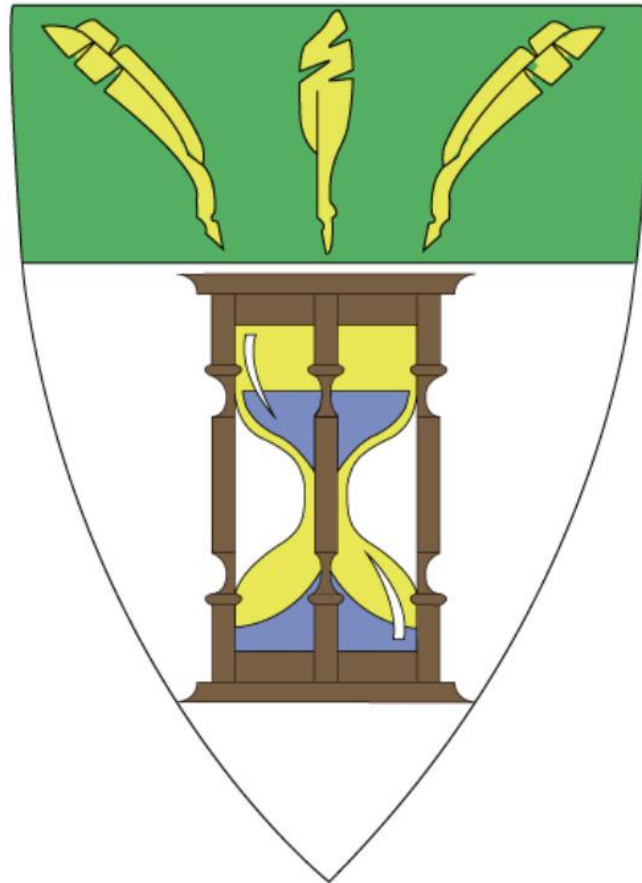


Mémoire individuel 2022/2023



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Autism spectrum disorder & music

Do people on the autism spectrum have heightened music skills because of their condition?

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1. Introduction

This year, I have decided to write my work about a condition that seems to get more and more common over the years. The autism spectrum disorder can be seen as a unique condition, since it is not yet precisely defined, and many people are still unfamiliar with it. Yet, the number of people diagnosed with ASD keeps extending, so I feel it is important to spread awareness on the condition.

During the last summer break, I got the chance to accompany people on the autism spectrum throughout four weeks, which gave me the opportunity to learn in what way the condition affects someone's daily life.



Additionally, I have found it interesting to associate this work with something that surrounds me on a daily basis: music. In the past, I have often heard individuals saying that autistic people tend to have better skills in certain fields, due to their condition. Personally, I have always found it biased to state that if some people did not suffer from ASD, they would not be so skilled. So, this inspired me to use my personal experience to discuss whether some people on the autism spectrum have such good music skills because of their condition or whether autism does not have an impact on someone's ability.

I have made sure to make this written work as personal as possible, meaning that I have tried to write everything in relation to what I was able to experience with autistic people, rather than researching information online.

2. Definition of autism

2.1. How is ASD defined?

ASD, short for autism spectrum disorder, has not yet officially been defined. However, there are a couple of factors that are used to vaguely define the condition. People diagnosed with this disorder mostly have difficulties with social as well as communication skills. Additionally, they might often have different types of behavior compared to what is seen as “usual”. However, autism is a whole range of several conditions, that vary from person to person depending on the condition’s intensity. That is why the word *spectrum* is used. To one end of the spectrum, belong individuals with so-called severe autism, meaning that they have very restricted to little ability to communicate. To the other end, however, belong those with high-functioning autism, whose IQ is either around or above average.

In fact, the autism spectrum disorder has been classified in a system containing different clinical variants of the condition. This helps categorizing the condition in several diagnoses depending on the individual’s disabilities.

Autism spectrum disorders:



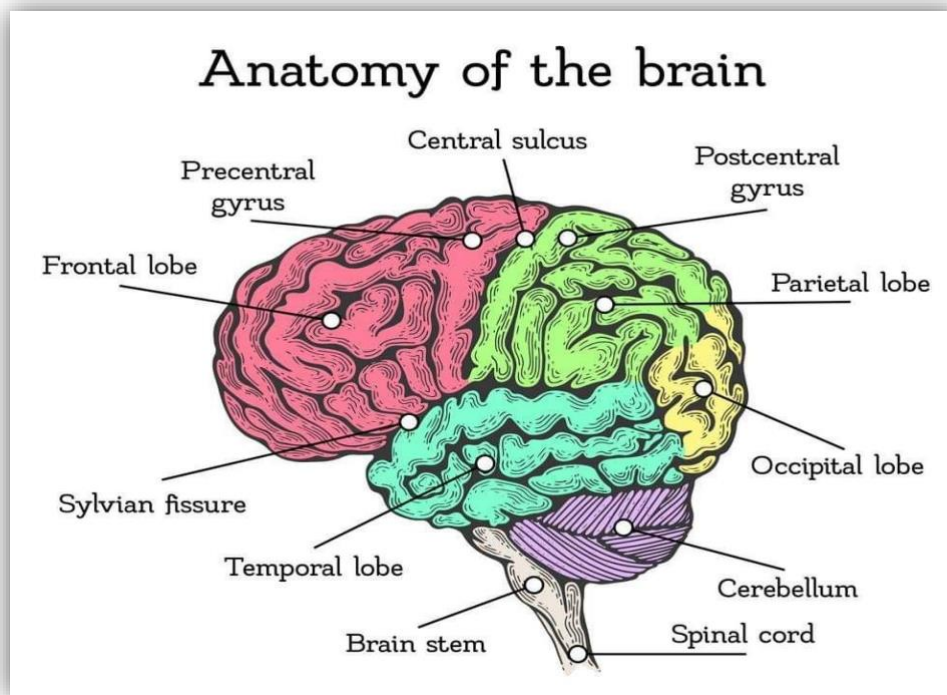
With that being said, it is important to realize that individuals suffering from ASD all have different struggles and strengths. Some might need life-long supervision and accompaniment, while others live a completely independent life.

All in all, people that are diagnosed with autism mostly struggle with social skills such as verbal as well as nonverbal communication along with behaviors. This does not mean that people who have difficulties communicating with others are automatically on the spectrum. Many individuals struggle with social skills, but that does not necessarily mean that they have a condition. However, for those who are diagnosed with ASD, these struggles can be extremely challenging and impact their personal as well as professional achievements.

