#### Handbook

Une experience de / An experience by

MARTINE ASSELIN & ANNICK DAIGNEAULT

**UNLTD** Opt.

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Experience the world with the sensitivity of an autistic person

Expérimentez le monde avec la sensibilité d'une personne autiste



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#### SECTION 1

#### **Presentation**

Autism fascinates, confronts, and inspires. While this distinct neurological condition regroups a range of characteristics, there are as many ways of being autistic as there are autistic people – hence the spectrum. Lou is a fictional character created from the testimonies of autistic people and inspired by the two directors' autistic children. You will witness a few days in the life of this charming yet vulnerable person, from his fifth birthday to his first day of high school. Lou does everything he can to adapt to the neurotypical world.

Through this virtual reality experience that is both metaphorical and playful, you will experience the world with Lou's sensitivity. Immersed in his sensitivity and specific interests, you will feel in turn fascination, sensory overload and autistic meltdown. You will need to use unique coping mechanisms, just like some autistic people do. This is an inclusive production. Several people on the spectrum participated in the production of the project. This work promotes empathy and a better understanding of this distinct neurological reality.



# The authors of the virtual reality work: "Lou"



## MARTINE ASSELIN

The concept of norm, as opposed to difference and what it brings, has always piqued my interest as a writer and director. Those whom we consider as "marginal" reveal the issues of our society and push us to think further. I have two wonderful kids. My oldest son is autistic (Asperger). Every day, he feels his difference and for him, this difference is positive – this is the way he is. Simple as that! But he realises that many only see it as a handicap. He is often sad to feel misunderstood or judged. "Lou" is a labour of love, conviction, and hope so that one day, my son along with autistic people are better understood and can find their place more easily with us, the



ANNICK DAIGNEAULT Being a content and experience creator leads me to navigate professionally between my passions for cultural mediation, the creation and design of digital works, the the game and all forms of communications. Sensitive and verbose, I am also a speaker and facilitator for the our project Lou. Twice a mother of colourful and atypi-Whose social causes are close to my heart. I founded Sur le Fil, a foundation for inclusion to carry out creative and inclusive projects that promote dialogue and empathy. As an activist, I am socially and politically involved in the positive recognition of neurodiversity (of all diversities) and act as a change agent for a more inclusive



## LOUIS-FRANÇOIS ARCHAMBAULT-THERRIEN Screenwriting consultant

I am an artist with Asperger's and have a tremendous passion for cinema. While I was diagnosed late, I realize that my autism has always been instrumental in my development and interactions. Knowing I am autistic has allowed me to accept myself as I am. And having a younger sister with autism, I had already been sensitive to neurodiversity for a long time. I met Martine and Annick during the project « Dans la tête – Une expérience immersive », a virtual reality project that involved autistic artists. They offered me to participate in "Lou". This project is important to me to show some of the challenges neurodivergent people face daily, in a lifestyle shaped by neurotypical people, for neurotypical people.



## VALÉRIE JESSICA LAPORTE Writer of this guide

I live in the Saguenay region and am the mother of three children. Diagnosed With autism once adult, I get invol-Ved and raise awareness about this difference in a colourful manner. Author of a novel featuring a young autistic girl, speaker, owner of the blog Bleuet atypique as Well as a TikTok and Youtube channel, I am known for my testimonial vignettes. In these insightful bridges to my World and autistic universe, I tell my challenges, failures, and successes. I was the 2018 recipient of the Michel-Francœur Tribute from the Fédération québécoise de l'autisme and I am now its official spokesperson. My Vision: help unite the two worlds to create a strong team among neurotypical and autistic people. I firmly believe in changing the way people look at things, one person at

# The allies of the project

# Broadcast service for the work with animation team

We offer an inclusive and caring workshop service tailored to create greater meaning with the work, as well as foster dialogue. A team of speakers, including an autistic person, mediates and animates a workshop adapted to your environment.

Note that our virtual reality headsets are available for rental should you not have the necessary equipment.

