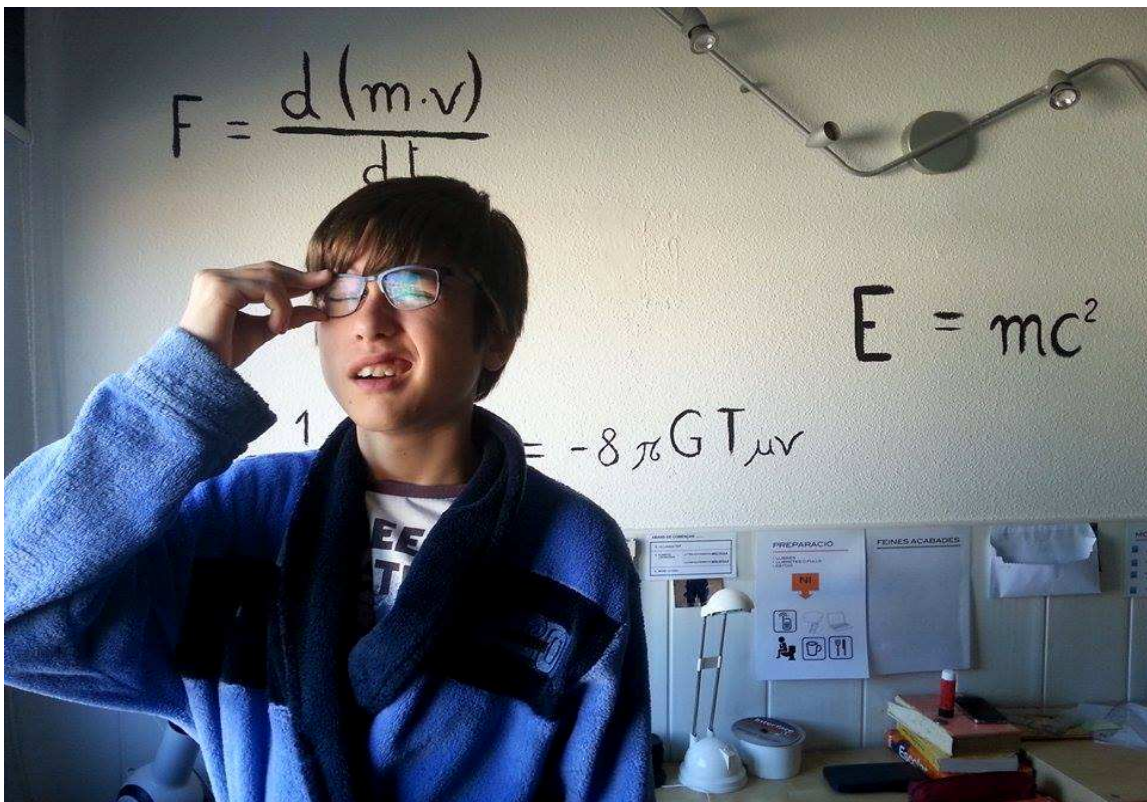
## **4.12 Adam Randal Young**

Adam Randal Young (born July 5, 1986) is an American singer-songwriter and multi-instrumentalist, best known for creating the electronica project Owl City.

He has mentioned he has Asperger's syndrome, and he has often referred to himself as being deeply shy and socially introverted.

# 5. PRACTICAL PART I: Interviews

## 5.1 Pol Santana



**Figure 12. Pol in his bedroom.**

Source: Anna Ram3rez

Pol is a 11 year old boy who has lived in Montorn3s del Vall3s for years, but he was born in Montcada i Reixac.

I know him because he is my neighbour and I help him with English.

We did the interview in English because he insisted he wanted to try it.

I have known him for 8 years and it is really difficult for him to understand jokes I always have to explain them to him. He has a really good visual memory and he is a

really smart boy.

- **Was it difficult for you to move?**

I don't remember, I was too young.

- **Do you think it is difficult to live with someone who does not have AS?**

I don't know because I don't know people without AS feelings so I cannot answer that question.

- **When and where were you diagnosed?**

In Granollers two years ago.

- **What kind of test did the specialist carry out to diagnose AS?**

A lot of tests. It was a test where they asked me some strange questions. For example, they showed me some targets and I had to say what was that for me. I also had to do some test in Catalan, Maths... I don't know, a lot of things.

- **Did all the testing take long?**

Two weeks more or less.

- **Who decided to go to a specialist? Why?**

My parents because they thought I was weird.

- **Do you have a low or severe grade?**

Low. I've got AS but not much.

- **Did going to specialist bother you?**

No.

- **Do you think that when you were diagnosed they made it easy for you and your family?**

Yes, of course. They helped me with my integration in the society. For example, every Friday I go to the hospital with two more boys with problems like me. We go to a room where there is a psychologist and we do some activities. She gives us some situations where we have to work in group to solve them. For example, we are in a boat and we have to choose six objects to be with us so we can survive there.

- **But six objects inside the boat?**

No, six objects. They can be whichever.

- **Do you have any mania or phobia?**  
Yes, I do. Manias... While eating. I have a timetable and my parents have to cook that because if not, I get nervous.
- **Do you have visual or auditory sensitive?**  
I have a lot of auditive sense, with high-pitched sounds. I can't stand them: whistles, the flute...
- **Do you have a really strict routine?**  
Mm... Yes. I wake up at the same hour every day, brush my teeth, eat... I do everything at the same hour every day.
- **And if you don't follow that routine, you get upset?**  
Well, sometimes.
- **Do you have any specific interests??**  
I love videogames and the space.
- **What about music?**  
Yes, in music too.
- **Do you do any activities to develop that ability?**  
No.
- **No? Anything?**  
Well, I read books about Einstein, Newton... I like them.
- **What is your IQ level?**  
Two years ago, 138.
- **Do you follow any kind of treatment?**  
Yes, that I group I told you about and for TDAH I take pills.
- **There are some people who decide not to tell their child that he/she has AS. What do you think?**  
I find it bad. I would tell my child, they must know it.
- **Do you have good marks?**  
Yes. The lowest mark I usually get is a 8 in P.E.
- **Do you stand out in any school subject?**  
Yes, maths and science.