2.2. Causes of the condition

If looked from a medical perspective, the autism spectrum disorder is mainly caused by differences in the brain. Yet, as mentioned before, it is still very vague and therefore not completely defined. Research is still taking place, hoping to find further causes leading to this condition.

However, professionals are convinced that the disorder is mainly caused by neurocognitive issues leading to certain social disabilities. Specific research suggests that the different difficulties, in the social as well as in the language fields, are most likely due to anomalies of cerebral growth. Additional defects are communicated by the neurons' organization as well as how they are connected to each other.



In cases of autism, several parts of the brain seem to malfunction:

- ✚ Cerebellum:
 - Located in the back of the head between the cerebrum & brain stem
 - Source of balance for several tasks such as walking and standing

- ✚ Temporal lobe:
 - Located under the lateral fissure¹ on both hemispheres
 - Helps processing sensory, auditory & pain stimuli

- ✚ Front lobes:
 - Part of the cerebral cortex²; placed behind the forehead
 - Largest lobes contained in the brain
 - Essential for several functions:
 - Expression of language
 - Certain motor skills
 - Classification and differentiation of objects

¹ Lateral fissure: separates the frontal, temporal & parietal lobes of the cerebrum

² Cerebral cortex: composed of grey matter & is the outer layer of the cerebrum

- Formation of long-term memories
- Attention managing
- ...

- ✚ Fusiform gyrus:
 - Structure that spans the basal surface of the temporal & occipital³ lobes
 - Is important for visual categorization

- ✚ Amygdala:
 - Neural system that is indispensable for the process of fearful & threatening stimuli
 - Allows to detect & response to threats by activating fear-related behaviors

- ✚ White matter of the corpus callosum:
 - Largest white matter contained in the brain
 - Keeps hemispheres connected

³ Occipital lobe: responsible for the interpretation of visual information

3. Diagnosis & development of the condition

3.1. Identification of the autism spectrum disorder


3.1.1. First signs of ASD


In most cases, signs of autism are obvious by the age of two. When diagnosed at such an early age, children can still learn to develop certain social skills by being accompanied by professionals. Unfortunately, research has shown that after 24 months of age, children usually either stop gaining new skills or end up losing those they once had, which is why an early diagnosis (before the age of two) can have positive outcomes later in life. However, many children are often not diagnosed until they are older. This delay means that they might not get the early help they need to develop certain skills and the opportunity for further development might have been missed.


Considering everything, it is extremely important that autistic children get the help they need as early as possible, in order to develop new essential strengths for their adult life.

Autism spectrum disorder usually affects children from the moment they are born. Still, most signs of the condition are not visible until later on. The first signs are usually acknowledged by parents, who notice the “flat affect⁴”. At this point, children might for example not have any reaction when being called by one of the parents. However, that does not necessarily mean that they are unable to hear them. Still, many children affected by autism do suffer from APD⁵, also known as CAPD⁶. This is a hearing condition that makes children unable to understand what they hear. The reason for this is because their ears are not in complete coordination with their brain, making it difficult to process auditory information.

Below are some specific and common examples of early ASD signs:

-  **Communication:**
 - Absence of response to name
 - Lack of comprehension
 - Unusual use of language
 - Inappropriate reactions to stimuli

-  **Social field:**
 - Lack of social interaction
 - Absence of imitations
 - Inability to understand emotions
 - Inability to react to other’s emotions
 - Inability to express own emotions
 - Lack of common (“stereotyped”) interests

-  **Restricted/repetitive interests and habits:**
 - Uncommon sensory responses
 - Unusual body posture
 - Repetitive movements
 - Attachment to unusual objects

⁴ Flat affect: lack of reaction to certain stimuli

⁵ APD: auditor processing disorder

⁶ CAPD: central auditory processing disorder

Other early signs of ASD can be visible due to the children's specific and fixated *interests and behaviors*⁷, which are explained more in detail in the upcoming chapter.

Recently, professionals have suggested that parents stay alerted to specific early signs when interacting with their infants. Early indications that adults should focus on are for example:

- ✚ Lack of eye contact
- ✚ Lack of response to parents' smile
- ✚ Reduced babble
- ✚ Lack of pointing at objects or people
- ✚ Difficulties with language development

3.1.2. Diagnostic evaluation

Autism is not an illness, but a condition. Therefore, there are no specific medical tests, such as blood tests, that can be done for ASD testing. Instead, a child's behavior in certain situations is observed and analyzed by professionals, who will then make the final diagnosis. A diagnostic evolution is done when certain deficiencies are noticed, either by the child's parents or a professional, in the fields of communication, social activity, interests and behaviors.



Additionally, it is essential to be aware that ASD cannot be diagnosed by only one symptom. This means that a child having difficulties developing language is not considered to be autistic until further tests are done in different fields. Still, the main fields mentioned above are essential for the diagnostic.

The diagnostic evolution of the condition is defined by a set of steps that must be followed and analyzed. Before the child is observed and tested, professionals start by gathering information from the parents. These must describe what alerted and concerned them in the first place. Only after having detailed information on the child, further exams can be completed to analyze the child's physical, cognitive and language development.

⁷ Details on restricted interests and behaviors in chapter "3.2. The conditions development" -> "3.2.2. Restricted interests and behaviors"

3.2. The condition's development

3.2.1. Verbal & non-verbal communication deficiency

As mentioned before, communication can be really challenging for some individuals on the autism spectrum. In general, most children usually start talking between the age of twelve and eighteen months, including those with ASD. However, in many cases, the ability to speak degenerates between the age of eighteen and twenty-two months. In severe autism cases, language development might not be acquired at all. Those who do acquire language often have difficulties with expressing themselves and understanding others. While people with ASD might struggle with verbal communication, non-verbal communication can be challenging as well. They often have specific types of body language such as avoiding eye contact during a conversation as well as being unable to understand and interpret facial expressions. A further difficulty might be recognizing and understanding other people's emotions, since they already struggle with regulating their own.

When achieved an elder age, the condition starts showing more, especially as a teenager. At that age, young adults suffering from ASD tend to have many difficulties interacting with their peers. It is extremely difficult for them to communicate with others and understand how they are supposed to behave in certain surroundings such as in school. Not being able to interact with others and make friends can often lead to serious additional conditions such as anxiety, depression, and attention disorders. When and if this is the case, further special healthcare is needed.

3.2.2. Restricted interests and behaviors

In some children, the ability of imagination is often deficient. Imagination usually starts developing at a very young age and mainly originates from games. When suffering from the autism spectrum disorder, children are generally not used to playing pretend games, which is one of the main factors for developing imagination. This eventually leads to difficulties with understanding others and interpreting their intentions and emotions. Yet, some children do have normal or in some cases, excessive imaginative activity. However, this does not necessarily mean that their social skills can be improved.