It is not uncommon during the workshop that people confide and make a coming out as a neurodivergent person. We create a safe space for sharing and welcoming these confidences. We rely, however, on your help and complicity to have local resources (organizations and others) on hand to refer people if needed.

Contact us for more information:

Contact: lespiedsenhaut@gmail.com

Website: lespiedsenhaut.com



## Before living the experience

Before living the experience, we suggest you open the discussion and ask the following four (4) questions to the audience/participants:

- --- For you, what does the word «difference» means?
- What do you think autism is?
- → Do you know an autistic person? Who?
- What would you like to learn about autism?

If you wish, you can also read the definition of autism in section 5.



The experience is not recommended for people with epilepsy.



# Activities to plan after the experience

After the experience, we suggest you exchange on what captivated you along the way, and come back on the situations you experienced. Section 6 will allow you to go further in understanding each scene.

Other activities around the experience are suggested at the end of this guide.

# Instructions for the virtual reality experience.





<u>ATTENTION:</u> If you are epileptic, this experience may not be suitable for you. If you get easily dizzy, we recommend that you sit down for the experience. For children under 13, parental consent is strongly recommended, and adult supervision is required.

To get the most out of his experience, make sure you are in a clear area of at least 2.15 m x 2.15 m (7 ft x 7 ft). This work is designed to be experienced standing up, but you can sit down on a swivel chair if need be. Plan approximately 15 minutes to view each chapter.



Do not walk! The experience is designed for the user to stand in one place. You must reach out your hands to perform the actions. If an object is too far and you can't pick it up, simply lean forward more, take a step towards the object or turn around. By reaching out, you should be able to grab it.

To pick up an object, you must reach for it, then hold the trigger on the front of the controller with your index finger. The hand in the experiment will close and hold the object. You release the trigger when you want to let go of the object, for example the blocks.

You will sometimes have to flap your arms like a bird: please do ample and fast movements. You will also have to close repeatedly the lid of the box (child chapter) and the lockers doors (teen chapter). To do so, hold the lid or door all the way until it closes, and repeat the gesture again and again.



# The definition of autism, by an autistic person:

Autism is a difference in the way the brain works. It changes the way a person perceives and interacts with its environment (people, places, objects, etc.). Autistic people may have difficulties interacting with others or do so in an unusual way. Some speak, while others may not and in this case, they may use other means of communication. A person with autism often needs routines and anything unexpected becomes more difficult to manage. Many autistic people have very strong interests that take up a lot of space. Most have hypersensitivities or hyposensitivities to certain senses, meaning they feel much more or much less information from the senses than the average person.

# Social interactions Social interaction is how a person interacts with others. Some autistic people are eager to interact while others are less inclined to do so. When they do, there are several challenges that can make them feel awkward in their interactions. For example, they may have difficulty understanding jokes, non-verbal cues, expressions, contexts and social rules, making it more difficult to bond and make friends. Some people with autism also lack verbal language, which is a significant barrier. If the person can communicate in

other ways, it is important to allow them to do so.