- **Have you ever been bullied?**

No. Never.

- **What do you do at playtime?**

I usually play basketball or speak with my friends about video games, youtubers...

- **People with AS usually suffer from bullying, especially in high school. Do you think that's because it is not known by the population?**

Yes. I always say: if people knew what's going on with us, because no one does, they'd treat us as we need to be treated. If I were not Asperger and I didn't know about it and I had a classmate with this syndrome, I'd ask him why is he that way but people don't. People just hurt without caring about other people's feelings. And if I was a teacher, I would tell my students about it.

- **That's another point, teachers don't know about these syndrome so they can't do nothing.**

They should acquaint oneself with these problems. That would help us a lot.

- **Asperger Syndrome is genetic. Does any of your parents have any symptoms?**

Mm... No. My mother has a bit of TDAH. I don't know. For me TDAH and AS are like a pack. All the people I know with AS have TDAH too.

- **Yes, but because it's really difficult to differentiate them. Well, which of the main symptoms would you say you present?**

I can't understand some jokes or sarcasm.

- **I think that people with AS has a different way of watching the world and people. What do you think?**

I think the same. We are more rational. I don't know how to explain it.

- **It's okay. Do you find yourself as someone imaginative?**

Yes, a lot.

- **Have you ever had an imaginary friend?**

No.

- **People with AS usually have difficulties to understand jokes, sarcasm...**

**You said that happens to you. Can you explain any anecdote?**

Let me think... Oh. I remember a day I was playing GTA with a friend and I was driving an old car and it did not run and he said "Este coche no tira ni para atrás" and I said "Yes, it does." and I made it reverse.

- **Hahaha. Can you remember anything else?**

No. I remembered that one because I laughed a lot.

- **Do you think AS is known by the population?**

No. Every time I say what I have them ask me and I always have to explain them. But everyone, family, friends, teachers...

- **What would you do to change that?**

Give talks to schools or instead of doing those awful programs they do on TV, they could do programs about syndromes, illnesses...

- **And what about writing a book?**

No, not me. I know what it is but I'm not an expert.

- **But about your experience?**

Maybe I could write a book about me, like a diary so they can know how a person with AS feels but I don't feel able to do it.

- **Are you a member of any association?**

Yes, my mother is a founder of an association, "Crèixer i educar en família". It has just begun. There are parents of kids with a lot of different problems and there is another boy with AS, he's younger than me.

## 5.2 Roberto and Karina (Iñaki's parents)

As I said earlier, I went to Andrea Lamount's documentary and was there when I met Roberto and Karina, Iñaki's parents.

Iñaki is a 12 year old boy who suffers from Asperger.

I have just seen him on TV and that they at the presentation but if we behold him, we can see he acts clearly different, he has a lot of tics, he has some problems while speaking...

When someone asked him

something, we could see that he does strange noises with his mouth, he is constantly blinking his eyes and he stammers a lot.

I thought it could be great doing an interview to his parents so I could know Iñaki from their point of view because in the documentary, I was able to meet him more or less.

- **When and where was he diagnosed?**

He was diagnosed when he was 9 years old but we kind of expected him to be "special" because he didn't act normal since he was 2.

- **Who decided to go to a specialist?**

The school. We went to the CDIAP (Centre d'Atenció Precoç) when Iñaki was 5 but they told us he had nothing, he was just an spoiled child.

He learned to talk quite late, when all children already knew but even though he couldn't talk, I (the mother) understood everything he wanted to say. It was



Figure 13. Iñaki

Source: Andrea Lamount's web.

actually me who decided to take him to do some tests because my husband already had some characteristics and he saw Iñaki as a normal guy but I knew something was wrong. Well, not wrong but different.

- **Does he have low or severe AS grade?**

It depends on the situation. I mean, for some things he's got a severe grade but for other things it's low. He normally has a medium-high grade.

- **How did affect him to know he has this syndrome?**

It affected him in a positive way because he finally knew why he was acting that way. For us it was good too because we saw that knowing that, helped him.

- **How did affect him going to specialist?**

That never bothered him because he likes it. He knows it's something good for him, something that will help him.

- **Do you think that when they diagnosed him that syndrome they made it easy to him and to you (giving you some information or any other kind of help)?**

Yes, they gave us enough information to know how to treat him.

- **Does he have any mania or phobia?**

When we're watching TV and there are commercials, he has to mute the TV. He really hates commercials.

When people come home, no matter who, before introducing himself or before saying hello he has to ask to clean their hands. He's really obsessed with hygiene.

He also has a specific pair of shoes for home. He can't go with other ones.

- **Does he have auditory or visual sensitivity? (Ex. In the film 'My Name Is Khan' there are some scenes where Khan could not stand really loud noises or yellow colour.)**

No, he doesn't.

- **Does he have a really strict routine? If he does not follow that routine does he get upset?**

Well... yes, he goes to the swimming pool and pretend he's dead. He stays floating. If one day he can't go to the swimming pool he locks himself in the room and he plays computer games or watch videos.

He gets really upset when he can't do one of these things. He starts screaming and crying out so hard that we can't control him.

- **How does he relax if he gets upset?**

He is relaxed when he's in the swimming pool or with the computer on his own.

- **Is there a subject where he stands out (music, history, maths...)? Does he do any activities to develop that ability?**

He stands out in Maths and English. He's really good at English because he likes informatics and almost everything's in English and he learned by himself. He watches a lot of videos and reads a lot of things in English too. He used to like music too. Last year he played saxophone but he got bored and this year he's doing informatics.

- **What is his IQ (intelligence quotient)?**

Inside the logic area he's got a 150 (more than the population) but when it comes about verbal expression he's quite shy and it's difficult for him to express what he actually want to say so he's a 115. That's the smallest punctuation he had in all the tests, 115.