As mentioned previously, one of the main symptoms of ASD is repetitive behavior. In this case, stereotyped and repetitive movements are very common. The condition potentially affects people's interests as well. Individuals of any age might, for example, get attached to unusual items. According to studies, those with an IQ above average generally feel passionate about unusual topics.

Also, important to know, is that individuals on the spectrum often have a very structured and organized schedule to orientate themselves. They like to stick to their habits and are extremely resistant to any type of change, meaning that their environment should stay unaltered. When this does not occur and just minor changes take place, it might put individuals in serious and profound distress.

3.2.3. Vulnerable aspects of the condition

Many people with ASD show signs of vulnerability to specific stimuli. The most common vulnerable aspects are either hypo⁸- or hypersensitivity⁹ to visual, auditory and tactile stimuli. Those with auditory hypersensitivity for example, feel bothered by loud noises. Such situations occur when people talk loudly/scream or loud music is turned on. This triggers discomfort and puts them in deep distress. The same occurs in public places. If surrounded by many people, an autistic person might feel stressed because they cannot process and acknowledge the visual images. Another major aspect to be aware of is the vulnerability to tactile stimuli. Individuals with ASD do not necessarily like to be touched by others, nor when someone approaches them. This makes them feel as if their personal space is being invaded.

⁸ Hyposensitivity: under-responsiveness to stimuli

⁹ Hypersensitivity: over-reaction to stimuli

4. Treatment

4.1. Therapies to develop & improve skills

Important to know, is that the autism disorder is incurable and can therefore not be treated. However, thanks to professional support, certain skills can be improved, and symptoms can be reduced over time. Several therapies have been set up, thanks to which children's competences in communication and behavior have been ameliorated. Of course, the different methods used mainly depend on the child's needs. Everyone has different strengths and difficulties, so it is important that they get therapies adapted to their necessities.

Below are some of the main therapeutic methods that have shown to have positive outcomes.

- The most common therapy used on children on the autism spectrum is behavioral management therapy. As the name suggests, its goal is to manage children's problematic behaviors by teaching them the "right" way to behave. In addition, it helps the children's parents too, by instructing them on how they are supposed to deal with their children's unwanted behaviors. However, this therapy can be applied to those who are not on the spectrum but struggle with behaving as well.
- An additional important therapeutic method is the CBT, short for cognitive behavior therapy. This one is more focused on the ability to connect feelings, behaviors, and thoughts rather than just the physical behavior itself. The purpose is for children to be able to identify their emotions that might lead to problematic behaviors. Furthermore, CBT has been shown to help many people on the autism spectrum to deal with anxiety and depression.
- To improve social skills, the social skills training (SST) can be extremely helpful. SST teaches children the right way to interact with other individuals by for example making them repeat wanted behaviors. Amongst others, children get to learn greetings, the use of body language while interacting with others, and to keep eye contact during conversations.
- As many autistic people struggle with communicating, speech-language therapy might be indispensable. It is used to improve not only verbal, but non-verbal communication as well. Many individuals on the autism spectrum do not have the ability to speak. For those concerned, non-verbal communication such as sign language is used. The use of pictures is essential for interaction as well. Those who do have the ability to speak, get to learn to express their emotions and feelings along with naming people and objects correctly.
- For many, medication is used in order to reduce some symptoms, mainly those associated with the behavior of the condition. Medication can reduce aggressive behavior and shows better outcomes when used cooperatively with behavioral therapies as well. Furthermore, anxiety and hyperactivity can be reduced.
- While it is crucial for autistic children to get the help they need, it is extremely important that their caregivers know how to deal with them as well. Through parent-mediated therapy, caregivers learn several techniques to interact with their children and understand their behaviors in specific situations. It also gives the children additional training throughout the day, while they are not accompanied by professionals.

5. Facilities registration process

5.1. How does the registration progress work in Luxembourg?

Over the years, many facilities to help people who might need special needs have been founded. In Luxembourg, there are a couple of them as well, meant to accompany individuals with all kinds of special needs. APEMH for example, is a Luxembourgish organization that was created in 1967 by parents of children suffering from a handicap. Another known foundation in the country is the “Institut Saint Joseph”, a home in which I had the opportunity to work in in the past. Here, mentally and/or physically disabled people are accompanied and taken care of daily. They learn to cohabitate with other people that might have a similar condition to their own and learn to be independent by taking part in different activities that correspond to each individual’s personal “level” of ability.

Moreover, there are currently two main associations focusing on the autism spectrum in Luxembourg. The “Association Autisme Luxembourg” is an educational facility that was created back in 1981. Its goal is to allow those who are on the autism spectrum to develop specific skills in certain areas. Additionally, the association offers professional training known as “SFP” (Service de Formation Professionnelle) students who have finished schooling and are looking forward to starting their professional careers. Finally, there is the “Fondation Autisme Luxembourg”, a home and daycare for autistic people whom I had the pleasure to work with last year.

(Further information concerning the home I worked in will be discussed in the following chapter: **7. Personal Experience**)

6. Music & autism

6.1. Are individuals on the spectrum gifted?

Unfortunately, many people on the spectrum are confronted with certain boundaries and do therefore not possess certain skills (in the social field for example). Yet, some are naturally talented in a specific field and therefore possess skills other people might not. As already mentioned earlier, some individuals that are on the spectrum actually have an IQ above average. However, the autism spectrum disorder should not just be defined as a condition where individuals have an IQ either above or below average. Throughout the last couple of chapters, we have learned that ASD is much more than just a condition with one simple definition. Autistic individuals are exceptional, but each and everyone in their own way.

It would therefore be wrong to state that individuals on the spectrum are gifted in any way. They might or might not be better skilled in certain fields. However, this does not declare them as gifted. Just like any other individual that is not on the autism spectrum, people with ASD have strengths in some fields and difficulties in others. Nevertheless, they can learn to improve certain difficulties they might have, just like every human being learns to strengthen their weaknesses over time.

6.2. Musicians on the autism spectrum

6.2.1. Donna Williams

Being on the autism spectrum does not necessarily restrict a person from being successful in certain domains. In fact, many individuals have managed to build a career, be they in the autism spectrum or not. A good example of this would be Donna Williams. Born in 1963, Donna, usually called Polly, was known for being an Australian singer-songwriter, artist, writer and sculptor. Before her passing in 2017, she created a website that gives information on her personal life as well as her very successful career in several artistic fields. As someone who was confronted with ASD, she stood up for the condition and communicated a lot about her personal experience.



