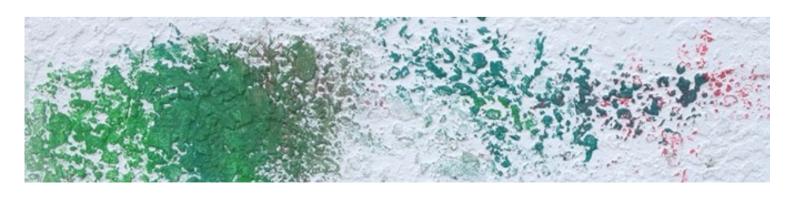


Is My Child Autistic?

A Neurodiversity-Affirmative Guide for Parents Questioning A Child's Development



Is My Child Autistic?
A Neurodiversity-Affirmative Guide for Parents
Questioning a Child's Development by Camille

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INTRODUCTION

This guide has been developed to support parents who find themselves questioning if their child may be autistic. The purpose of this tool is to introduce autism within a neurodiversity-affirmative context, as parents navigate the medical system and the descriptions of Autism Spectrum Disorder (ASD) as outlined in the Diagnostic and Statistical Manual of Mental Disorders (DSM-V), which is used to diagnose ASD. This guide has been useful in my personal experiences navigating the diagnostic process as a mother of two autistic children, and in my professional experiences as a Registered Social Worker (RSW) and Registered Clinical Counsellor (RCC) supporting parents of children with suspected neurological differences.

In 2013 the DSM-V was released, and various diagnoses that once existed were either done away with or placed under the umbrella term of ASD. In addition, individuals are now assessed as Level 1 (requiring support), 2 (requiring substantial support), or 3 (requiring very substantial support), based on the level of determined support needed, though not all practitioners will provide a level at the time of diagnosis. Some of the more common labels that once existed that are now lumped together under this broad term include High-Functioning Autism (HFA), Asperger's Syndrome (AS), Pervasive-Developmental Disorder Not Otherwise Specified (PDD-NOS), Aspie, Autie, references to high and low functioning levels, and so on.

Unfortunately, this change also means that some who would have at one time met the criteria of AS or HFA are being overlooked, screened out, and are facing difficulty accessing necessary accommodations to address their differences and needs. This does not mean that those differences suddenly do not exist, nor does it mean that these individuals no longer have lagging skills requiring accommodation, understanding, and support. What it does mean is that in order to access such services, parents will need to be as prepared as possible when advocating for an autism assessment for their child.

Within the autistic community several impacts have been noted since this diagnostic change. The first is an evolving understanding of autism, with some confusion around the previously identified differences between each diagnosis. Secondly, some individuals who would have received a diagnosis in the past are finding it difficult to identify and access needed support due to these changes. Further, despite the adoption of the statement "levels of support needed" instead of "high and low functioning labels," many professionals continue to use and perpetuate the use of these functioning labels, further contributing to confusion among parents and teachers regarding what autism is, and which individual supports and accommodations might be helpful.

The estimated rate of autism in children and youth across Canada and the United States is one in every 66 and 68 respectively; that is, one in 42 males and one in 165 females. However, emerging research is challenging these rates, as researchers are discovering the ways that autism can present differently in males and females. This indicates that the incidence of autism may be significantly higher than previously thought. Some of the explanations for this increase include:

- A better understanding of autism, particularly how it can present differently in females due to differences in socialization;
- More accurate assessment tools, recent diagnostic changes that are more inclusive, and a focus on standardizing diagnostic procedures; and,
- More information about autism is now available to the general public on the Internet, which means that there is greater public awareness.

Without a diagnosis a person is judged, but with a diagnosis a person can be supported.

Support and understanding are the main reasons that most individuals seek a diagnosis of autism. The world as we know it is set up for the dominant kind of brain, also referred to as the neurotypical (NT), allistic, or nypical brain. For this reason, autistic individuals may struggle with everyday tasks that are considered necessary and important by the wider society. This perspective has been birthed from the neurodiversity movement, which proposes that individuals are simply different than NTs, not less, and certainly not a defective version of a "normal" person. The neurodiversity movement challenges the very concept of "normal," asserting that neurodivergent individuals (people with atypical brain wiring), such as autistic individuals, are oppressed by the very nature of the pathology through which they are perceived.

HOW THIS TOOL MIGHT HELP

This Tool May Help You:

- Understand autism, as laid out in the DSM-V;
- Learn about the neurodiversity paradigm;
- Know what signs to look for that may indicate your child is autistic, beyond the stereotypical ideas and classic signs of autism;
- Understand your child better;
- Jog your memory, and help you to make notes with specific examples to facilitate memory recall in answering the interview questions if you proceed with an autism assessment;
- Determine if you believe your child is autistic or not;
- Better advocate for your child in seeking an autism assessment; and,
- Better advocate for your child in seeking further assessments beyond an autism assessment.

DSM-V CRITERIA FOR AUTISM SPECTRUM DISORDER (ASD) 299.00

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

- Deficits in social-emotional reciprocity, ranging, for example, from abnormal social approach and failure of normal back-and-forth conversation; to reduced sharing of interests, emotions, or affect; to failure to initiate or respond to social interactions.
- Deficits in nonverbal communicative behaviors used for social interaction, ranging, for example, from poorly integrated verbal and nonverbal communication; to abnormalities in eye contact and body language or deficits in understanding and use of gestures; to a total lack of facial expressions and nonverbal communication.
- Deficits in developing, maintaining, and understanding relationships, ranging, for example, from difficulties adjusting behavior to suit various social contexts; to difficulties in sharing imaginative play or in making friends; to absence of interest in peers.

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

- 1 Stereotyped or repetitive motor movements, use of objects, or speech (e.g., simple motor stereotypes, lining up toys or flipping objects, echolalia, idiosyncratic phrases).
- 2 Insistence on sameness, inflexible adherence to routines, or ritualized patterns of verbal or nonverbal behaviour (e.g., extreme distress at small changes, difficulties with transitions, rigid thinking patterns, greeting rituals, need to take the same route or eat food every day).