- **I have a friend who suffers from AS and his psychologist told him to do some exercises to practice facial expressions, to be able to look at people faces when you are talking to them, etc. Does he have to do something similar? (In case of a yes) Explain it, please.**

He doesn't follow any kind of treatment or does any kind of exercise but we always try to explain him that he has to look at people's faces while he's talking to them.

- **Does he have any specific interests? Does he usually talk to people about his interests or he prefers just keeping them to himself? (Ex. I'm a Harry Potter fan and I'm always talking about it.)**

He doesn't because he's always changing. Nowadays he really likes playing Super Mario games.

- **Does he have good marks? Does he stand out in any school subject?**

He's not good at all of them. He's got several problems in those you need to do something physical. For example, he's horrible at PE or plastics. He stands out in the logical subjects like Maths, Physics... He's really good at English too.

- **Has he ever felt left out?**

Yes. In primary school (from 2nd to 5th grade) when we moved so he changed school he felt really really bad. He didn't have any friend.

- **Do you think that part of this bullying is because AS is not known by the population?**

It's not known at all and they propose us to make people know about this syndrome, that's why we accepted to do this "film" so we could talk about it on the news and the newspaper. At school, all teachers should know about it to avoid bullying but the problem is that most of them don't know so that makes these kids be bullied.

- **Did he ever say or do something and hurt someone but didn't mean to?**

He never hurt anyone but he always says what he thinks even though it's not politically correct.

- **Which of the main symptoms of this syndrome would you say he presents?**

He's obsessive with things he likes and he's good at but after some time, he gets bored and forgets about it.

He hates when someone changes things about its place for example the furniture. He also hates the "social rules" like "You must give two kisses to say hello". He hates lies and talking to people who don't understand him.

- **I think that "Aspies" have a different way of approaching the world and people from people without this syndrome. They have feelings but it's really difficult for them to express themselves. Do you agree?**

We both agree. A lot of professionals say that they have no feelings but they do show that they have feelings but in a particular way. For example, Iñaki was bullied at school and he used to arrive home, lock himself in the room and cry.

- **Do you consider him as someone imaginative? Has he ever had an imaginary friend?**

Yes, he's a really imaginative guy but he never had any imaginary friend. He's really creative too.

- **People with AS usually have difficulties to understand jokes, sarcasm... Does it happen to him? Can you tell me a story that happened to him?**

Yes, it happens a lot to him but it's not such a big deal because he always asks what he doesn't understand. I can't remember anything right now.

- **At school, do teachers do something to develop his IQ?**

Not until 5th grade. A teacher came and gave him different homework, more difficult ones so he didn't get bored.

We think that they don't care if people who stand out get bored or are too clever for that class. They just care about people who have more problems to understand things.

- **What do you mean when in the documentary you say that your kid has a different sense of reality from anyone else?**

When I said that I meant to say that he sees life in a logic way. I mean... let's see... everyone sees life in an emotional way and emotions it's something difficult for him to understand so he can't see life that way.

- **When you want to have a lovely moment with Iñaki but he doesn't want to talk to you, what do you feel?**

I feel frustrated and sad. Now this doesn't happen that much because when he doesn't want to have any contact he just tell me and if I need a hug or a kiss I just ask for it.



### 5.3 Rosa del Hoyo



**Figure 14. Rosa del Hoyo**

Source: Rosa del Hoyo

When I went to Barcelona to watch Iñaki's documentary there was a young girl who asked to speak and she told us a little bit of her experience as a girl with Asperger syndrome. After it all finished I went to talk to her and asked her for an interview and she immediately accepted.

She gave me her email address so we could communicate better.

I told her that I was doing this project in English and she told me she could speak English so I could interview her in English and that made my work easier, I sent her the questions to make sure everything was okay, I asked her if there was a problem with recording the interview, I sent her a

photo of me just in case she did not remember my face, etc.

After all, we met in the city hall of Mataró on 11th of September. I was really scared and nervous. I did not know how to react but I have to say that she was very friendly and she helped me a lot with this project.

When I interviewed her, she was about publishing an autobiography book. It's the book I talked about before "Mente, encuéntrame. Dos meses y medio en la vida de una Autista".

Her name's Rosa del Hoyo Pérez and she lives in Mataró. She's 25 years old. She studied biotechnology and worked in a quality assessment agency. This year she's studying to be a librarian.

- **Have you always studied and lived in the same place? (In case it's a no). Was it hard for you to change?**

I have always lived in the same place what it's a huge relief because I really don't like change but I have not always studied at the same place. I have studied in the elementary school, then I went to high school and then to university. It was hard, really hard. Especially from elementary school to high school.

- **Do you live alone?**

No, I live with my parents and my brother.

- **Do you think it's difficult to live with someone who does not have AS?**

Yes, but I think it's more difficult for them than for me actually because... well, I am not always in control of what I say or what I do. Above all, I'm not in control of how I affect people but they know how they affect me, they know how they feel when I make them feel bad which is not always what happens to me. I'm quite bad at realise if I make them feel bad and I really don't realise that I have an effect on them. It's not that I'm blind to these kind of things but it happens quite often. And it's not that I don't care about my parents or my brother it's just that I'm like that.

- **When and where were you diagnosed? What kind of tests did the specialist carry out to diagnose AS? Did all the testing take long?**

I was diagnosed when I was 23-24 in Mataró's Hospital. It was with two tests: one for my parents and one for me.

The only that was for me it was 2 hours long and it involved reading a... well, actually it was not reading, it was describing a tale they gave me with images and I had to describe what was happening. That was quite long.

Then I had to answer questions about my friendships, my marks, my beliefs,

etc. They asked me my opinion about human behaviour, human ethics and things like that. They were tests that they do to children too but when you're not a children they kind of modified to make it for adults.

Then they made me do mimics. They told me "You have to clean your teeth." and I had to do as if I was cleaning my teeth but with no brash. Just me.

And at the end I had to make up a story with toys, weird toys like a sponge and things like that. They weren't really toys. They were objects and I had to make them toys.

- **And do you know what was your parents tests about?**

Yes, they asked them about my experience at school, my behavior at home and this kind of things.