Pollys' condition did not stop her from getting several degrees such as a Linguistics degree. Additionally, she became a consultant in the autism field in 1996.

On her personal website, she defined autism to be a “fruit salad” scenario. With this description, she focuses on communicating once again, that every person with ASD is different. She mentions the lack of awareness leading to individuals assuming that every autistic person has either an IQ above average or is gifted in a specific field.

Polly is one of many examples that prove that a condition does not (necessarily) define someone's talents.

6.2.2. Patrick Samuel

An additional artist and musician who is confronted with ASD, is Patrick Samuel. Patrick actually got diagnosed on the autism spectrum at the age of 38. However, he had been suspicious about being on the autism spectrum since the age of twenty but did not manage to get a diagnosis until later. As we know, the first signs of autism usually appear around the age of two. Meaning, that Patrick Samuel has probably always been on the spectrum, just had not been diagnosed.

In his case, communicating with other individuals is extremely difficult. Especially when surrounded by unknown people, Patrick might feel anxiety, leading him to not being able to process conversations and shutting down completely.



At an early age, Patrick Samuel discovered his passion for painting and drawing and has kept it up ever since. Additionally, he got to learn to play several instruments such as the piano, guitar and flute. In an interview, the artist and musician states that art is his key to communicating.

“I know what color or shape I'm feeling, but I often struggle to express myself with words.”

“Ask me how I feel and tell me to answer with a piece of music and I can play you exactly how I'm feeling, but if I have to use a full sentence, I wouldn't know what words to use.”

- Patrick Samuel

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These sentences expressed by Patrick Samuel himself, reflect on his struggle in the communication field due to his condition. In 2019, he released his second album called “Distant Star”, which reflects on his personal experiences as someone diagnosed with ASD.

6.3. The effect of music

Fortunately, I have actually had the pleasure to meet a musician that is on the autism spectrum disorder. A close friend of mine was diagnosed with ASD at a very young age and kindly agreed to share their personal experience and gave their permission for me to write about it.

This person was officially diagnosed around the age of five after their parents started noticing some aspects their child struggled with. As it is very common on the autism spectrum, its first signs were lack of comprehension and concentration along with restricted interests. After the diagnosis, my friend started discovering the musical industry by visiting music schools, still at a very young age. Eventually, the parents filed an application and their child started learning its first instrument: the violin. As I asked questions about the process of learning the first instrument, I was not surprised by its response: *“easy, without any trouble”*. As I have known this individual for a couple of years now, in- and outside the music world, I have noticed how easily they manage to learn and discover new techniques in the field and am still extremely impressed by their exceptional musical skills. Over the years, they have grown to be passionate about music and have discovered several instruments ever since.



The person itself talks about their condition openly and is aware of the impact music has had on them. As they described it from their personal perspective, doing music has improved many skills that seemed to have been lacking earlier. Ever since they started gathering musical experience, their ability to concentrate has significantly improved and has even encouraged and inspired them to learn.

Additionally, we discussed what it was like being in a school specialized on the autism spectrum disorder. From their personal point of view, it was not a great experience. They did not appreciate being in a school/facility that is only meant for individuals suffering from the same condition since it seems to classify all autistic people under the same “category”.

Over the years, most of their autistic traits that were visible before, have disappeared now. Thanks to their hard work as well as their parents’ help and support, they have managed to create a life in which the condition does not define who they are or what they can and cannot do. On the contrary, they feel that they have changed a lot over the past couple of years. Today, they have no trouble being around other individuals and do not struggle with comprehending their surroundings. When they find themselves in stressful situations, they deal with it by listening to and/or practicing music.

As they revealed during the questions they were asked about their personal experiences, they declared that the reason they have managed to work on certain skills and be the person they are today, is thanks to their parents who always had their back. This shows the importance of being surrounded by people who understand the condition and are willing to help dealing with it.

What truly fascinates me about this person, are the improvements they were able to make over time. Their hard work and development prove that individuals are not defined by a condition and can in fact, be successful in whatever field they feel passionate about. It takes a lot of hard work for someone

who used to struggle a lot with social interactions and have outbursts to learn to shut down certain behaviors and feelings and live an independent life afterwards.

I am specifically delighted about how music has in some way changed their life. They discovered their true passion as a child and have not given it up ever since. In fact, they are planning on getting a musical degree and work in that field later. This shows in what way music can serve as therapy for some individuals.

7. Personal experience

7.1. “Fondation Autisme Luxembourg” (FAL)

As I have mentioned in the beginning, I had the opportunity to accompany autistic people between the ages of eight and seventy. For exactly four weeks, I worked at the autism facility “*Fondation Autisme Luxembourg*” (FAL) located in Rambrouch, Luxembourg. This facility has welcomed over one hundred people on the autism spectrum since 1996. The FAL workers, which are mainly educators, accompany and take care of people on the autism spectrum day and night, since their families might not have the capacity to fulfill their children’s needs. The facility has managed to spread throughout the country. In Rambrouch, the facility is divided in three homes (the so-called “foyers”). Further homes are located in Capellen and Munshausen.



The foundation additionally offers different activities where every resident will spend their day doing something fitting their interests. These are extremely helpful to develop certain strengths and learn to cohabitate with others. The activities include cooking, gardening, and doing handiwork (DIYs). From Monday to Friday, every resident starts their corresponding activity at ten in the morning and spends the day there. Later in the afternoon, each person is taken back to their homes, where supper is prepared and served by the educators. Then, every resident has some free time during which most of them will entertain themselves. Others will be showered and getting ready for bed while dinner is being prepared. That way, most of the residents can be put to bed right after having had their meal.

Throughout those weeks, I had varied schedules thanks to which I was able to work not only with elder people, but with children as well. The first two weeks, I spent the mornings in a home for elderly people suffering from this condition.

7.2. Elder people on the autism spectrum

While children are more active and (most of them) need to be entertained all the time, elder people tend to be calmer and manage to entertain themselves. As I have mentioned before, I spent the mornings in the “Foyer 4”, where the elder people live in. This allowed me to compare the development of ASD in elderly people and children.