#### Specific interests

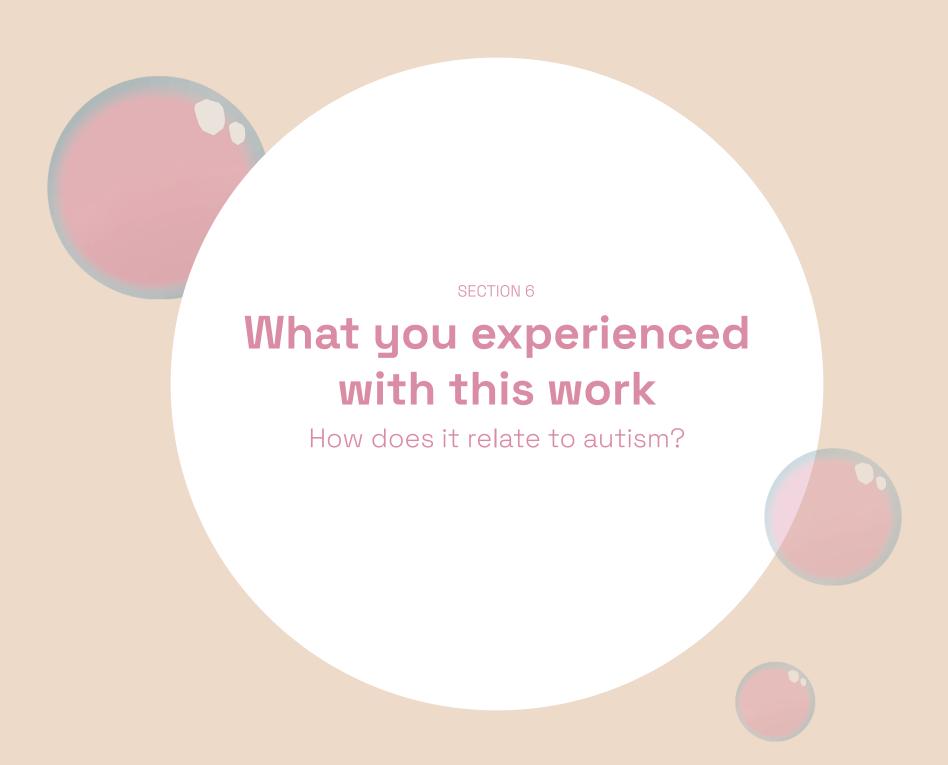
Most people with autism have specific interests – passions that are strong or collections on which they spend a lot of their time. They often want to talk about these interests a lot, and do not get bored doing so. Interests can vary and change over time, and it is possible to have more than one at a time.



#### Hyper/hyposensitivities

Having <u>hypersensitivity</u> to a sense means that the information coming from that sense arrives in very large quantities, making it difficult to sort and manage. This can result in all sorts of reactions. A person who is hypersensitive to noise may use their hands to cover their ears, have difficulty concentrating and try to escape from the noise. A person with visual hypersensitivity has difficulty with lights or sometimes certain patterns or colours.

Having <u>hyposensitivity</u> to a sense makes it difficult for the information coming from that sense to reach its destination. It is not a paralysis of the sense, but more like as if the information was looking for its way. For example, a person who is hyposensitive to pain may sprain their ankle without noticing it. In the evening, with the other information from their senses becoming scarcer when it is time to sleep, the person may realize, several hours later, that they are in pain. The information found its way.



## Kid chapter



#### SCENE WHERE LOU RUNS AWAY WHEN WE SING HAPPY BIRTHDAY. How can this be overwhelming?

Sounds are a lot of information. If we are sensitive to it, it may be difficult for us to sort, as if we were bombarded from all sides. Imagine you were thrown a lot of balls at the same time. It would be impossible to catch them all and throw them back. Because there are too many of them, it would even become stressful. Escaping can help you avoid any bad feeling. Some people will wear shells over their ears to reduce sounds.

#### SCENE WITH THE BRICK WALL WHERE LOU TRACES **BETWEEN THE BRICKS:**

An interest for repetitive patterns

Many people with autism have an easier time with anything that is visual, and it sometimes even becomes very interesting. Certain patterns, movements or colours can be stimulating or soothing to look at. You can sometimes see a person bringing an object very close to their eyes, like a fan or colourful object, or the person could try to recreate the patterns themselves, like Lou with the wall.



The colour blue, lines and dots help me feel better, and their structure helps me sort my feelings and emotions. That's why I always have socks with these patterns. I often stretch my legs, especially when sitting, to look at them because it makes me feel better.



## Kid chapter





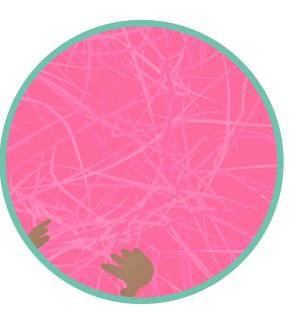
Notice some things more than others.