- **Who decided to go to a specialist?**

I did. I didn't decide to go to a specialist because I had those symptoms. I decided to go to the psychiatrist because I wasn't feeling really well. At the beginning they diagnosed me with obsessive-compulsive disorder, later with other disorders and at the end they diagnosed me with Asperger.

- **Did it take long to end up with the asperger's diagnosed?**

No, it didn't because I decided to go to the psychiatrist but it was hard because I had to take a lot of drugs and most of them were not good for me.

- **Do you have low or severe AS grade?**

I don't know. I know I have Asperger's Syndrome but no one told me. I imagine I might be in the medium range but I don't know.

- **Did going to a specialist bother you?**

Bother me in the sense that I felt that I wasn't being understood but at the end when I found the Asperger's specialist, then I felt understood. I felt things were

coming into place and that I was starting to improve.

- **Do you think that when they diagnosed you that syndrome they made it easy to you and your family (giving you some information or any other kind of help)?**

Well it was easy for my parents to adapt to my behaviour. For me it didn't make a difference at the beginning because I was sort of denying because I wanted to have something that was curable so I denied for a couple of months and now I kind of... live with it. I don't like it. I'm not those kinds of Asperger's people who are proud. I don't think they are wrong but I just think that it's an impediment.

- **Do you have any mania or phobia? (Ex. Iñaki is used to muting the tv when there are commercials.)**

I have phobias. Quite a lot. They could be ten or something like that. You know, little phobias like cannot go into elevators, I cannot go to places where there is not enough signal for my phone because I feel like I'm isolated by the world and that makes me feel scared. Things like that. Little things like that but my main phobia could be... being separated from my parents, thinking that they could abandon me because I'm different.

- **Do you really have auditory or visual sensitivity? (Ex. In the film 'My Name Is Khan' there are some scenes where Khan could not stand really loud noises or yellow colour.)**

I have more auditory things than visual ones. Bright lights used to bother me a lot when I was a child but it had to do because I've got problems with my eyes, not because of my Asperger's Syndrome. I don't like fireworks. They produce me anxiety. If I'm in a place with people and suddenly there are fireworks I kind of get frustrated and I can't act normally and pretend that I don't care. I close my eyes and cover my ears

- **Do you have a really strict routine? If you do not follow that routine do you get upset?**

Not really strict but some aspects of my routine are really important. For example, I have to do what I think I need to do for the day. Not every day I have to do the same but if I don't do what I've planned to do in the morning I get very very sad. Not frustrated or angry, just sad and it makes me feel worthless. Sometimes I can't calm myself and what happens is that I usually rock myself (S'ENCONGEIX EN UN RACÓ).

- **Is there a subject where you stand out (music, history, maths...)? Do you do any activities to develop that ability?**

Well I studied biotechnology so I'm good at biology, chemical engineering. I also like music in general and I play the piano and the violin.

- **What is your IQ (intelligence quotient)?**

I don't know. I've never taken any test.

- **Me neither actually. I have a friend who suffers from AS and his psychologist told him to do some exercises to practice facial expressions, to be able to look at people faces when you are talking to them, etc. Do you have to do something similar? (In case of a yes) Explain it, please.**

No but I have to do two exercises of empathy that were a little more complicated than do expressions and all those things. It had to do with subtle people. For example, when someone makes a joke but they are angry and they make that joke because they want to show you they're angry, that's why they make that joke. I just don't get it. Or for example, I need to improve my vision of the world in general. I always think that I'm the centre of the situation I'm in but in a bad way. Not as if I were a leader but as if I were horrible and everybody hates me so that's what I have to change. And it has to do with

Asperger's syndrome. People with these syndrome is used to be very lonely although they're with other people. So when I start to feel isolated, you start thinking you are the centre of the world because there's no one else with you in your mind.

- **Do you follow any kind of treatment?**

Yes. I go to a psychologist who is a specialist in autism and I go to a psychiatrist, who subscribes my medication.

- **Is there really much medication?**

Yes. There's quite a lot.

- **There are some people who decide not to tell their child that he or she has AS. I read long ago about a mother who decided not to tell her daughter she had Asperger because she didn't want to make her feel different. What do you think about it?**

Uf... that's a complicated question. A good question. Mm... Well, I think that it's good for a child to know how they are and if they have AS then I think they should know because that's a part of who they are. It's like not telling a child they are black or that they have green eyes. It's kind of blind them to the world. They can't develop properly.

- **Yes, I totally think the same. And would you like to had known you had AS before?**

Yes. I think my life would have been easier. I think I wouldn't have been bullied. I would have been more confident.

- **Do you have any specific interests? Do you usually talk to people about your interests or you prefer just keeping them to yourself? (Ex. I'm a Harry Potter fan and I'm always talking about it.)**

I like science fiction and fantasy a lot. And actually, it depends. If it's someone

with whom I am comfortable talking with I'd probably talk to him or her about this.

- **When you studied, did you use to have good marks? Did you stand out in any school subject? Well, I guess biology, technology...**

Yes. I really liked biology, maths, physics... I kind of stagnate with chemistry. I don't like it but I got good marks in everything. I like languages too. I like English. I like French. I speak Spanish and Catalan too. I LOVE philosophy. Actually, I didn't study psychology but I think I would have loved it really much.

- **As you said last Thursday, you had really bad moments at school, especially in High School. If you don't mind, of course, can you explain your experience?**

As I said, I was bullied in my first and second year of High School by a girl and then the other girls kind of followed her.

- **Yes... that's typical.**

I was very lonely, scared, isolated. Some boys helped me. For example if a girl was going to hit me and she was hidden somewhere, boys always told me "Hey Rosa, she's there and she wants to do something. Be careful". That was cool.

- **OMG! People is really mean and cruel sometimes... And what about university?**

I thought I was going to find people like me in the social aspect but it didn't happen. I found very intelligent people, very responsible people which I hadn't found in high school but they weren't like me. I saw that I lacked something not people but me.

It was very hard because I really wanted to be a part of them. Some people with AS don't want to be a part of a group. They are happy being lonely but I'm

not. I like people but it's very difficult for me to be part of a group.