When I first met the residents, I noticed they were extremely calm. After having been showered and dressed, they patiently sat on the living room couch, waiting for breakfast time. While none of them, except for one has the ability to speak, each has different strengths. On the one hand there is Marcelle for example, who does not know how to communicate with other people in any way. The only way that allowed me to acknowledge her feelings was by analyzing her behavior. However, she is capable of

listening and following orders. In other words, she understands what happens around her, she is just not capable of expressing her thoughts. Johnny on the other hand, is the eldest of the entire “foyer”. Yet, he is also the most independent person in the group. In the morning, he gets showered and dressed all by himself. All he needs is his so-called “Bichelchen¹⁰” containing pictures that describe the different steps of shaving his beard for example. An organized schedule is usually indispensable when working with people on the spectrum. If they do not know what their next move should be, it might lead to frustration and even outbursts in the worst cases. Johnny can slightly talk, even if it is very difficult to understand his words since they are not fluently spoken. He is also very talented, as he likes to spend his free time completing amazing paintings. When Johnny seemed to be stressed and having anxiety, an aggressive outburst would usually follow. These were challenging to handle. Even if the educators were mostly expecting these kinds of outbursts, they were very sudden. When they did happen, it took at least two educators and a lot of time to calm him down.

Another example is Robert, who is usually called “Robi”. For what I have noticed, he is very calm and likes to entertain himself rather than being entertained by other people. Every day he would complete two different puzzles, which he did with no difficulties. When something bothers him, he usually starts screaming slightly. His screaming sometimes ends up bothering his roommates which will cover their ears or leave the room. However, I have never experienced him having any kind of outburst.

All in all, the elder people got along pretty well and mostly spent their time on their favorite spot of the home, without bothering anyone else.













¹⁰ A little folder containing pictures describing the single steps to follow

7.3. Children on the autism spectrum

During summer breaks, the FAL often welcomes children to stay at their facility for a limited time, in order for the parents to be able to get some time off. Besides, they have a children's day care center (SAJE: Service d'activité de jour pour enfants) where parents can drop off their children every weekday until noon.

During those first fourteen days, I would either start working at 6am or 3pm on weekdays and at 7am during the weekends. In the morning, I would usually help the other educators prepare breakfast for the residents and give them a hand while they woke up the elder people, showered them, and dressed them. Then, around 8am I would wake up a nine-year-old boy, named Clément, who stayed at the facility during the two weeks I worked there. My job was to accompany him on a daily basis, creating a routine with him. Every morning I would wake him up, help him shower, get him dressed and give him breakfast. Then around 10am, every resident would be dropped off at their activities. In my case, I would drop off Clément at the children's day care center, where he would be surrounded by other children that were about the same age as him. In the meantime, the elder people from the home would each be in the activity they were signed in. Some would for example be practicing culinary skills in the kitchen department, while others would be helping in the laundry room or doing gardening.

After dropping him off, I would have a little break during which I was supposed to write the so-called "rapport". This is basically a document that every educator must complete, concerning the habitants' morning routine. Below are some examples of questions and answers contained in the document:

- | | |
|----------------------------------|--|
| Sleep: |  How much sleep did they get? |
| Morning bathroom routine: |  Did they cooperate? |
| |  Did the educator have to take over the complete process? |
| Mood: |  Did they seem happy? |
| |  Did they seem sad / angry? |
| |  Did they seem frustrated? |
| Breakfast: |  What did they eat? |
| |  Did they refuse to eat? |
| |  How much did they drink? |
| Behavior: |  Did they behave well? |
| |  Did they bother any of their cohabitants? |
| |  Did they show any signs of aggression towards themselves / towards others? |

In my experience, Clément behaved really well during the first couple of mornings. It was very important to me that he and I both worked together, rather than him just having to follow my orders. Therefore, I would for example ask him to help me choose his outfit for the day, rather than me just picking it out by myself. As far as I am concerned, I believe that letting him take part in choices made him feel more comfortable around me. Important to know is that Clément is a young boy suffering from severe autism. This means that he is unfortunately unable to talk. He can form different sounds

as if he were trying to talk, however, he is not able to form complete words, except for “mama”. In order for him to communicate with us, he would either use sign language or his folder in which he had certain images such as: a glass of water, food, smileys (representing different emotions), ... Additionally, he possessed a printed alphabet which he would use to “type” if he wanted to say something more specific.

Every day after having completed the document concerning Clément’s morning routine, I would join the children at the day care center. From there, we would try and benefit from the weather as much as possible, by taking the children out on walks before lunchtime. During these, I would notice differences in their behaviors. While at the day care center, most of them would be frustrated, either because of the noise other children made or because of the amount of people they were surrounded by. Individuals on the autism spectrum, especially children, often struggle when it comes to being surrounded by others. When approaching them, they might feel uncomfortable and react to it in a specific way. So, going out with them was extremely important and they usually looked much happier then.



Children playing at the air tramp.

Each day of the week, walks were completed in the mornings, and a different activity was planned to entertain the children in the afternoon. While I was there, we took them to outdoor parks to barbecue for lunch, went on long walks by the river, or played at the air tramp with them. During all these activities, we would notice several different kinds of behaviors. Many studies have proven that the majority of people with ASD are confronted by anxiety. At an elder age, they might learn to deal with it. However, children having anxiety usually

get frustrated and express their emotions and feelings in ways that might seem “strange” to others. In our case, they expressed their anxiety by hitting, running away, and/or having (aggressive) outbursts.

Below are some examples of actions and behaviors that I experienced while accompanying children on the autism spectrum:

- ✚ During long walks one of the boys named Scott would show signs of physical aggression towards himself and others. Mostly, he would stop several times during the walks and throw himself on the floor. Unfortunately, he does not have the ability to talk either, which makes it extremely difficult for him to communicate and express his feelings. So, Scott’s way of showing his frustration was by constantly hitting himself. As I tried to keep him from hurting himself, he would kick me away and pinch me. Even if seeing him hurt himself bothered me, this taught me that during such outbursts, it was better to give him some space and let him calm down for himself. When this occurred another couple of times, I made sure to step away and not invade his personal space. Instead, all I did was talk to him very calmly by telling him that it was okay and once he calmed down, we were able to pursue the walk.
- ✚ Another example is the nine-year-old Niels who was probably one of the most energetic, active, and attention-seeking children. He was also one of the few who were able to speak. He can form basic sentences, although sometimes we struggled to understand what he wanted to

communicate. In- as well as outside the foundation, at least one of the educators had to constantly keep an eye on him, since he is known for running away as soon as he gets the chance. At the children's day care center, we would make sure that someone was persistently near the entry door. When nobody was, he would quickly run out of the foundation and into the garden. When this happened, one to two educators would have to run after him to make sure he does not exit the facility. During one of the picnic barbecues, Niels seemed very happy and excited to be outside. We were sitting on wood tables near a lake when Niels suddenly got up and ran straight into the lake. Our first thought was to run after him and take him out of the water. Nevertheless, we let him play a bit since we noticed that there was no danger. He looked as if he were enjoying it and seemed extremely happy. Eventually, as we stepped further away from where he was, and told him he could have some of his favorite fruit when he got out, he got out of the water by himself. That same day, as we were on the bus getting ready to leave, Niels unfortunately had an outburst. He suddenly started crying, trying to hit himself and everything around him. In that case, three educators had to step in to try and hold him still and make sure he did not hurt himself or anybody else. Since we had taken one minibus as well as a car to get there, we thought it was best to place him in the car, so he would not have to be surrounded by other people. The key to calming down autistic children is often to give them space and some alone-time rather than trying to "force" them to quiet down. It is extremely important that they feel understood by those surrounding them.