American Psychiatric Association. (2013). Diagnostic and statistical manual of mental disorders (5th Ed.). Washington, DC: Author

DSM-V CRITERIA FOR AUTISM SPECTRUM DISORDER (ASD) 299.00

- 3 Highly restricted, fixated interests that are abnormal in intensity or focus (e.g, strong attachment to or preoccupation with unusual objects, excessively circumscribed or perseverative interest).
- 4 Hyper- or hypo-reactivity to sensory input or unusual interests in sensory aspects of the environment (e.g., apparent indifference to pain/temperature, adverse response to specific sounds or textures, excessive smelling or touching of objects, visual fascination with lights or movement).
- c. Symptoms must be present in the early developmental period (but may not become fully manifest until social demands exceed limited capacities, or may be masked by learned strategies in later life).
- D. Symptoms cause clinically significant impairment in social, occupational, or other important areas of current functioning.
- E. These disturbances are not better explained by intellectual disability (intellectual developmental disorder) or global developmental delay. Intellectual disability and autism spectrum disorder frequently co-occur; to make co-morbid diagnoses of autism spectrum disorder and intellectual disability, social communication should be below that expected for general developmental level.

HOW TO USE THIS GUIDE

"C. Symptoms must be present in the early developmental period" (American Psychiatric Association, 2013).

This means that if your child is autistic, they were born that way. Much of the diagnostic process has to do with examining your child's early developmental period from birth to age five. Other problems can present like autism in later life, but have roots elsewhere that can be more difficult to determine.

When making your notes in this guide, refer to your memory boxes, journals, social media statuses, baby books, photos, videos, emails, and any other mode of record-keeping you may have used during this time to document milestones, behaviours, observations, quirks, preferences, and so on.

"D. Symptoms cause clinically significant impairment in [...] important areas of current functioning" (American Psychiatric Association, 2013).

The key in this domain is to pay attention to what degree the observed behaviour(s) or symptom(s) interfere with the child's daily life, and in what ways.

When making your notes, be specific about what your observation or concern is, when and how often it was/is a problem, and in what ways it impacted/impacts your child's ability to function and/or cope.

"E. These disturbances are not better explained by intellectual disability (intellectual developmental disorder) or global developmental delay. Intellectual disability and autism spectrum disorder frequently co-occur; to make comorbid diagnoses of autism spectrum disorder and intellectual disability, social communication should be below that expected for general developmental level." (American Psychiatric Association, 2013).

It is important to keep in mind that delineating between disorders and disabilities as outlined in the DSM-V is the professionals' job. Please see the next page for my disclaimer.

When prompts are provided in this tool, use them as a starting point from which to go deeper in your exploration of that specific category. Remember to be specific and provide dates and/or approximate ages as often as possible

DISCLAIMER

Using examples that fit under each of the categories listed in this tool does not necessarily mean that your child is in fact autistic. This guide is meant to support a more thorough examination and presentation of your observations, concerns, and experiences, but is in no way a diagnostic tool in itself. It can be helpful to use while your child is awaiting or undergoing developmental assessments.

As with many other disorders and disabilities, there are often overlapping symptoms and presentations that might be better explained by a different label. Only a registered psychologist or professional who is trained to conduct autism assessments can make this determination.

This guide is designed to support parents who are questioning if their child may be autistic, to aid with the assessment process, and can even be helpful in future assessments as it will involve you taking detailed notes based on your child's early developmental period. This information will be vital in your quest to determine how best to understand and support your child, whether they are autistic or not.

It is also important to recognize that it can be difficult to delineate between behaviours that are indicative of lagging skills and behaviours that are expected based on a normative developmental trajectory (i.e., typical milestones and developmental phases). It is important to take time to observe your child. To help you better determine if what you are seeing is typically considered to be age-appropriate behaviour for young developing children, or if it may be indicative of a developmental difference such as autism, I suggest also observing other children as much as possible (i.e., at playgroups, at daycare, pre-school, or school events, at playdates, etc.). The goal in doing this is not to compare your child to others, or to say that autistic children are deficient when compared to typically-developing children. Rather, it is to draw your attention to similarities and/or differences that may be indicative of a different neuro-configuration (i.e., a different brain wiring; a diverse brain type; a different way of being human and processing information).

NEURODIVERSITY

Dr. Nick Walker is an autistic advocate and forerunner for the neurodiversity movement. They author the website **www,neuroqueer.com**, which is dedicated to sharing their notes on autism, neurodiversity, and cognitive liberty. Based on their dissemination of the pathology paradigm, which presents the most common brain (NT) as the "right" kind of brain, in their article Throw Away the Master's Tools: Liberating Ourselves from the Pathology Paradigm, they challenges these common assumptions, pointing to the stigma and shame that they perpetuate.

Instead, Dr. Walker and other neurodiversity advocates suggest that autistic voices should have a place in our society. They challenge the notion that there is an autism epidemic, asserting that individuals with these traits have always existed, and in fact have offered numerous gifts to human and technological development over the years. They shutter at the idea of a cure or treatment for autism, stating that autism is a part of what makes them who they are: a key part of their identity. In fact, throughout history there have been countless attempts to cure and treat autistic individuals at great cost. In his book Neurotribes: The Legacy of Autism and the Future of Neurodiversity, Steve Silberman does a wonderful job of sharing some of these accounts throughout human history.

Seeking and receiving an autism diagnosis can be a scary and daunting experience, especially for parents who know little about neurodiversity or autism. There are pros and cons to seeking out and receiving a diagnosis. Early diagnosis can provide timely access to necessary support and services within the education system, home, and community, open the door to better understanding oneself or one's child, and connect you to others with similar experiences. On the other hand, without a positive understanding of autism, many are at risk of thinking that autism is something to be feared, fought, or cured. Starting families off on this note is not helpful or healthy for anyone. The neurodiversity paradigm presents a refreshing and necessary shift away from the medical model of disability to the social model of disability.