Did you notice in the bedroom that some objects are lighter in colour while others are very colourful and stand out? Some bits of information are sometimes prioritized and come first in the brain of an autistic person. For example, if a person is particularly attracted to a colour or a type of movement, such as something that spins or sway, that's all they will see, and their brain will ignore whatever else is around. In this case, taking in a room to get a general idea of what is in it can be very difficult.



Lou feels calm and has a pleasant feeling when he strikes the hair of his yeti. It's as if he was soaked into softness.

Textures can provoke very intense sensations. They are sometimes pleasant, sometimes unpleasant, and sometimes there are just too many of them. So, textures could be used to calm or soothe. But even if this is surprising, it is important to understand that some textures can be very disgusting or even painful. The tag on a sweater can ruin the day of a person on the spectrum. Now imagine all sorts of textures all over the body... yes, we are talking about clothes! Many are aggressive if you are sensitive to them, and dressing comfortably then becomes quite complicated.





# SCENE WITH THE BOX WITH WHICH LOU MAKES MUSIC: Repetitive behaviour and using objects differently.

Autistic people often use objects differently. That is, if an object has a function, the person may use it another way. For example, Lou uses the box to make music. Another example: a glass is used to drink, but looking through its base to play with surrounding lights can also be interesting! For autistic people, the senses often take up a lot of space and they use them, among other things, to regulate themselves. They will not notice the same things in the same way. Maybe non-autistic people would sometimes like to do this as well, but they don't give themselves the right to do so?

If the object being used is helping the person feel better, removing it may be painful for them. Some autistic people will not understand why the object is being removed. The unexpected is also a challenge. Giving the person advanced notice of the end of an activity may help and improve the odds of making it easier.

# Kid chapter



#### **SCENE WITH THE BLOCKS:**

#### The mental plan

It is often necessary for people on the spectrum to have a mental plan of what will be happening. This allows them to anticipate, prepare and avoid having to constantly adjust. Sometimes, however, things don't go as planned and seeing their plan not materialize is like constantly having to recreate a new image of the reality to come. This can be very difficult to bear and requires a lot of energy. Since it is impossible to control everything, exposing the person to certain changes in contexts that are safe and respectful of their way of functioning is advisable. This will allow them to develop strategies. And while this exercise may seem light, it can be painful to endure.

#### A GLIMPSE INTO MY LIFE:

When I need to walk across a room, such as a room with chairs and people, I need to create the lines of all my moves before I actually make them. I decide how to place my arms, when I will change angles while I move along and what I will touch. I also try, as much as possible, to make any sensation symmetrical. If that line, that crystal clear picture is broken, I must work hard to adjust myself, and this means that I might forget to control one aspect of the movement. For example, an arm might end up in a strange position because I momentarily forgot it exists. One might say that I just simply need to let myself go naturally, but the funny thing about that is that if I move without thinking about it, it can be very jerky-like, awkward and energy draining. I am more fluid in appearance by being prepared, and it's also more comfortable for me to "draw lines" on the ground, like a path that would be drawn in advance to show us the direction in a video game.



#### A GLIMPSE INTO MY LIFE:

I am a photographer and expose my work. My specialty is abstract work, small details in the environment that surprise me or grab my attention. I use my difference

#### SCENES WHERE SOME (NOT ALL) OBJECTS APPEAR AT SCHOOL: Notice details more than the overall picture

School is an unfamiliar place for Lou, and Max is a new person. He needs more time to decode what is new.

There is a joke going around on social media that autistic people see the needle before the haystack! It's funny, but it's kind of true. Non-autistic people see the big picture and then focus on the details, but for autistic people it is often the other way around. Sometimes the environment is "read" in bits and pieces before forming a whole.

In the virtual reality experience, all of Lou's attention is focused on certain objects, or specific sensations: at first, Max's glasses float in space on their own! Lou feels the intense movement of the students, without really "seeing" the students...