✚ Children as well as adults with ASD, all have different kinds of behaviors and ways to communicate. For instance, we accompanied nine-year-old twins Sara and Sam. Both are on the autism spectrum, yet they are extremely different from one another. Sam seemed to be an energetic and playful boy, while his sister Sara was very calm and enjoyed being by herself. Sadly, neither of them has the ability to verbally communicate, yet I got the impression that they were able to understand each other.

Sara was usually very still unless something bothered her. As we were on our way to the air tramp, I sat next to her in the minibus. As time passed, she suddenly started trying to hit her head and bite her arms. I gently placed my arm on her legs and tried talking to her which eventually made her calm down. Sam had a different way of expressing his feelings. When he felt frustrated about something, he would mostly start crying and sit on the floor. Something they both have in common is the hypersensitivity to noise. If other children were loud or there was music someplace nearby, both of them would immediately cover their ears and distance themselves from it.

✚ While accompanying Clément daily, I noticed a couple of outbursts, although they were usually very short. As he was entertaining himself at the playground, he approached me trying to communicate something. Since he does not have the ability to speak, it can be very challenging to understand what he is trying to say. In this case, Clément became very frustrated as he noticed that I did not quite understand what he wanted to communicate. So, he started screaming and throwing himself on the floor. In these situations, it is usually easier to let him be by himself, and he will eventually calm down.

Then, as we were in the minibus on the way back to the foundation, I sat next to him and tried communicating with him again. This time we used his folder in which he kept his printed alphabet along with images, also called pictograms. As he told me he was hungry by using sign language, I then tried asking further questions. I started by asking him what he wanted to eat and using his alphabet, he typed "glace" as a response. As I then continued by questioning what his favorite ice cream flavor was, he typed "chocolat". I kept on asking questions and noticed how happy he was that someone could finally understand what he was saying. It was the first time that I had managed

to have an actual conversation with him, and he seemed to enjoy it, as he kept laughing and hugging me.



Printed alphabet used to communicate.

This experience showed me the importance of showing children on the autism spectrum that even if not being able to talk, it is necessary that they feel understood. Especially when interacting with children who are more vulnerable. In this case, diverse ways of communication should be used to make sure every child learns to communicate in their own way.

7.4. In what extent is every autistic person different from one-another?

Throughout the four weeks at the home, I worked with different people from all kinds of backgrounds and all different ages. Every single one of them is different, even if they all have the autism spectrum disorder in common. Having the same condition does not mean that every autistic person is the same. Every individual's condition has a different level of intensity, leading to some people having trouble in a certain area while others manage to be very skilled. Essential to understand is that many of those from the foundation do not only suffer from ASD but might have other conditions as well.

Thanks to the varied observations, I got to learn to what extent every autistic person differs from one-another. As I have already mentioned in the last chapter, elderly people with ASD differ a lot from children having that same condition. Nevertheless, not every child has the same skills and strengths as other children. At the day care center, I specifically noticed that some are very energetic and extroverted while others seem to feel uncomfortable around people. As previously indicated, Niels for example, needs to be around people to entertain himself. He seems to be very active and animated when surrounded by other beings. Additionally, he is capable of talking and manages to express his feelings to a certain level. Then there are the twin siblings Sara and Sam, who are both on the spectrum, yet differ a lot from one another. On the one hand, Sam appears to be very calm and quiet, unless he is happy and excited about something. During some days, he would like to be by himself, while during others, he would join other children to play and entertain himself. On the other hand, his sister is quite the opposite and does not really enjoy getting any close to individuals. Sara loves to be all by herself and does not like anyone bothering her. On top of that, I got the impression that she



does not really acknowledge when someone is trying to talk to her. While she does not show any reaction when trying to communicate with her, Sam seems to listen and understand, even though he might not respond. A characteristic both of them have in common is their vulnerability to loud noises. Any time one of the children started screaming, both of them immediately felt bothered by it and covered their ears. The same would happen when we were in the minibus and the radio was on.

This proves that ASD is in fact defined by a spectrum containing a whole range of conditions and symptoms.

7.5. Expectations compared to actual experience

7.5.1. Preparation for working with autistic individuals

Sometime before actually starting my student-job at the foundation, the FAL¹¹ gave me a folder containing important information concerning the disorder and how to act in different situations, some ground rules that should be respected, along with information on safety precautions. This helped me develop some sort of knowledge and comprehension on the autism spectrum disorder. Additionally, the folder contains a document from “Autism-Europe¹²”, which gives information about the autistic people’s rights.

Below is a list containing some examples of the mentioned rights:

- ✚ The right for autistic individuals to have an independent life. (nr.1)
- ✚ The right for autistic people to have access to appropriate and accessible education. (nr.3)
- ✚ The right for autistic people to take part in any decision that might affect their lives. (nr.4)
- ✚ The right for autistic people to receive an income or a salary, sufficient to provide for food, clothes, and shelter as well as other necessities in life. (nr.7)
- ✚ The right for people with autism not to be exposed to the fear or threat of unjustified confinement in a psychiatric hospital or any other closed institution. (nr.16)

Furthermore, the folder that was given to me, contained a list created by the “*Fondation Autisme Luxembourg*” itself, with twelve so-called “golden rules” for the autism spectrum. This document was extremely helpful throughout the journey while accompanying individuals that are on the spectrum. It gave me a slight idea of how I am supposed to behave and act in certain situations.

Below are some examples of the rules with concrete explanation:

1. Understand the autism spectrum disorder:

- ✚ Before working with people that are on the spectrum, it is important to get as much information on the condition as possible. Mostly recommended are books and articles, since the internet might spread some false information.

2. Adapt your communication to the individual:

- ✚ Adapting language: Speak clearly and precisely using only short and simple sentences.
- ✚ Being visual: Use gestures during conversations. Work with objects and pictograms for better and easier comprehension.
- ✚ Being appropriate: The body language (posture, gestures and mimics) should correspond to what is being said.