DIFFERENT, NOT LESS THAN

Autistic individuals may certainly present with various struggles or challenges due to the nature of their neurology. These challenges are emphasized by the structures within which we expect them to function; structures within our homes and societies that were built, developed and implemented with the NT brain in mind. Some of these structures are physical, such as schools, churches, and malls. Others include intangible structures like the busy schedules we keep with appointments and lessons, the social norms and expectations that are often unspoken, and the onslaught of auditory, visual, gustatory (sense of taste), and olfactory (sense of smell) stimulation that we are accustomed to in our homes, workplaces, and schools.

While we all can relate to the experience of feeling overwhelmed by a loud sound or strong smell, autistic individuals are constantly bombarded with sensory input from both external and internal environments and process this information differently than NTs. Further, these experiences cannot always be communicated to the outside world, and so these individuals are often either not understood or misunderstood by NTs. Because the majority of people do not struggle in these situations to the same degree, difficulty coping or the inability to cope can be viewed as though something is "wrong" with that person.

The truth is, autistic individuals are different, neurologically-speaking. They are different, but not less than NT individuals. Their experiences are not often shared by NTs, but they are just as valid, real, and fully human. Keeping this in mind, it is understandable why parents questioning their child's development reach out to professionals for support or help, especially when a parent is NT. It can feel like you and your child are speaking different languages, and in many ways - you are.

Part of your new role might entail learning your child's language, and becoming an interpreter for your child.

Knowing that autistic individuals have different experiences, perceptions, and needs from NTs, it is important to become aware of and question our expectations and assumptions as parents, educators, and professionals. Even when we know these things, it remains strangely common to expect and assume that a differently-wired child can and should be able to cope with the same experiences as an NT child. Often his or her experience is undervalued, under-appreciated, and subjugated to that of the dominant experience. When a parent can approach his or her child with empathy, entering into what life might be like for that child, expectations can then adjust accordingly, and assumptions can be acknowledged and dropped.

When raising a child with autistic wiring, the modes of communication may look and sound different from what you might have expected. Regardless of what those manifestations are, it helps to see all behaviours as communication.

THE ROLE OF THE PARENT

The number one thing to keep in mind along this journey is to remember that your child is a child first. Before any diagnosis is sought and before any other needs are determined, it is essential to see your child in a developmentally accurate way: with physical, emotional, psychological, and biological needs that must be met. Being a human, your child is pre-wired to act in ways that will try to communicate their needs to you so that they can survive.

Seeing your child as a human who is capable of communicating to have his or her needs met, it becomes your job to determine exactly what is being communicated. This can be a challenge! But as long as a child is approached from a place of love and acceptance, a secure base of attachment can be built for all future communications. A secure base is one in which a child's competence is presumed. Love can be expressed unconditionally through the implementation of personal boundaries and loving limits. Children can be supported in finding healthy ways to relate to others, get their needs met, and express difficult emotions.

As a parent of a differently-wired child, your role may expand to include being a mediator, facilitator, educator, and even a social worker. The goal shifts to interdependence, as opposed to independence, which perpetuates the myth that a fully independent life is the ideal, or even at all possible for everyone. After all, do we not all have sources of support in our lives upon which we rely to meet different needs?

Every child's developmental trajectory is different, and so a focus on an ultimate goal of independence from all sources of support can seem impossible when faced with a grim prognosis provided by a professional. Rather than instilling hope, such a focus can engender feelings of fear, anxiety, despair and hopelessness. Meeting a child where they are at today, focussing on what can be done now to help building skills, is the best place to start. This keeps you present, so that you can celebrate their accomplishments and face challenges as they arise.

GIRLS, AUTISM, AND MASKING

The underrepresentation of autistic females has received considerable attention in recent years. There is new evidence that suggests that there may be a significant number of undiagnosed autistic females who have either been misdiagnosed or overlooked altogether. The mental health implications of misdiagnoses and/or masking of autistic traits are vast. In recent years, more undiagnosed adult women have sought a diagnosis, finding great relief, self-understanding, and support therein. Yellow Ladybugs is an advocacy group dedicated to bringing awareness to the different ways that autistic females may present.

These may include some of the following (and truly are not limited to females):

- Extreme focus on a special interest such as animals, nature, or princesses
- Extremely shy or unaware of social nuances and boundaries
- Masking anxiety and other traits, appearing to be compliant and quiet at school - "flying under the radar" only to meltdown, shutdown, or flip-herlid once home
- Interested in socializing and making friends, but not necessarily able or sure of how to maintain friendships
- Sensory sensitivities (this is expanded on later)
- Extreme reactions to changes, expectations, things not done just so
- Literal interpretations
- Gender fluidity, and
- High levels of empathy, care for people/objects/animals, and sensitivity

Craft, S. (2019). Females and asperger's: A checklist. The Art of Autism. Retrieved from https://the-art-of-autism.com/females-and-aspergers-a-checklist/

Kreiser, N. L. & White, S. W. (2013). ASD in females: Are we overstating the gender difference in diagnosis? Clinical Child & Family Psychology Review, 17(1), 67-84. doi:https://doi.org/10.1007/s10567-013-0148-9 Yellow Ladybugs. (n.d.). Autism traits in females. Retrieved from https://www.yellowladybugs.com.au/img/YLB_GirlTraits_A3.pdf

EXPLORING YOUR OBSERVATIONS

Breaking it down...

In the pages ahead, you will be guided through the DSM-V criteria for an autism diagnosis. You are encouraged to take notes as you explore whether and in what ways your child may meet the criteria.

Take some time to review and familiarize yourself with the first criteria of an autism diagnosis: Social Communication & Social Interaction. On the next page, I provide a list of things to take note of that might fit under this category. In the pages following, spend some time to examine your child's early developmental period (ages 0-5), as well as ages 6 to present. Add pages as needed. Write your notes within these pages, providing specific examples and approximate ages/dates where possible.