#### A GLIMPSE INTO MY LIFE:

One day, a client sent me the picture of a sweater. It wasn't what I expected so we went back and forth a few times, thinking it was a bug. After a few tries, I noticed and yelled: Oh! There's a guy in the sweater! I can usually see the information in the image, but I must have been tired, so the challenges of autism came out with more vigour. I laugh about it.



#### **DISCUSSION WITH MAX:**

Looking elsewhere when someone is talking

Did you notice that if you look at Max directly during the experience, you cannot understand what he is saying at the same time?

Many people with autism have difficulty looking in the eyes of others. For many, it is too much information, for others it is uncomfortable and for some, emotions are easier to decode when looking at the mouth. Sometimes they look away, and since every autistic person is different, you must know them well to know whether they are listening or not. When you think about it, ears are the ones that allow you to listen! Looking into the eyes can be so challenging at times that the person no longer understands the meaning of what is being said.

The stove repairman was upset that I wasn't looking at him during his explanations. Me, I wanted to associate his explanations to the object, the stove! So, it's only logic that I was looking at the object, and not him.

#### **ECHOLALIA:**

Repeating words, numbers

Echolalia is when there is a repetition of words or sounds. Some people with autism use memorized words to communicate, and that is a form of echolalia. There are also people who repeat the words of the person in front of them. Like Lou does when talking with Max. They don't usually do it all the time, and it can be amplified by a lack of understanding or because there is an emotion or interest in certain words or sounds. The reasons vary and it is not disrespectful, it is a form of communication.



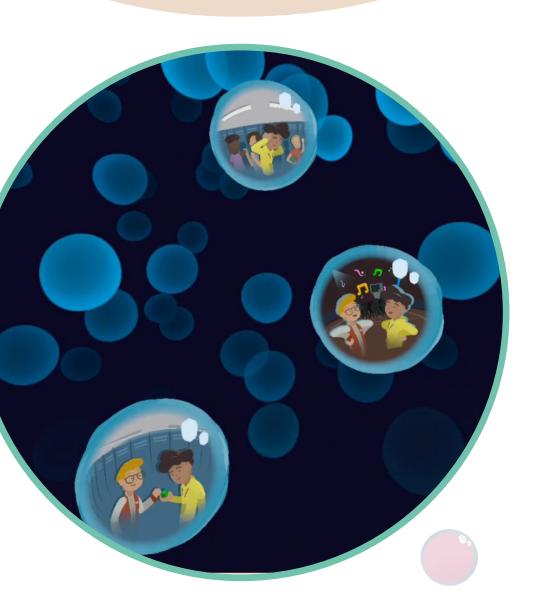
# SCENES WHERE WE SLAM THE DOORS OF THE LOCKERS FOLLOWED BY THE SCENE OF THE EYES LOOKING AT LOU:

Self-regulation and misunderstanding by others

In a new environment, the overload of stimuli, novelty, unexpected things and new data can result in unexpected reactions. If, for example, someone can manage themselves by creating rhythm or sounds, as Lou did with the lockers, they may spontaneously do so in contexts we would expect the least. Over time, it becomes easier to find the right tools for the right places. For example, an autistic person could use sensory tools such as small objects to manipulate, look at or chew on that are safe and non-disruptive to those around them.

In the case of an unexpected reaction, things will get worse if the person is judged for their behaviour or if there are too many reactions. The ideal is to simply convey the information to the person in a way they will understand, and at a time when they are able to understand.

Just because autistic people often have difficulty interpreting and understanding emotions well, it doesn't mean that they can't see when people are having a negative reaction. This can be very hurtful and disturbing. Knowing you are different already comes with its load of stress. Being accepted therefore has the opposite effect: it takes a weight off your shoulders. A person with autism already has a lot to consider to function in an environment that is not their own, that is not adapted. So, adding social pressure on top of that is absolutely useless and harmful.