So at university it was even more difficult than in high school. Firstly because I expected a lot from it so the downfall was epic and secondly because the social interactions were more complex. I don't even know how to describe them but felt like I wasn't growing up and that made me very sad.

- **In Andrea Lamount documentary, Iñaki said that teachers let him stay alone in class in the playtime. What did you do in the playtime?**

When I was in elementary school I was with the "not popular kids" hidden, invisible. We were a group of five people and we used to sit on a bench and talk. We were different. Each of us had their own... thing that made us want to be hidden.

- **Do you think that part of this bullying is because AS is not known by the population?**

I think it is because it's not known by children and it would be very important to explain AS to them. Not like a disease. Just explain them in a way that they can understand us. I think it's important to explain them very well.

- **How did being bullied affect your parents? Or well, your brother... your relatives.**

Well, my brother was bullied too. We don't know if he has AS. My mum was bullied and my dad was bullied. So we have a long history of bullying in my family.

It affected them a lot. At the beginning I didn't tell them because I thought it was normal. Maybe I was afraid because this girl... she followed me out school and used to sing songs to bother me when she followed me so I was afraid of her to enter into my house and somehow bother my parents or don't know. At the end I kind of exploded and they were very worried and angry at the teachers because they knew everything.



- **So teachers knew you were in that situation?**

Yes.

- **Good teachers then... Asperger's Syndrome is genetic. Do either of your parents have this syndrome or present any symptoms?**

My father presents some symptoms. For example if you give him a hug he says "Okay." which is weird. He's not very... warm. He loves you but he doesn't show it. He's quite lonely. He has no friends and he doesn't care. He's got his family.

- **But he hasn't gone to any specialist or...**

No, he hasn't. He doesn't need to because he's happy. I wasn't happy that's why I decided to go to a specialist.

- **Which of the main symptoms of this syndrome would you say you present?**

A lack of social growth.

- **Just this one? Or you said it because is the most important one?**

That's the most important one.

- **I think that "Aspies"... Well sorry, do you like that name for people who has Asperger?**

No please. People with AS. I don't like "Aspie" but I respect it.

- **Okay, sorry. I just read it and I said "Well, I'm going to write it and then see if she wants or not. Well, I think that people with Asperger have a different way of approaching the world and people from people without this syndrome. What do you think?**

Well, everyone has a different way of seeing the world. I don't think AS is a

normal variation like having green or brown or blue eyes because it makes people unhappy so I just think that it's something that makes you see the world differently but that's it.

- **Do you consider yourself as someone imaginative? Have you ever had an imaginary friend?**

Yes, I do. Well, I think I don't have a normal imagination but I think AS influence in my imagination. I have written some books and they are quite original. They are not copycats of any other book. So I have proof that I've got an imagination. But I never had an imaginary friend.

- **People with AS usually have difficulties to understand jokes, sarcasm... Does it happen to you? Can you tell me a story that happened to you?**

I can't recall anything at the moment...

- **Well, don't worry. Long ago, I read in an article that "aspies" love reading but they usually don't understand what they read. Is that true?**

In my case it's not true. I haven't heard of it anywhere but maybe it's true in very severe cases when people can't understand if there are many interactions like love relationships, complex friendships...

- **Do you think that AS is known by people?**

I found that people really don't know about it. I used to ask "Do you know what that is?" when I explained people what I have and they always said "No, no I don't". And then I asked "Do you know what autism is?" and they used to say "Well, not really. That's when kids hate themselves, right?"

- **Hahahaha Mm... No? OMG!**

It has happened with my family, with my friends (who are not really much people), my colleagues at work... So no, it's not known. Not at all.

- **Well, just in case you want to know. I did an inquiry in my high school. ( I showed her the results).**

That's sad.

- **What would you do to change this situation?**

Well, I've written a book that it's going to be published this month or next month at the beginning. I hope this book impact people and it makes a change reaction.

- **Wow. Later I would like to know more about that book. And apart from the book, is there anything else you could do to change it?**

Well, I could do conferences, inform teachers and students about it but I'm kind of shy so... I'm in an association about mental illness in general. I was in an Asperger's syndrome association but it didn't last really much because I was very busy at that moment and it was a lot money so I had to stop paying. And obviously, when you stop paying, you're not longer there because I couldn't be a volunteer either because of the time.

## 5.4 Victoria González



Figure 15. Victoria González

Source: Carlos García González

Victoria González is a pedagogue and speech therapist who works in Sant Paul's hospital, but also has a centre of speech therapy, education and psychology for children and teenagers.

She studied Therapeutic Pedagogy and psychology. She also has two masters, one in speech therapy and another in Psychopathology and Mental Health.

I know her because she is a friend's mother. When my friend told her about my project, she immediately offered her help.

**Do you like your job?**

A lot.

**What kind of relation do you have with your patients?**

I have two functions. In Sant Pau's hospital I just diagnose people and in my centre I diagnose but I also treat them.

**What do you like the most of your job?**

Treat the patients, be with them.

**What do you dislike the most or what do you find the most difficult?**

Actually I love my job and I like everything but the hardest thing would be the interviews with parents because they are always worried, confused... They sometimes take what I tell them like if I were questioning them and like if I were an enemy.

**How would you define AS?**

I would define children and medium-adults separately. I would define medium-adults as normal teenagers with a way of approaching the world very different. Albert, a boy who is 21 and he is finishing his mathematical career and he is a really smart boy, always says: "Victoria, yo soy un acoplado de la vida" and when I ask him what does

that mean he always says "I'm always late, I don't understand what other people want and when I interactionate with someone I have to think about it a lot and when I finally understand what he/she wants and I want to say something they are gone. It's too late" So that's it, they have a different way of approaching the world, it's hard for them to know how normal people work.

A child is simply a chaos. They are always scared because they don't understand our world. They have a world which they understand, but he does not understand that we want him to understand ours. They are happy children until there is so much demand, especially in high school where they told these children to follow some rules they don't understand.

### **What kind of tests do you carry out to diagnose AS?**

We have to do tests and of course, observe.