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

- Deficits in social-emotional reciprocity, ranging, for example, from abnormal social approach and failure of normal back-and-forth conversation; to reduced sharing of interests, emotions, or affect; to failure to initiate or respond to social interactions.
- Deficits in nonverbal communicative behaviors used for social interaction, ranging, for example, from poorly integrated verbal and nonverbal communication; to abnormalities in eye contact and body language or deficits in understanding and use of gestures; to a total lack of facial expressions and nonverbal communication.
- Deficits in developing, maintaining, and understanding relationships, ranging, for example, from difficulties adjusting behavior to suit various social contexts; to difficulties in sharing imaginative play or in making friends; to absence of interest in peers.

Things to take note of:

- Literal interpretations of language
- Difficulty understanding jokes, metaphors, and idioms
- Different or no use of language: sing-song quality to voice; various sounds; grunts instead of words; random squeals; mixing up words; made-up words/language; and, body language
- Lack of facial referencing (looking up at you to "check in" now and then)
- Engrossed in what she is doing, sometimes tuning everything else out
- Does he look up when his name is called, or respond to his name?
- Does she acknowledge when you or anyone comes in the room?
- Empathy: Is it extreme or does it seem to be missing?
- Shared Experiences: Is he interpreting his interactions and experiences in the same way as the other children?
- Does she express interest in others' interests outside of her own interests?
- Parallel/Interactive/Cooperative Play: Does he play alongside others, with them collaboratively, or not at all interested?

Things to take note of:

- Is her eye contact intense, fleeting, non-existent?
- Does she seem to have the ability to understand how others might perceive her?
- Is she very self-conscious? Not at all self-conscious?
- Does he seem to understand how his words and actions impact others? Or does he seem oblivious to it?
- Does she seem to have difficulty communicating about feelings?
- How does she communicate with you?
- How does he get his needs met?
- How does she get your attention?
- Does he seem to pay attention? To what?
- What would you say is her learning style?
- Is there reciprocity in his relationships/play?
- Can she ask for a break when needed?

Provide specific examples, including your child's approximate age at the time (focusing on ages 0-5):

Provide specific examples, including your child's approximate age at the time (focusing on ages 0-5):

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Provide specific examples including your child's approximate age at the time (focusing on ages 6 to present):

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Provide specific examples including your child's approximate age at the time (focusing on ages 6 to present):

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Take some time to review and familiarize yourself with the second criteria of an autism diagnosis: Restricted, Repetitive Patterns of Behaviour, Interests or Activities. On the next page, I provide a list of things to take note of that might fit under this category. In the pages following, spend some time to examine your child's early developmental period (ages 0-5), as well as ages 6 to present. Add pages as needed. Write your notes within these pages, providing specific examples and approximate ages/dates where possible.

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

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

American Psychiatric Association. (2013). Diagnostic and statistical manual of mental disorders (5th Ed.). Washington, DC: Author

Things to take note of:

- Repetition: Does he repeat words, songs, sounds, phrases from movies, the teacher, other kids?
- Do you find he repeats a lot of what you say to him, either right after, shortly after, or later on?
- Does she have any interests, passions, or favourite topics beyond common fads and interests that seem more intense than the average child? (Note: Girls may have interests that seem common, such as stuffed animals, princesses, or ponies, but with a more intense focus than is common)
- Does he have collections or obsessions? What does this look/sound like?
- What does he do with it?
- Does she ask the same questions in the same context each time even when she knows the answer?
- Does he seem to have difficulty leaving the house, a favourite place, school, the car, and/or with other transitions?
- Escalations in behaviour: Do you notice escalations with upcoming transitions, changes in routine or caregiver, etc. When else? What does this look/sound like?

Things to take note of:

- Does she do a lot of spinning, running in circles, jumping, hand flapping, excessive blinking, hand gestures, or other movements?
- Does he seem to get into people's personal space, or have difficulty respecting others' space?
- Do you notice repeated themes or patterns in her play?
- What does his play look like?
- What is the content of her play?
- Is he rule-bound? Does he make rules for his play beyond typical-age peers?
- How does he react when rules are broken? Can others suggest or change rules?
- How flexible is she when plans need to change?
- Does he watch the same show over and over? Or does he enjoy a variety of shows?
- What about music?

Provide specific examples, including your child's approximate age at the time (focusing on ages 0-5):

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B: RESTRICTED, REPETITIVE PATTERNS OF BEHAVIOUR, INTERESTS OR ACTIVITIES

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SENSORY INPUT

Section B, number 4. of the DSM-V criteria for ASD describes the following: Hyper- or hypo-reactivity to sensory input or unusual interests in sensory aspects of the environment (e.g., apparent indifference to pain/temperature, adverse response to specific sounds or textures, excessive smelling or touching of objects, visual fascination with lights or movement).

Some autistic individuals experience sensory stimuli differently than NTs. With the communication challenges and differences inherent in autism, autistic kids can struggle to communicate what they are feeling, wanting, or needing. Sometimes this can result in challenging behaviours that leave parents puzzled, exacerbated, and searching for answers to help their child cope. Once a child is diagnosed with a sensory processing disorder (SPD) or autism, an occupational therapist (OT) can help parents understand their child's sensory needs.

There are some things to watch for that can help your child avoid sensory overload, and keep your child more balanced overall.

Hyper-reactivity to sensory input refers to an over-aroused system that requires less input to have the same effect as a typically-developed sensory system. When a system is over reactive, one is likely to avoid sensory input.

Hypo-reactivity to sensory input refers to an under-aroused system that will require more input to have the same effect as a typically-developed sensory system. When a system is under reactive, one is more likely to seek out more input. Children can engage in both seeking and avoiding behaviours at different times, however most children tend to fit in more of one category than the other.

Sensory-seeking behaviours and sensory-avoiding behaviours are signs that your child is seeking balance in their sensory system.