¹¹ Fondation Autisme Luxembourg

¹² International association focused on advancing the rights of autistic people & their families.

- ✚ Being patient: The conversation should not be rushed. Communicate one information at a time and be patient while waiting for an answer.
- 3. Consider sensory particularities:**
 - ✚ Being aware of visual, auditory, tactile, olfactory, (etc..) hypo- and hypersensitivity.
- 4. Motivate individuals by using their interests:**
 - ✚ Use their strengths and skills to improve their weaknesses.
- 5. Develop independence:**
 - ✚ Employ an adapted communication and let individuals take part in decisions.
- 6. Being aware of triggers for problematic behavior:**
 - ✚ Try to prevent challenging behaviors in order to manage them better.

7.5.2. Actual experience & observations

Note: As I entered this experience, my initial plan was to pursue an activity in which I would try to “test” the individuals’ music skills and observe what impact music could have on them. However, after acknowledging their behavior, I realized it would be extremely hard to take this idea any further, since I felt it could confuse and eventually frustrate them, since they are used to sticking to a specific schedule.

Even when being informed, it is impossible to truly understand individuals on the autism spectrum before getting the chance to accompany them. When I first met the elder people at the “foyer 4”, I felt as if I was not aware of the actual meaning of the disorder. I remember thinking that their behavior was very similar to the handicapped people’s behavior I have worked with in the past. I had expected some of them to be very extroverted and communicative while others would be extremely calm and reserved. Eventually, I noticed that most elderly people do not even have the ability to communicate in any way and do not necessarily enjoy interaction. As the days passed, I learned to gather information on the condition by only focusing on my observations at the foundation. Additionally, I understood how to act and react in certain situations as I got to know every individual. Realizing that not everyone on the spectrum has the same skills and challenges definitely helped me understand certain actions and behaviors.

Accompanying children suffering from the condition taught me to have more patience and be more tolerant around them. Once again, it made me realize that working with people suffering from mental disabilities is an extremely difficult job and is not meant for everyone. It is essential that educators have specific skills (such as patience, comprehension, tolerance and compassion) in order to take care of people requiring special needs.

Working at the foundation ended up being more difficult than I thought it would be. It took a couple of days for me to adapt to the environment and everyone’s needs. Previously, I had the wrong expectations regarding ASD. Still, even if it was not how I expected it to be, I would definitely want to relive the experience. In a certain way, working with children calmed me down a lot. In general, I believe to have little patience to be around children. However, I learned to feel the opposite while accompanying them at the foundation. I deeply enjoyed seeing how the children developed themselves and learned to live with their condition. During the four weeks, I experienced many outbursts, but over time I learned that that is simply their way of expressing certain emotions. Since most of them do not have the capability to communicate like most people do, they grew to learn to do it differently. Personally, I admire and look up to every individual suffering from the condition, because of how they manage to get along with what they have. Most children who do not speak, attend specific schools to learn sign language. Elder people living at the foundation might not have the ability to be independent, yet the FAL suggests different activities thanks to which they learn to work and be creative.

8. Conclusion

Working with individuals that are on the autism spectrum has taught me a lot. Specifically, it showed me different perspectives on the condition and how everyone has a different way of dealing with it. Even though some days at the foundation were a little stressful, I would still repeat the exact same experience. I truly enjoyed working with individuals with ASD, especially with the children, since they are still in the stage of growing and learning the essentials for life. In the future, I would love to go back to the FAL and accompany the same children once again to see how they have grown and eventually developed certain skills that they might not have had previously.

Do people on the autism spectrum have heightened music skills because of their condition?

Personally, I see myself incapable of stating whether the autism spectrum disorder is the cause for some people to be more talented in the musical field or not. Especially since the disorder is still not completely defined and its causes are still very theoretical, it is something that cannot be proved. In my case, the answer to the question ***“Do people on the autism spectrum have heightened music skills because of their condition?”*** is completely based on the information and experience that I have gathered over the past year. Therefore, there is no right and wrong answer to this question since the condition itself is still very unclear and undefined.

From my personal point of view however, I believe it is not right and somewhat unfair to declare that people on the autism spectrum have good music skills because of their condition. This would mean that they would not be as talented and have the ability to do music if they were not on the spectrum. When I first came up with the question, I was very unsure about what my answer would be. The reason for this is that in many cases, autistic people are in fact extremely skilled in specific areas. However, having spent a month accompanying individuals with ASD and observing their interests and behaviors has shed some light on the topic.

Considering that my answer is neither right nor wrong, since there is no way of proving it, I have stated a theory that explains **why** people on the autism spectrum might have heightened music skills.

From what we know, one of the main characteristics that defines ASD is that most of those diagnosed with it have very specific and/or restricted interests. If we think about it, human beings enjoy spending time doing what interests them. They will commit to their interest and spend a lot of time practicing whatever it is they like to do. So, when talking about music, we could say that certain people are very attracted to and fascinated by the music world. When this is the case, they will use any free time that they have, to practice their music skills. Generally, when you feel passionate about something you will try and spend as much time as you can doing what you love to do. So, I came to the conclusion that autistic individuals might have better skills in a certain field, not because they are on the spectrum, but because they tend to be very focused on what interests them. As “practice makes perfect”, when you spend a lot of time practicing something you will eventually get better at it. All in all, I believe that the condition itself is not the reason for someone to have great music skills. However, I agree on the fact that the condition makes individuals focus on their specific interests. For many, after having figured out what they are passionate about, this passion turns out to be their comfort zone. One of my closest friends that I have mentioned in one of the previous chapters is a perfect example of that.

After starting to practice music, it has become their passion and doing music is what they feel most comfortable doing.

All in all, the autism spectrum neither defines someone as a person, nor their ability to do something. Yet, it does help focusing on specific interests that will eventually lead to the development of new skills.

Thanks to the information and experience I have gathered on the spectrum I feel like this is the best explanation on why certain individuals with ASD might be extremely skilled in the musical field.

To conclude, we now know that the autism spectrum disorder is still not completely defined which leads to unrecognition of the condition. From my point of view, the main issue concerning autism awareness is that society tends to classify every individual into one same category. This means that people do not yet manage to distinguish every individual from one another, which makes it harder for those concerned to feel understood. As explained many times beforehand, every single person is different from one another, be they on the spectrum or not. Therefore, autism cannot just be defined as one since it is a spectrum containing many subtypes.