We use psychometric tests to assess the psychological profile of patients. Because they are usually smarter and we have to discard a mental retardation. Even though they are usually gifted, that does not mean they are always, they can have a normal intelligence.

Then we use ADIS and ADOS. The first one is a semi-structured interview guide for parents that takes about two hours. The second one is a scale to evaluate the children. And after that, we diagnose.

And DMS is a manual of clinical classification so after we do all those tests, this manual tells us what results must you have to diagnose those diseases. I don't have it here, but it says "to diagnose an X syndrome it has to meet you items" and if the child does, then you can label him with that disorder. But to label someone, you have to pass those tests.

### **Do you work with all kinds of AS grades?**

Yes, I do.

### **What kind of difference do you see between a boy and a girl with AS?**

I would find any difference. Maybe the interests. Boys normally like planets and dinosaurs and girls do not have those interests so clear. Girls tend to be much more introverted and parents just take them as shy girls so they don't go to a specialist. But I could not tell you exactly because I have only worked with two or three girls with AS

in my 22 year job.

I know that girls are much more difficult to be diagnosed because they are not noticed. It's not that they are difficult to diagnose, but they go to specialists later. Because actually, now, AS is not difficult to diagnose, it was years before. Now we have problems with schools because they always diagnose TDAH when it's actually TEA.

**Once you diagnosed the syndrome do they have any kind of treatment like therapy, medication...?**

Yes. Drug therapy that is medication starts when you need it (usually when they grow up, in high school) because it's normal to become stressed with all that demand or for attention deficit. That does not mean that all them need this medicine, but sometimes, well, usually we give them all that to make the therapy easier.

I always say that if school helped, it wouldn't be necessary all that medication.

There are other kinds of therapy which I always recommend:

First of all, language development with speech therapy to give meaning to objects, to make them have a language, not all people with TEA develop language so they must learn to communicate. First, we start teaching them how to say yes and no. After that we try to make them ask for usual things: "I want to pee", "I'm hungry"... Later we try to make them ask questions: "I'm hungry" and we ask "Ok. What do you want to eat?". And finally, we make games to make them employ symbolization through language.

Once there is communication, they need a psychologist for social skills, to teach them how to share their feelings, how to interpret other peoples' feelings, to put a limit so people don't take advantage of him, say hello and goodbye, thanks, please...

And finally, they must learn cognition with a pedagogical therapy. They must learn how to process information from perception and experience. It is important too, but it's the less important one.

**Is there any help for parents (counselling, associations...)?**

Yes. When I work in the private part, in my centre, well, I always say that all this doesn't work if you don't advise parents because they need to help the kid too because the kid lives and grows up with the family at home. That's why at the beginning all parents are in the therapy.

Another counselling is the specific one where we explain them what they need to do,

how much they act because it is complicated. They need help when they are kids, but when they are teenagers is sometimes worse because it's really difficult for them to let their child go out on his own, when they have to choose what to study is even worse because they can make a career but that's not a normal thing. Typically, they are an absolute academic failure because the system does not work for these people, does not help them.

In November I had a discussion with a school about an 18 year old boy who is very smart, but since he was 14 he doesn't go to school. From 14 to 18 he had his school certificate at home and now he started in a new school to study chemistry and the school told him to leave because he does not have the social skills he need to study there. But that's what I told them "To study, he does not need to have social skills, he just must pass the exams and study. He cannot change that, he will always have TEA." But no, they don't understand that they must explicitly tell him to take out the material, the fact that he cannot organize his diary... They just say "He's 18, he should know that. It's basic."

So the normal thing is to leave their studies in high school because they are also bullied.

### **Which is the common reaction of the parents and the patient?**

For the kids who have a high intelligence they are normally rested with the diagnosis because they finally know what's wrong.

In parents there are different reactions the ones who deny it. They just say his child is a difficult child. In other cases, they feel guilty because they say that's exactly what they do. When a child has AS, normally the father has AS too, but they don't notice it because they have a low grade and they can live normally. These parents always tried to solve it with punishments so they stop being like them, but what I always say is "If you have a diabetic child, even though you don't give them sugar, they're still diabetic, right?". And I also have to explain that even if we do the therapy, they'll always be that way.

### **Is there any case of AS who particularly surprised you?**

Some years ago I had a boy, Roger. I dreamed with him, I dreamed he could talk, but in real life he couldn't. Now he's 28 and he still doesn't talk. It was one of my first

patients and it made me feel really insecure. I had to ask for a lot of help but I finally accepted that I could not handle it. I ended up really bad and depressed. It was so hard to make parents understand I could do nothing and after that I didn't treat more AS like him until another boy, Albert, came and he was the opposite. Nowadays, Roger comes to visit me with his parents and he's a really well-built boy.

**Most of the children come to the centre or to Sant Pau's hospital for their choice?**

No. They are usually upset when they come. Well, when they're kids, no because the therapy is by playing games.

**Do you think a person with this syndrome can have a normal life (become independent from parents, have their own family...)?**

Of course. In fact, there is a lot of AS who hasn't been diagnosed and they are doing a normal life.

Is it possible not to have an Asperger son or daughter if you are Asperger?

Well, it depends on the other parent too, but yes, it's possible. But you have to think something, if you are Asperger and your son it's not, he will watch you and as in your house there are a lot of rules and manias and he will get all that.

**And if you see one of the parents who you think is Asperger, do you tell them?**

No. Sometimes they just notice they are like their children, but they don't usually ask for a diagnosis for themselves so I don't give it to them. I just diagnose the ones who ask me to do it.

**As you know, in DSM 5 specialist decided to include food addiction, for example, but remove syndromes like AS and autism and name it all with TEA.**

**What do you think?**

There's a big dispute now. They've done it with a lot of mental disorders. It is true that we found autism and Asperger had huge differences with communication disorders. For example, we used to diagnose a pragmatic use of language disorder in an Asperger boy so they decided to difference TEA which comprises autism, Asperger and others from these kind of language disorders.