SENSORY INPUT

Seeking behaviours can include: getting in other people's space; jumping, running, spinning, swinging, crashing, screaming, yelling, etc.; rubbing against you/skin-to-skin/a favourite fabric or texture; high pain threshold; rough-housing; chewing, biting, and mouthing things; and more.

Avoiding behaviours can include: an adverse reaction to touch; avoiding hugs/kisses/closeness/crowds; dislike of of loud noises, bright lights, etc.; strong preferences for clothing, shoes, socks, tags, etc.; avoiding swings, rough-housing, heights, etc.; and more.

There are also three lesser known senses that may require your attention when exploring possible neurodivergence.

Proprioception refers to one's sense of body position: the movement of arms, legs, and torso, the amount of effort and force exerted to do so, and the feeling of heaviness or lack thereof. This process is facilitated by receptors in the skin, muscles, and joints which connect to the brain through the nervous system to communicate the body's position in space. For autistic individuals, this sense can be affected, resulting in sensory-seeking behaviours, sensory-avoiding behaviours, difficulties with motor planning and control, and postural challenges.

The vestibular sense is part of our body's way of maintaining balance and posture, movement, and reflexes. For autistic individuals, this sense can be affected, resulting in sensory-seeking behaviours and/or sensory-avoiding behaviours.

Interoception is the internal felt sense. It is what lets us know we are hungry, thirsty, hot, cold, need to use the bathroom, have a sore stomach or headache, if we are tense, and so on. This sense communicates to the brain what is needed to regain homeostasis. For autistic individuals, this sense can be affected, resulting in difficulty identifying or interpreting one's internal sensations. This can be difficult to communicate or understand for all involved.

THE TASTE SENSE: FOOD, FEEDING & ORAL INPUT

Consider:

0-5

- What did he eat?
- How did she eat?
- What were mealtimes like?
- What was it like to eat out at a restaurant?
- Did he breastfeed/bottle feed?
- Were there any problems?
- Aversions?
- Preferences?
- Gagging?
- Putting objects into his mouth?
- Did she bite, chew, lick, or mouth objects or clothing?

- What does he eat?
- How does she eat?
- Can he use utensils? Does he?
- What are mealtimes like?
- What is it like to eat out at a restaurant?
- Are there any problems with eating?
- Aversions?
- Preferences?
- Gagging?
- Does she bite, chew, lick, or mouth objects or clothing?

The Taste Sense: Food, Feeding, & Oral Input
Provide specific examples, including your child's
approximate age at the time (focusing on ages 0-5):

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Provide	te Sense: Food, Feeding, & Ordi Input specific examples including your child	'S
approxir present	mate age at the time (focusing on age	es 6 to
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THE TOUCH SENSE

Consider:

0-5

- Were there certain textures or fabrics she sought or avoided?
- Did he wear underwear?
- Was there a preference for clothing types?
- Did she refuse certain clothing items?
- Did he prefer bare feet?
- Did she touch objects excessively?
- Did he seek skin-to-skin contact?
- Was is too much? Too little?
- Did tags in clothing bother her? What happened when they did?

- Are there certain textures or fabrics she seeks or avoids?
- Does he wear underwear?
- Is there a preference for clothing types?
- Does she refuse certain clothing items?
- Does he prefer bare feet?
- Does she touch objects excessively?
- Does he seek skin-to-skin contact?
- Is is too much? Too little?
- Do tags in clothing bother her? What happens when they do?

The Touch Sense

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The Touch Sense

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THE VISUAL SENSE

Consider:

0-5

- Did he seem to be easily distracted?
- By what?
- Lights?
- Movement?
- Large crowds and lots of people?
- Did she have a vacant stare and appear to look through you?
- Did he seem easily overwhelmed?
- What did that look like?
- Did she prefer to play in dim or bright light?
- Did he need to wear sunglasses outside?

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The Visual Sense

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The Visual Sense

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THE AUDITORY (HEARING) SENSE

Consider:

0-5

- How did he respond to loud noises like public bathrooms, hand dryers, vacuums, airplanes, etc.?
- Was she especially loud?
- In what instances did you notice this?
- Did he cover his ears when he heard something?
- Did she seem to notice sounds that no one else did?

- How does he respond to loud noises like public bathrooms, hand dryers, vacuums, airplanes, etc.?
- Is she especially loud?
- In what instances do you notice this?
- Does he cover his ears when he hears something?
- Does she seem to notice sounds that no one else does?

The Auditory Sense

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The Auditory Sense

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THE SENSE OF SMELL

Consider:

0-5

- Did smells bother her that others didn't seem to notice?
- What was her reaction?
- Did he have an especially keen sense of smell?
- Or not seem to notice scents at all?

- Do smells bother her that others don't seem to notice?
- What is her reaction?
- Does he have an especially keen sense of smell?
- Or not seem to notice scents at all?

The Sense of Smell

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PROPRIOCEPTION

Consider:

0-5

- Did she walk on her toes?
- Did he crash or bump into things a lot?
- Did she run or spin in circles?
- Did he jump or flap his arms a lot?
- Did she ask for tight squeezes and hugs?
- Did he slouch or slump over the table often?
- Did she fall a lot?
- Did he climb on things a lot? Did she like to rough-house more than others?

- Does she walk on her toes?
- Does he crash into things a lot?
- Does she run or spin in circles?
- Does he jump or flap his arms a lot?
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Proprioception

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VESTIBULAR SENSE

Consider:

0-5

- Did he struggle to ride a bike?
- Did she fear heights?
- Did he enjoy or despise swinging, bouncing, rocking, etc.?
- Did she take excessive risks with movement?
- Did he spin in circles or spend countless hours on the trampoline?

- Does he struggle to ride a bike?
- Does she fear heights?
- Does he enjoy or despise swinging, bouncing, rocking, etc.?
- Does she take excessive risks with movement?
- Does he spin in circles or spend countless hours on the trampoline?