This written work was mainly completed in hopes to spread awareness on the autism spectrum disorder. I believe that ASD is still a “taboo” topic since people suffering from it seem to be seen as “different” and “unusual” by society. I truly hope that every person that is on the spectrum gets the help and support that they need rather than just being classified as “autistic” and therefore being treated differently. Every person shall remember that the very first rule concerning ASD is: **“Understand the spectrum disorder”**. Hence, society should feel more compassion towards those in need rather than judging them for being “different”.

Coming to an end, I would like to thank those who have helped me gather information on the condition and writing about this vulnerable, yet extremely fascinating topic. First, I am extremely thankful to the association “Fondation Autisme Luxembourg” for allowing me to work with them for a month. It is thanks to that experience that I have managed to understand individuals that are diagnosed with ASD, and they have taught me a lot on how to behave around and interact with them. Still more importantly, the one-month experience is what truly showed me that every person on the spectrum is different from one another and therefore has specific difficulties and strengths. Additionally, I frankly appreciate my friend who was very open-minded throughout our conversations and allowed me to share a little of his personal experience related to a topic that many people feel uncomfortable talking about. Last but not least, I leave a huge thank you to Daniel Balthasar, who accompanied me and my work all the way until the end and gave me extremely good advice on how to structure and write this “mémoire”.

9. Sources:

9.1. Definition

<https://www.autismspeaks.org/what-autism>

<https://www.cdc.gov/ncbddd/autism/facts.html>

<https://www.spinalcord.com/temporal-lobe>

<https://www.medicalnewstoday.com/articles/318139#functions>

<https://www.kenhub.com/en/library/anatomy/fusiform-gyrus>

<https://www.dictionary.com/browse/lateral-fissure>

<https://my.clevelandclinic.org/health/articles/23073-cerebral-cortex>

<https://www.medicalnewstoday.com/articles/occipital-lobe>

9.2. Development of the condition

<https://www.authenticalllyemily.uk/blog/hypo-and-hyper-sensitivity-in-autistic-people>

<https://kidshealth.org/en/parents/central-auditory.html>

9.3. Treatment

<https://www.nichd.nih.gov/health/topics/autism/conditioninfo/treatments>

<https://www.nichd.nih.gov/health/topics/autism/conditioninfo/treatments/behavioral-management>

<https://www.journeyautismcenters.com/aba-blog/how-does-behavioral-management-therapy-help-with-autism/>

<https://www.nichd.nih.gov/health/topics/autism/conditioninfo/treatments/cognitive-behavior>

<https://www.nhs.uk/mental-health/talking-therapies-medicine-treatments/talking-therapies-and-counselling/cognitive-behavioural-therapy-cbt/overview/>

<https://www.nichd.nih.gov/health/topics/autism/conditioninfo/treatments/social-skills>

<https://www.appliedbehavioranalysisprograms.com/faq/social-skills-training/>

<https://www.nichd.nih.gov/health/topics/autism/conditioninfo/treatments/speech-language>

<https://www.autismspeaks.org/speech-therapy-autism>

<https://www.nichd.nih.gov/health/topics/autism/conditioninfo/treatments/medication-treatment>

<https://childmind.org/article/autism-and-medication/>

<https://www.nichd.nih.gov/health/topics/autism/conditioninfo/treatments/parent-mediated>

9.4. Personal experience

<https://www.fal.lu/fondation/>

9.5. Studies

<https://www.autismspeaks.org/science-news/autism-genetic-study-finds-80-risk-inherited-genes>

<https://www.autism.org.uk/advice-and-guidance/what-is-autism/the-causes-of-autism>

<https://elifesciences.org/digests/42256/how-does-autism-affect-the-brain>

<https://www.kennedykrieger.org/stories/interactive-autism-network-ian/anxietys-toll-people-autism>

9.6. Music & Autism

<https://www.donnawilliams.net/index185b.html?id=about>

<https://www.autism.org.uk/advice-and-guidance/stories/stories-from-the-spectrum-patrick-samuel>

9.7. Facilities / associations

<https://www.elisabeth.lu/institut-saint-joseph/>

<https://www.apemh.lu/a-propos/qui-sommes-nous/>

https://www.autisme.lu/2-2-1-3_historique.php

<https://www.fal.lu/fondation/>

<https://www.chl.lu/tags/autisme>

<https://www.autismeurope.org/who-we-are/>

9.8. Images

<https://www.lizardcentre.com/what-to-expect-from-an-autism-spectrum-test-and-why-asd-testing-is-important/>

<https://www.copas.lu/membre/fondation-autisme-luxembourg/>

https://www.google.com/search?q=printed+keyboard+alphabet+pictogram&tbm=isch&ved=2ahUK EwipgaKXrNb9AhXI5LsIHc5DBQcQ2-cCegQIABAA&og=printed+keyboard+alphabet+pictogram&gs_lcp=CgNpbWcQAzoECCMQJ1DjBFj6K2DVLWgEcAB4AIABdYgBjwmSAQOxNC4xmAEAoAEBqgELZ3dzLXdpei1pbWfAAQE&sclient=img&ei=Nr8NZKmOC-XJ7 UPzoeVOA&bih=587&biw=1280&client=firefox-b-d#imgrc=hhPK0TN8PKhCFM

<https://www.google.com/url?sa=i&url=https%3A%2F%2Fwww.pinterest.com%2Fpin%2F564920347010299992%2F&psig=AOvVaw2Y4o603V4a4MSjxtnzNJXY&ust=1682612137465000&source=images&cd=vfe&ved=0CBEQjRxqFwoTCPjEituFyP4CFQAAAAAdAAAAABAg>

<https://www.google.com/url?sa=i&url=https%3A%2F%2Fwww.redbubble.com%2Fpeople%2F1210donna%2Fworks%2F23403932-donna-williams-aged-27&psig=AOvVaw0vTJFvSnfOcgRTZB5UMhl6&ust=1682623995979000&source=images&cd=vfe&ved=0CBEQjRxqFwoTCKDZl GxyP4CFQAAAAAdAAAAABAE>

<https://www.google.com/url?sa=i&url=https%3A%2F%2Fpatricksamuel.bandcamp.com%2Falbum%2Fdistant-star&psig=AOvVaw1F4bFKNpnOO5NE3Uz7O0q3&ust=1682624093042000&source=images&cd=vfe&ved=0CBEQjRxqFwoTCMcvq5-yyP4CFQAAAAAdAAAAABAE>

<https://medicinetoday.com.au/mt/2022/march/regular-series/children-autism-spectrum-disorder---consultation-tips-gps>