We used to say "This kid has AS, this one have autism and this one has symptoms of autism spectrum disorder." The last one was when he had some of the characteristics.



Now, what we do is englobe those three as TEA.

But it's also true that there are people who has already been diagnosed, there are associations, there are people who don't consider themselves as an autistic person but an Asperger one... So there was and there is a lot of controversy. But I think that now is better diagnosed because that enables us to assist them in the best and most efficient way.

They are the same person with the same characteristics, but we have more tools so we can make school give them more help, we can make the family understand the situation...

**But people with this syndrome who had been diagnosed with DMS-4, does still have all the help they had before DMS-5?**

Yes, of course. The label has nothing to do with the treatment.

Look, when they have a low grade, I try not to diagnose so I'm not mistaken: "Your son has TDAH, now he's not TDAH, now he has AS, now he has whatever".

I always say "I suspect it's a TDAH but it may change, only his evolution can tell, he has all these symptoms and they conclude in TEA, we're going to start the treatment and we'll keep the diagnose for the end. What gets better isn't part of the disorder, what doesn't get better in time it's the disorder."

There are a lot of parents who thinks that therapy depends on the disorder. NO. From the symptoms, I evaluate which are his disabilities and his abilities so I take his abilities to work on his disabilities.

**Do you think AS could become an individual disorder again?**

Of course. If now arrives another group of specialist and in the new revision of DMS (they revise DSM every 4-5 years) say that this doesn't work, of course it can become again an individual disorder.

**Would you change it or do you like DSM-5?**

Well, it has some things that need to be improved just as DSM-4. We simply need to do it better every time.

**And what would you say are the causes?**

Well, we've been through lots and lots of explanations: a lack of maternal attachment, chemical poisoning...

For me, the main cause is the genetic one.

It is true that neuroimaging tests say that there is an abnormal activity in specific parts of the brain, but it's also true that with stimulations, there are parts that activates. Nowadays, what we have is with magnetic resonance, we see that after working the language, the language part of the brain activates. With this resonance, we can see that this part of the brain is more stained than usual.

We think that these kids, just as other kids, their frontal lobe has a dysfunction, but if you work on that, it activates a little bit.

I don't think that causes TEA, I think TEA causes that.

**But then, being autistic has a cure? Because, as you said before, if you stimulate the parts of the brain, which are affected, you won't have a problem anymore.**

No, it has no cure. TEA is a personality disorder, not a brain disorder. They have a different personality. Where is the personality located?

**Mm... No where.**

No where. It's just that if you work on those parts of the brain, you'll be able to communicate, to talk, to do a lot of things in a better way, but you'll still have all your manias, you'll still have this syndrome.

## 6. CONCLUSION

I have really enjoyed doing this project. It has not been easy, but after all, I am more than satisfied with the results.

What I liked the most was interviewing all those amazing people, they were essential to make this project. Hearing Rosa's experiences, Victoria's anecdotes...have made this project a memorable experience to me. They were all really nice.

At the beginning I just wanted to do this project to inform myself about it, but while I was doing it, I found out that people did not know what it was. It was then when I decided to do the annexes.

I first started with the questionnaire and seeing the awful results I got, I decided to make a video by myself.

I liked the fact that in every class I did the inquiry, they asked me what it was. They were interested, which is a good signal. I hope they have not forgotten about it.

People who suffer from AS are usually bullied at school and that has a lot to do with the fact that people do not know what it is so what we can do to avoid bullying is disseminate information about this syndrome so that people can get to know them and understand them.

So the project that started being just informative, has ended up being a project with an audiovisual part to increase understanding among children, youth and of course, teaches.

I have written about series, films and books with people who suffer from it so instead of giving information, maybe just watching these films or reading these books, people will be able to understand AS and they will not need to read the theoretical part of the project. What matters is not knowing the history or the causes but understanding how they act and how to deal with them, not just refuse them because they are different.

With this project, I also found out that this is what I want to study. This is what I want to do. I want to treat people with these difficulties and help them with everything I can.

I loved the way Victoria spoke about those kids. She told me they remember her and associate her with someone who helped them. I want that, I want to do something for

them, I want them to be successful, I want schools to understand their difficulties to be able to help them rather than exclude them.

This project has helped me to find what I really want to do in the future. This is the main reason why I am so proud of it.

# 7. ANNEXES

## 7.1 INQUIRY: Is bullying to Asperger's people because of the ignorance?

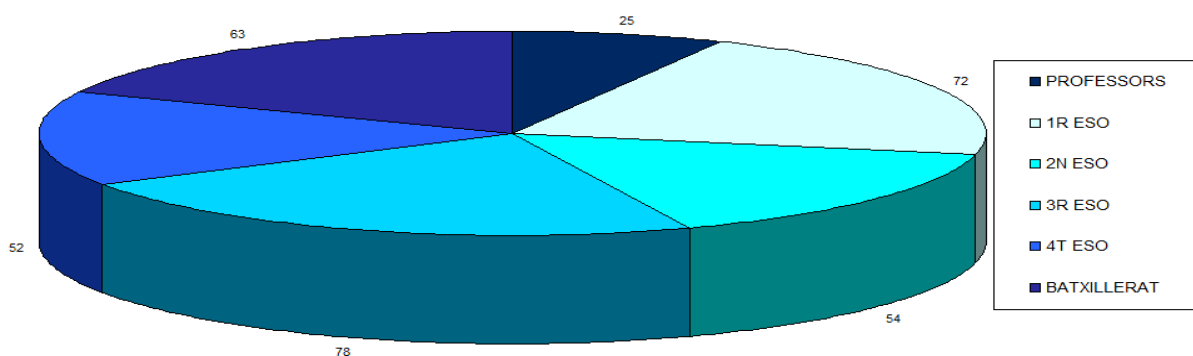
While I was doing this project I found out that many people did not know about it so I decided to make an inquiry into my school to prove that people really don't know what it is.

I knew that the results were not going to be really good, but I did not expect such bad results.

It consisted of three questions:

- School year
- Do you know what Asperger Syndrome is?
- (If you know it) Explain it.
- (If you know it) How did you discover what it was?
- Do you have any friend or relatives with Asperger Syndrome?