The Vestibular Sense

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The Vestibular Sense

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INTEROCEPTION

Consider:

0-5

- Did she seem oblivious to cold temperatures?
- Did she wait until the last possible moment to run to the bathroom?
- Did she complain of pain or discomfort but be unable to express where it was or what it felt like?

- Does she seem oblivious to cold temperatures?
- Does he forget to take his sweater off in gym class and get overheated?
- Does she wait until the last possible moment to run to the bathroom?
- Does he forget to eat or drink?
- When she complains of pain or discomfort, is she unable to express where it is or what it feels like?

Interoception

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SLEEP OBSERVATIONS AND CONCERNS

Provide specific details when possible:

DIFFICULTIES WITH EMOTION REGULATION

For children, feelings can come and go pretty quickly. When an adult is well attuned to a child, it can be easy to tell if the child is hungry, tired, or scared, and can be acted on proactively to avoid an inevitable tantrum or meltdown that comes when less connected. Most people understand that "negative feelings" like sadness, anger, frustration, annoyance, fear, or exhaustion can be difficult to experience, but rarely do we acknowledge that "positive feelings," especially the big ones of excitement and extreme joy, can also feel overwhelming and difficult for kids to contain.

Some common signs that a child is having difficulty regulating their emotions include:

- Whining/fussing
- Making demands
- Complaining
- Crying
- Hiding
- Clinging
- Sensory seeking or avoiding behaviours (covering ears, spinning, rocking, thumb sucking, chewing, etc.)
- Yelling or increasing volume
- Running or difficulty slowing down
- Appearing to be "not listening" or ignoring you
- Appearing to be displaying "bad behaviour"
- Hitting, biting, or other forms of behaviour that disregard the safety of other people or property
- Rosy cheeks
- Tensing body, face, or fists
- Upset facial expression
- Demand avoidance
- Extreme silliness
- Losing control of their body

These can be attempts to self-regulate or soothe, as well as steps of escalation that adults can use to cue into the child's experience and need for support. Sometimes all a child needs is to know that a confident leader is by their side. Other times they may need help navigating a conflict with an adult's supportive facilitation skills. And other times still, a child may need to be removed from a situation that they find overwhelming to be provided a safe place to de-escalate.

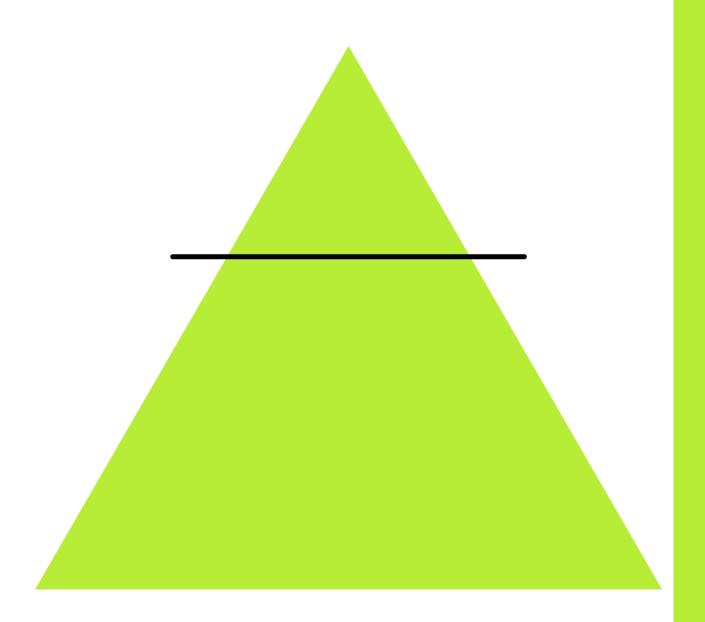
It can help to know that a child who seems to be giving you a hard time, is usually having a hard time themselves. This is when they need you most!

It can be helpful to think of the behaviours listed above as steps of escalation. Each child will have different signs or steps that a parent or teacher can clue into as a sign that help or support is needed. If you can step in before too many steps are made up that Hill of Escalation, you will likely avoid a tantrum or meltdown. If however, you miss several steps of escalation up that hillside, there will come a time that the child will experience overload and will step into the top curve of the hill - the point of no return: the tantrum or meltdown. Once at this point, no amount of talking, consoling, supportive presence, conflict resolution, or comfort will do much good. Actually, at this point those actions may only serve to add more clutter into an already overwhelmed child's brain (see Dr. Dan Siegel's book The Whole Brain Child for the scientific explanation of this). When a child is in an escalated state, they are in "fight, flight, or freeze" mode, and cannot use the "logical" part of the brain during that time.

On the way back down the hill, it can be helpful to provide your child with a quiet, safe, and calm space to de-escalate. Some children need closeness at this stage, while others simply need space and your available presence when requested. Still, while a child is descending this hill, it is not recommended to do much talking. All too often parents rush into problemsolving mode. However, high cortisol levels (stress hormones) within a child's brain can keep this from being a constructive problem-solving time.

Once a child has completely come down the hill and is on the other side, completely calmed and walking on the flat land beside the Hill of Escalation, efforts can be made to problem-solve, repair, and/or make a plan for how to address a similar situation in the future. Validation of feelings is helpful at this time. It can also be helpful to explore and describe exactly what your child was feeling in her body (physical sensations) when those steps of escalation were occurring. Naming your observations, like increased volume, increased heart-rate, or the clenching of their fists, can teach them to pay attention to the signs from their body - building self-awareness, and the foundations of empathy. They can also learn that feelings are temporary - like visitors, coming and going all the time.

In the upcoming pages, I will ask you to examine what your child's triggers, signs of escalation, and point-of-no-return look like. You may choose to write them on this page as a visual representation.