# WHEN LOU SAYS HE IS AFRAID TO BE "HIMSELF" TOO MUCH, PEOPLE MIGHT GET ANNOYED: Challenge of conforming to what is expected

Ever so often, autistic people are so desperate to be accepted or pass under the radar that they spend tremendous amounts of energy trying to hide the way they function. This can cause a great deal of suffering, as the person no longer knows how to be themselves and worries about what might happen if they allowed themselves to be. Being yourself is a beautiful gift you can make yourself but for that to happen, others around you must allow it! What better way to show kindness than to accept people as they are. There is a big difference between bad behaviour and different behaviour.

# Kid and Teen chapters



#### THE GREY STORM THAT TURNS: Emotional or sensory overload

The unexpected is hard to manage for autistic people. It's pretty much as if their whole world was replaced with another one. Sometimes, it is impossible to avoid this situation, and it can result in tremendous suffering as well as lead to disorganization.

When a person on the spectrum receives too much information from their senses or they are confronted with too many emotions, it can create a surplus that cannot be evacuated. The grey storm in which Lou is stuck illustrates this overflow. The person can then have several reactions. They can have a crisis that looks like anger or a panic attack, or they may become totally or partially unable to function.

Someone could for example lie on the floor, scream, or lose the ability to speak. The person cannot decide to stop feeling as such, and even when it is over, the person is exhausted.

That is why many things are important. The unexpected is to be avoided as much as possible. You could, for example, warn a person that something is coming to an end with a timer (such as TimeTimer tools), rather than abruptly ending it (like Mom did when she took the box away from Lou). If someone needs a sensory break or is emotionally overloaded, it is best if they have the opportunity to rest in a quiet place. This will not prevent every uncomfortable situation from happening, but it can still make a nice difference, not to mention that it is a sign of respect for the autistic person and the way they function.

# Kid and Teen chapters



#### **FLAPPING:**

Self-regulation and autistic mannerism

Many autistic people, as well as others who are living with differences, have unusual movements. Two common manifestations are flapping (shaking arms or hands), or rocking. These are natural gestures, and they have several functions. They can help self-regulate (to calm down, concentrate, release the overload) and they can also be used to communicate.

The important rule to remember when dealing with a difference is: if something is not harmful to anyone ... is trying to make the different behaviour go away relevant? Depriving the person of this tool that is easily accessible and does not harm them or anyone else is unnecessary and even harmful. Sometimes, when they are very happy or very anxious, even non-autistic people let these movements slip.

# Kid and Teen chapters



# LOU DOES NOT SEEM TO ALWAYS UNDERSTAND WHAT IS GOING ON:

Delay to process the information

That is what we may think at times, but that is not it for the person with autism: it's a matter of processing delays.

An autistic person may take longer to respond at times. This can be caused by a number of things. Occasionally, the person must consider several elements such as tone of voice, facial expressions, verbal expressions, and context. For non-autistic people, this happens more spontaneously. They guess and fill in the gaps of any missing information in a natural way. While this can lead to misinterpretations, exchanges are faster. But since the person with autism must make the effort to understand, not to mention the environmental stimuli and any other challenge that may fatigue them, a delay in the treatment of the information, and consequently in the response, can be observed.

# **OBJECT MANIPULATION:** Motor skill challenges

Autism rarely happens alone. People are also prone to having other challenges, and movement coordination issues are one of them. For many people on the spectrum, planning and organizing their movements is a challenge. This makes it more difficult to manipulate objects, especially the first few times. Improving this is possible with repetition, but when faced with a new context, starting from scratch is at times inevitable.



#### Believe

It is possible that people on the autistic spectrum do not live or feel things in a typical way. Which is why some situations can be painful or very uncomfortable but seem minor to a non-autistic person. It is important to believe the autistic person who shares their feelings.

# Forgive social mistakes

Autistic people sometimes make mistakes, and they do not always realize the impact of words. Every now and then, the context, the meaning of an expression or simply the emotion that a sentence can provoke in another person will escape them. When someone's last intention is to hurt anyone, you can't hold it against them. If this happens, simply explain how it felt and why. Most likely, the person will feel sorry and apologize.