I first separated the result in School year. I had 344 in total:



**Figure 16. People surveyed.**

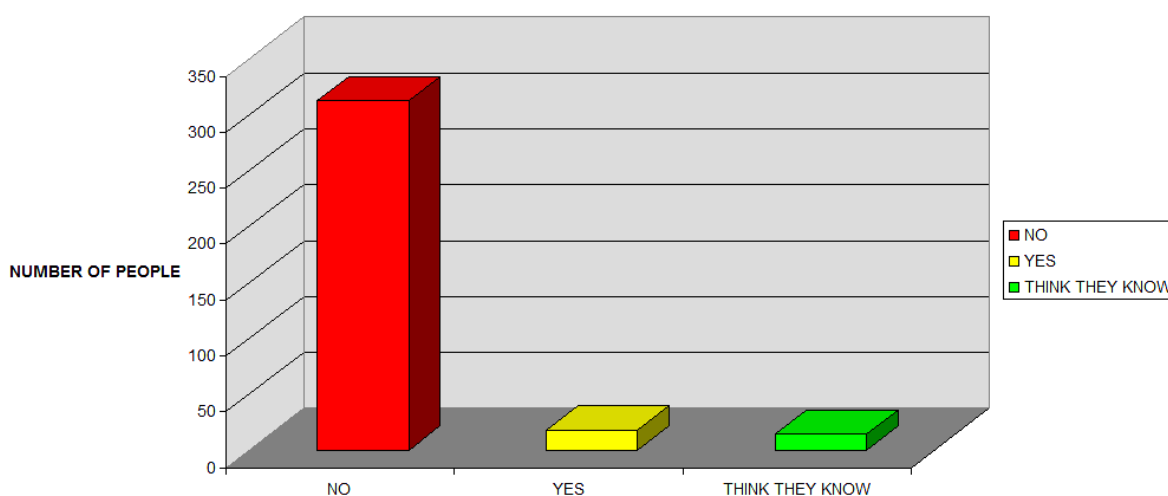
Source: Anna Ram3rez.

- 25 teachers
- 72 from 1st ESO
- 54 from 2nd ESO
- 78 from 3rd ESO
- 52 from 4th ESO
- 63 from Batxillerat

And here is what I got:

- 312 people said they did not know what it is.
- 18 people said they knew what it is and they actually knew it.
- 14 people said they knew what it is but they did not explain it properly.

## KNOWLEDGE AT SCHOOL



**Figure 17. Knowledge at school.**

Source: Anna Ramírez

As you know, people with AS are usually bullied at schools and this is one of the reasons why. People do not know what it is, not even teachers.

How is someone supposed to teach a kid if hw/she does not know his problem?

How are you going to accept someone if you do not know what is wrong with him?

## 7.2 VIDEO: ~~Weirdo~~ It's Asperger.



**Figure 18. Blaine at school. Everyone is doing homework, talking and he is alone. He is rejected by their classmates.**

Source: Anna Ramírez

After making that inquiry I got sad because it is not fair for those kids to be treated badly because people do not know their problems.

That's why I decided to make this part of the project, because I think everyone should know it.

My first thought was to put all around the school, information about AS but after thinking a lot, I thought it would be better to make a video because that would not be so boring for people.

In this video there are two parts:

In the first one you can see a boy, Blaine, having a normal day. He gets up and prepares his breakfast. Here we can see some manias:

He does not open his eyes immediately, he gets up (with his eyes closed), he sits

down on the bed, counts to three and then, he opens them.

While he is in the kitchen, he is preparing his breakfast and puts some cereals in a bowl, but he puts too much and instead of removing some cereals, he empties the whole bowl to do it all again.

After that, he goes to school and in class he seems to be alone, but looking around trying to say something.

He comes back from school and stays in the bedroom doing homework, playing video games... but someone makes a noise and he gets upset with it and starts shouting. As you can see, he is sensitive to strong noises.

Later, we can see him in the dining room all alone again having dinner. In this scene we can see one mania about the food. He has different things on the plate, but it is all organized so there is no contact between them and he eats it one by one.

To end the day he is again in his bedroom reading a book and going to sleep.

In the second part, we can see Blaine is doing exactly the same things when he gets up but at school he is not alone. We can see him surrounded by his classmates, they are talking, laughing but he is alone watching them, he wants to talk, but he cannot, it is impossible for him to speak.

That is a metaphor: he wants to talk, to socialize with people, but he can't because of his problems so he is alone.

It is also different when he is having dinner. He is not alone, he is with his mom and she wants to converse with him, but he does not talk so she touches him to catch his attention and his reaction is negative, he is uncomfortable with physical contact.

After that, he reads a little bit and goes to sleep.

So as you can see in the video, his main symptoms are: a lack of social skills, have repetitive behaviours, and strict routines.

But in case you did not notice, at the beginning of the video, you can see some sports



cups and medals to prove he is good at sports. I decided to make him good at sports to prove that not everyone has all the symptoms. He has Asperger but he plays basketball like Rafer Alston.

We also can see some of his likes. In his bedroom we can see (apart from basketball), that he likes cars, reading and physics because at the moment he is reading a book about Einstein's theory of relativity.

I hope you like this video as much as I do and you get to know more or less the characteristics.

## 8. ACKNOWLEDGEMENTS

First of all, I want to thank my friend Carla Cáceres because she was the one who told me about Andrea Lamount's documentary.

I also want to thank all the people I interviewed: Rosa, Victoria, Karina, Roberto and Pol.

All the people who helped me with the video: Oriol, Aitor, Marc, Maria, Albert, Ariadna, Maria, Ana, Jared and Laura.

Victoria's son, Carlos, because he was the one who organized the interview with her.

My teacher but also friend Cristina Sardanyés for helping me correcting the mistakes and giving me help whenever I needed without expecting anything in return.

And finally, my lovely friend Judit Serral and my best friend Roger Gallardo. They were essential for the video and I really appreciate what they have done for me.

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