ANTECEDENTS TO ESCALATION

It can be difficult to determine exactly what happened to cause an explosive reaction from a child. For parents and teachers of autistic children who innately struggle with communication and sensory input, this can be even more challenging. Children whose challenges are more difficult to observe or who mask their autistic selves (often females or those who would fit an "Asperger's profile"), tend to hold it together for as long as they can in an effort to not stand out in environments that do not feel safe to them. This can result in a delayed effect, which can be anywhere from hours to a day or more after the actual event that triggered the explosion.

Each child may have different "triggers" or "triggering events" that can send them up their Hill of Escalation. The trick is to determine what they are in order to minimize them. Sometimes official accommodations must be made, while other times just having an understanding and adjusting expectations can help. While not all challenges can be avoided, many can be predicted and therefore proactively prepared for. This can best be achieved in collaboration with the child when possible.

The best way to avoid having to deal with an "explosion" is to look for the child's signs of escalation and to intervene early to support regulation before things get out of hand. This will take time to understand and implement in practice, as each child has their own challenges and triggers, but it is well worth the effort.

ANTECEDENTS TO ESCALATION

Some common antecedents to escalation include:

- A sensory need / problem (i.e. volume, lighting, chaotic environment, unwanted touch, etc.)
- Any interoceptive need (unable to recognize the need or verbalize it): to use the bathroom; hunger; thirst; temperature, etc.
- Competition, particularly losing; missing out on a reward or prize Feeling threatened or in danger (real or perceived)
- Difficulty understanding what is being asked of them or meeting expectations due to lagging skill development; expectations are beyond their perceived ability to meet them
- Difficulty understanding the rules / social norms or to interpret what is expected of him
- Difficulty approaching adults to ask for help
- Difficulty interpreting facial expressions or body language
- Difficulty with transitions or change in routine
- Anxiety
- Being singled out or made fun of
- Difficulty navigating conflict with others
- Seeing another child do something, and copying it without understanding why it might not be appropriate or why it elicits a reaction from others

"KIDS DO WELL IF THEY CAN" ~ DR. GREENE

Most kids, including autistic kids, know all the answers to what's right and wrong, what they should do when someone's hurt, how to be courteous, and how to be kind. When "in a good place", a calm and regulated state, they can demonstrate these behaviours with ease, because by nature kids want to be "good." However, when flooded with an emotion (anger, frustration, excitement, jealousy, sadness, hurt, anxiety/fear, etc.), differently-wired kids may have difficulty thinking rationally due to the intensity of their emotional and sensory experiences and the nature of their lagging skills (i.e., in the domains of flexibility, executive functioning, etc.). As described with the Hill of Escalation and the antecedents to escalation, these kids often find themselves in their fight, flight, freeze, or fawn stress response so quickly. This is a pattern that can be somewhat predictable and therefore can be proactively supported to minimize overwhelm and escalation.

If you are not very familiar with autism, the typical response to "undesired behaviour" is to punish the child for their "bad behaviour." However, differently-wired kids do not respond to time-outs or punishments in the same way that typically-developing children do. Instead, it fuels their feelings of isolation, misunderstanding, and anger, which then fuels their anxiety and increases the likelihood of a meltdown.

Unfortunately, this is the downside for these kids. The fact is that many of them know right from wrong and how they should have behaved, and if they could have done well in that instance, they would have (see Dr. Ross Greene's book The Explosive Child: A New Approach for Understanding and Parenting Easily Frustrated, Chronically Inflexible Children and the website www.livesinthebalance.org to learn about the Collaborative and Proactive Problem-Solving Model). What is most concerning is how this can impact a child's developing self concept, which is why they need the adults in their lives to recognize what is going on for them, and arrange the necessary accommodations to help them succeed.

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SIGNS OF ESCALATION

Prevention of escalation is key, especially when raising or supporting kids with lagging skills and asynchronous development. It is best if you can become aware of your child's signs of escalation and catch them quickly and early. You will later be prompted to consider what your child's signs of escalation are. If they can be caught prior to the "point-of-no-return" (which is different for everyone), collaborative strategies, redirection, problem-solving, or a solitary regulating activity can work wonders.

Escalations can become much more predictable and prevented when working proactively to support a child. Some kids seem to go from 0 to 60 in no time flat! The reason for this is because many of these kids are actually going from 30 or 40 to 60, as their systems are more sensitive to and less discriminating of sensory stimulation. This is why it is important to understand a child's sensory profile, and to be prepared with as much information as possible to prevent them from crossing that line, at which point safety becomes priority until the "wave" has passed.

Signs of escalation may look different for neurodivergent kids than they might for typically-developing kids. Here are some examples of what you might see in addition to the previous list:

- Change in facial expression that is incongruent with what is actually happening
- Smirking, grimacing, frowning, etc.
- Intense eye contact or staring
- Avoiding eye contact
- Hiding
- Telling people to leave her alone (usually not in a friendly way!)
- Chasing other children, even when the other child wants them to stop
- Disregarding adult requests to stop, or attempts at redirection
- Non-compliance: Inability to attend to a task or follow directions

SIGNS OF ESCALATION

- Becoming overly silly or floppy, lacking body control
- Uncontrollable laughter
- Increased volume and intensity
- Spinning in circles and seeming to be unable to stop
- Using mean, inflammatory, or profane words intended to incite a strong reaction from others
- Making threats
- Appearing dazed, confused, shutdown or zoned out
- Baby talk or non-sensical language
- Throwing things
- Grunts, growls, and squeals
- Increase in rigidity and rule-setting; decreased flexibility
- Increased echolalia or a repeated phrase that has significant meaning relevant to that child

As noted earlier, once past the "point-of-no-return," ensuring the safety of the child, yourself, others, and property becomes the priority. The goal is to become so familiar with your child's signs of escalation that getting to that point becomes less and less common.