Respect is also about the boundaries that we may not necessarily understand. Like a need for some not be touched, to need more time to accomplish certain tasks, the need to be alone or to be unable to participate in certain activities that are overcharged



# The questions!

Allowing the autistic person to ask their questions without loosing patience is a beautiful gift to give them. They will collect better information which in turn will allow them to interpret better, plan better and react better to various situations.

On the other hand, if an autistic person does something that you don't understand, it is easier to ask them directly than to try to imagine answers and assume their intentions.

#### Accompany

Every so often, just knowing they can count on a known presence, knowing that someone will be there if needed, can take a lot of pressure off the autistic person. You can be this ally and offer yourself when needed.

#### Kind dialogue

Which words to use, which words to avoid, how to communicate

The proper way to name autism ... is autism! Most autistic people who publicly display the fact that they are, prefer this word. Many hate the term ASD because the D means "Disorder". Autism is not a disorder: it is a difference. Some autistic people prefer other terms, and that is something quite personal that should be respected.

Another element that is personal is the diagnostic. It is essential to never disclose someone's diagnostic without their consent. In some circumstances, it's even illegal. Some people on the spectrum feel it is a difference, others feel it is a handicap and while no one is right or wrong, it is a question of life experiences, feelings and contexts.

The word autistic is not an insult, it is a condition that you are born with. In the same category of words from another time that are slow to disappear as insults are the words triso, moron and mongol. They all refer to disabilities in an insulting and hurtful way.

There is no point in talking to an autistic person as if they can't hear or understand. Above all, it is imperative to restrain from screaming or being very authoritarian. Each autistic person is unique and the idea is to adapt to the person in front of us without treating them like a child. We therefore address the person and do not act as if they were not there, and if communication is truly impossible, it will be named.

Some autistic people prefer we speak fast, others prefer we speak slow, but most prefer we speak clearly using a calm voice. There are also some who like it when we express ourselves with visual aids, such as pictograms. If adjustments are necessary, they will usually be easy to see or will be requested.



At all times, we recommend creating a caring conversational environment to go along with the content of this virtual reality project. When used and anchored properly, this tool is conductive to bonding and facilitating inclusion.



It is not uncommon during the workshop that people confide and make a coming out as neurodivergent. Make sure you welcome them and have the appropriate regional resources on hand to refer them if needed.



Invite one or more autistic people around you to come and talk about their reality and condition. For example, reality and conditions to which they prepare five (5) questions to which they can answer. Make sure you create an emotionally safe environment for the exchanges.

Precede the virtual reality activity with the projection of a few videos accessible on Youtube.



ex: from Bleuet atypique, «Mon petit frère de la lune», «Les souliers de Louis», CHU Ste-Justine, or the documentary of Louis T.

Use the following fun group activity to illustrate as well as help understand sensory overload and information processing peculiarities (requires about a dozen participants):

- Place a wet towel on a participant X.
- Invite this person X to come to the front of the room.
- → Divide the rest of the participants in three (3) groups around person X.
- A person Y is placed a few feet in front of the soaked person X.
- Each group has a specific action to do: sigh loudly, clap hands, laugh. The soaked person X must answer person Y's questions and, if you wish to complicate things, identify the emotions that person Y is trying to share.
- You can add water to the towel during the activity. At the end of the experiment, ask the participants what they felt and understood.

The towel represents the impression a person with autism will have when being touched by a stranger. While it may not be unbearable, it certainly is unpleasant and keeps the mind busy.

People on the spectrum can adapt to demands depending on their abilities. But imagine when the whole day is spent in hyperstimulation. No wonder some people feel the need to withdraw in a reassuring silence without being asked questions, or Let's be supportive!

Difficulties in information processing are normal in this group dynamic for person X who must also respond to person Y who has expectations of them.

Living up to social, academic or professional expectations can be a challenge and sometimes requires a lot of energy when there is too much information at once.



# Links to explore further.

Bleuetatypique.com

Autisme123.com

TikTok: Bleuet atypique

TikTok: Lautrehumain.e

In English:: thomashenleyUK