

## INTERVENTION SHEET #5

### WHAT YOU NEED TO KNOW ABOUT AUTISTIC PEOPLE

By Brigitte Harrisson and Lise St-Charles, 2012

Current estimates are that 1 percent of Quebec's population of more than 8 million inhabitants is autistic. Many of these 1 percent could have a higher quality of life if autism were dealt with directly. Until someone shows up to help an autistic person, the autistic person must manage their condition on their own full-time. Since they are autistic 24 hours a day, they have no choice but to "deal with it." It's impossible for them to progress as long as they are not in control of how their autistic condition is managed.

Autistic individuals are part of families, and they have unique needs related to their autistic condition (Harrisson / St-Charles) that must be addressed to help maintain the family balance. The presence of an autistic individual in a family affects everyone in the family. All family members, including any autistic individuals, must deal with autism. So, we must focus on the unique needs of the autistic person and not on the demands of those around them.

#### HERE'S WHAT YOU NEED TO KNOW...

##### 1. The right to live their lives

Over the course of their lives, autistic people do not share the same interests as non-autistic people. Parents, guardians, caregivers, and professionals should not assume that autistic people (whether they're children, adolescents, or adults) enjoy the same interests as non-autistic people. Nor should they force them to feign an interest in the activities of non-autistics. Moreover, they should recognize that their interests are perceptual in nature, as is typical for autistic people.

##### 2. Recognizing the autistic person's anxiety

Like every other person on Earth, autistic people experience emotions. Parents, other family members, caregivers, and professionals should expect and consider their feelings. And they should know that while autistic individuals do have emotions, their feelings might not have the same triggers due to their particular way of processing information. Remember: autism is experienced 24 hours a day—not just when non-autistic people are available.

##### 3. Expectations of the autistic person with particular development

Autism is neurodevelopmental. This means that the "neuro" aspect, or the autistic condition, has a major impact on development. An autistic person didn't choose how they should develop. The autistic condition sets the structure of autistic thought, and the autistic structure is particularly more marked if someone's autistic condition is more intense. Parents, family, caregivers, and professionals should therefore remember that they are interacting with someone with a particular developmental type. They should not expect a regular developmental response from an autistic person.

##### 4. Expect autistic behavior

An autistic person presents autistic manifestations that are often confused with behavioral disorders. Parents, family, caregivers, and professionals should be aware of autistic manifestations (Harrisson, St-Charles), respect the autistic person's integrity, and support them through the different stages of development so that the autistic manifestations might reduce—not disappear—while addressing their unique needs.

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#### 5. Set realistic expectations according to someone's developmental level

Do not set extraordinary expectations for an autistic person that would never be asked of anyone else. Parents, family, caregivers, and professionals should keep in mind that they shouldn't make untenable demands.

#### 6. Explain the environment to create a feeling a safety

When someone has a very particular perception (Frith; Mottron; Gepner) or is cut off from the meaning of information (Harrisson, St-Charles), they can't always properly assess their environment. Autistic people perceive their environment and its details from a point of stasis. Parents, family, caregivers, and professionals should expect to explain the meaning of the environment to the autistic person in their own language.

#### 7. The opportunity to meet peers

An autistic person may need to meet peers who have the same map of emotions to "solidify" and thus turn towards non-autistic people who do not have the same map. Parents, families, caregivers, and professionals should expect to help someone autistic meet other autistic peers to help with identity, not to make "friends."

#### 8. The opportunity to obtain information

Because of their different way of processing information, an autistic person should receive information in their conceptual language (SACCADE Conceptual Language™) (Harrisson, St-Charles). This will allow them to know what is happening or give them the time to process and access information. Parents, family, caregivers, and professionals should never allow an autistic person to be cut off from the meaning of information.

#### 9. The autistic person's anxiety about what's coming

An autistic person is not unlike someone who is vision impaired, Deaf, or Hard of Hearing. They have the right to supports that allow them to anticipate a minimum of what to expect in their daily life. They should be able to receive explanations of the "meaning" of what is happening in order to avoid anxiety. Parents, family, caregivers, and professionals should expect to work at reducing an autistic person's anxiety by explaining meaning with information, not emotions. Autism is not an emotional problem but a cognitive peculiarity (Vermeulen).

#### 10. Include both girls and boys

We must not confuse the profiles of autistic girls with other issues and leave them aside. If a girl is diagnosed with autism, it is normal for her profile to be different from that of a boy's. It is cruel not to give her the right to be who she is just because the image of autism in girls is misunderstood.

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#### 11. Communication

Autistic people have a right to learn a conceptual language (such as the SACCADE Conceptual Language™) (Harrisson, St-Charles) to be able to communicate (as the Deaf or Hard of Hearing can use ASL). Parents, family, caregivers, and professionals should not leave any autistic person without the language skills to communicate, and they should not confuse speech with communication. Someone autistic has difficulty expressing their needs because accessing their experience is such a challenge, and they may speak with very few words if ever they do manage to. They work very hard to create a sentence. Try to recognize this challenge. Slow down and talk less so that they can respond to you. Don't answer for them. Processing information from their entire environment takes time. Their brain takes only one input at a time; there is often too much information to take in. They may even feel bombarded by sounds, lights, movements. They need time and support to measure it all. Remember: their brain accepts physical characteristics, and anything concrete first. It works with closed images (Leverson). Therefore, it is better to speak to them in concrete and precise language. (Harrisson, St. Charles).

#### 12. One-on-one time with parents

Autistic youth, adolescents, or adults are unable to interact with the non-autistic people around them. Every day, they hear rules to follow, where they are talked about in front of them without them having time to react. Parents, family, caregivers and professionals should know that if they want to communicate with autistic individuals, they need to SLOW DOWN. Because autistic individuals also need to know the people around them.

#### 13. Highlight the positives and turning points in the autistic person's life

We should understand that an autistic person only sees people who come to share information or provide instructions. They spend the day trying to meet demands that are not feasible for most, since few people consider the particularities of autism in their interactions with autistic people. Parents, family, caregivers, and professionals should be mindful not to give only negative feedback to the autistic person they're interacting with. They should learn to "read" autism so that they can highlight the positive and significant moments in the autistic person's life.

#### 14. An autistic person will consider their parents' perspective over their own

The parents' perspective will be transferred to everyone the autistic person loves. It is essential that parents know what autism is, so that they can share the reality of autism with the family, not myths and misrepresentations. The parent and family have the right to demand that they be shown how to deal with autism so that they can progress together, and to be able to communicate with the autistic family member, involving them in family life. Confusing autism with an intellectual disability or a behavioral disorder will lead to major family challenges while increasing roadblocks for social integration.

#### 15. Include the autistic person in your definition of "family"

An autistic person is part of their family. The parent tries to create a "we" with family members but gets an "I" from their autistic family member when autism is untreated or not accepted. We do not choose autism: autism chooses. Like any other person, an autistic person, regardless of their level of functioning, needs their family in order to overcome obstacles and build their life.

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#### 16. Reach out to someone autistic

An autistic person, it must be remembered, is a person above all, with their own thoughts, emotions, interests, etc. Like anyone else, they need to be loved. They need to participate in their life. They must participate in the intervention plans and decisions that are made for them to the extent of their means. They must be an agent of their own development.

#### 17. Learn more about life

Don't assume that an autistic person isn't learning, or that they have an intellectual disability. Remember that they're not "sick". Their brain needs special management. An autistic person who speaks but doesn't understand language is equivalent to someone whose vision is impaired, who can speak, but can't see a picture. The language of the autistic person is conceptual (SACCADE Conceptual Language™). It is not a choice.

#### 18. Create programs specifically for autistic people, based on the autistic structure

Focus on their unique strengths and needs—not yours, and not those you'd like them to have. We must distinguish between what someone cannot do, what they have no control over, and what they can do, what they can control. They can refuse to do things over which they have control but not those over which they don't. So it's essential, among other things, for a neurotypical person to distinguish autistic manifestations from inappropriate behaviors (Harrisson, St-Charles). It is also essential to understand that an autistic crisis always has a trigger, and it might be one that would impact a neurotypical person. Read the literature to understand autism and go beyond what interests you. Read the history of autism to stop making the same mistakes as your predecessors.

#### 19. Include autistic people in advisory committees and family policies

And stop trying to make them neurotypical. The history of autism is written by people who have interpreted the needs of autistics without ever being able to address them. Neurotypical people have spoken for them, and they have considered their own needs, but not those of autistic people. Autistics know their needs and they don't talk about autism like neurotypicals (Chamak). It would be more dignified to stop pretending autistics don't exist when it's time to make real decisions that affect them and try to understand the true needs of autistic people. Try to understand that because you don't understand, they are being treated as if they are monsters. Instead of saying that an autistic person doesn't have emotions, focus on seeing that they do indeed have them, and ask yourself how you can help them to identify their feelings. Stop interpreting autism via one single school of thought and read through the literature to understand what the condition really is.

#### 20. Fund services for autistic people who are not in line with services for intellectual disability, behavioral disorders, or mental health

Recognize the specificity of autism spectrum disorder. Help support human beings as they forge an identity and self-esteem based on who they really are.

**Please note:** This text was created after reading Don Meyer's "What Siblings Would Like Parents and Service Providers to Know."

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