INTERVENING EARLY

Here are some helpful tips to try when intervening before your child has crossed their "point-of-no-return":

- Remove him (kindly and gently) to a low stimulation area to have some "quiet time alone" or "calm down time" (away from sounds, movements, and other people)
- Minimize verbal commands, prompts, questions, and directions
- Have a quiet space he can retreat to at home or in/outside of the classroom, with calming activities such as lego, drawing supplies, puzzles, etc.
- If possible, arrange "sensory breaks" throughout the day. It is helpful to think of a child as a pop bottle, and each upset throughout the day is a shake of the bottle. Sensory breaks can help to dissipate the buildup of tension, to avoid the huge overflow that can happen at less predictable times throughout the day
- Logic is on your side! It is helpful if rules make sense to him and have a logical and reasonable explanation. For example, when talking about not kissing others without their permission, it may be helpful to talk about how he can get germs and become sick from doing so, as opposed to trying to get him to understand the other person's experience (though it is still important to mention)
- Many of these kids are big reaction kids, in that they will do things
 repeatedly IF they gets a big reaction from others (i.e. if your reaction to
 something she does is to laugh, yell, or cry, these may elicit something
 inside of her that may encourage her to repeat the behaviour again in
 the future). This is why it is best to remain as calm, consistent, and
 confident as possible when responding to a behaviour or inappropriate
 words she has used
- Provide vestibular or proprioceptive input as needed (i.e., jumping on a trampoline, wrestling, heavy lifting, deep breathing, meditation or yoga, etc.). This will be dependent on that child's sensory needs. What works for one child may not work for another.
- Redirect him to a job or task that can provide a sense of accomplishment When not escalated, try to collaboratively include the child in problem-solving, to elicit ideas from her that she believes may help. If this does not work the first time, do not give up! Sometimes kids have great ideas that we would not have thought of on our own. They are also more likely to buy into an idea of their own, than to latch onto an adult-imposed solution

MY CHILD'S SIGNS OF ESCALATION

Note Frequency, Duration, & Intensity

Take some time to brainstorm and consider your child's signs of escalation. Provide specifics, including what it looks/looked like, sounds/sounded like, feels/felt like, your response(s), what indicates their "point of no return," etc. What do you think may have been an antecedent (i.e., sensory needs, expectations, etc.):

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MY CHILD'S SIGNS OF ESCALATION

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STRATEGIES THAT HELP MY CHILD REGULATE

Take some time to brainstorm and consider what kinds of strategies currently work or might work to help your child calm and regulate when you notice their signs of escalation arising:

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STRATEGIES THAT HELP MY CHILD REGULATE

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SIGNS THAT I AM ESCALATING

Kids are not the only ones that get dysregulated Take some time to brainstorm and consider signs that you are escalating. What does it look like? Feel like? Sound like? What triggers you and gets you going? Are there certain behaviours/people that seem to bring out your worst?:

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SIGNS THAT I AM ESCALATING

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STRATEGIES THAT HELP ME REGULATE

Take some time to brainstorm and consider what kinds of strategies currently work or might work to help you calm and regulate when you notice your signs of escalation arising:

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SCHOOL / OTHER OBSERVATIONS AND CONCERNS

Describe any comments, concerns, or observations made by others (i.e., teachers, peers, other parents, coaches, friends, etc.):

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SCHOOL / OTHER OBSERVATIONS AND CONCERNS

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TEACHER FEEDBACK REQUEST LETTER

Dear Teacher:

We have some concerns about (child's name)'s development, and while he does participate in class and is very intelligent, there are some key things that we would like to request you watch for. This will help us moving forward as we determine what assessments and/or assistance he may require.

- Social-emotional reciprocity (showing empathy or not; understanding and reading social cues; give and take in conversation with peers about things that are of interest to both him and others; insistence on responses to questions; noticing when others are not interested in his topics and being ok with that; greetings and goodbyes; acknowledgement of people talking to him; shared interests with others) Non-verbal communicative behaviours (grunting; whining; body gestures; facial expressions; literal interpretations; spinning, jumping or rocking)
- Developing, maintaining, and understanding relationships (are his friends the same age, younger or older; are friends assertive or meek; will he accept friends suggestions; will he accept friends refusals; does he respect others' "bubbles of space"; will he play with others or spend the game talking about the rules or how to play the game; does he play alone/with others)
- Repetitive use of objects, games, speech, behaviours (are the games that he plays varied; does he use various toys; do you notice repeated phrases/words/statements/questions; does he spin when talking/thinking/excited; does he draw various/same things; is speech appropriate for age or precocious; do you notice patterns of behaviour)
- Insistence on sameness, inflexible, adherence to routine, ritualized patterns of verbal/nonverbal behaviour (how does he do with transitions; structure vs. unstructured environments; outdoor or free play time)

TEACHER FEEDBACK REQUEST LETTER

- Restricted fixated interests that are intense (does he play with toys in a typical way, or with just parts of toys; does he collect toys; are his drawings varied/same; what are his interests as expressed in conversation and games)
- Sensory difficulties (does he seem to react immediate or delayed effect - to too much stimulation, movement, noise/sound/volume; sensitivity of feelings of self and others around him - especially fear/excitement/anger; clothing and shoes; textures; lighting; temperature; sensory play)

Thank you for your attention to this request. We will followup with you in (length of time).

Sincerely, Parent

CHILD'S MEDICAL HISTORY

Describe any significant information regarding your pregnancy, the child's birth, hospitalizations, allergies, medications, medical / mental health (past and present), significant family health issues, previous tests / assessments, etc.:

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DEVELOPMENTAL MILESTONES

Take a moment to list the ages and ways that your child met any developmental milestones (i.e., rolled over, crawled, walked, first words, first foods, making sounds, reactions to others, etc.)

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OTHER OBSERVATIONS AND CONCERNS

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OTHER OBSERVATIONS AND CONCERNS

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CHILD'S STRENGTHS AND COMPETENCIES

All kids have strengths and abilities. Take a moment to brainstorm and list your child's here:

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CHILD'S STRENGTHS AND COMPETENCIES

All kids have strengths and abilities. Take a moment to brainstorm and list your child's here:

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MY CURRENT SUPPORT SYSTEM AND EXTERNAL RESOURCES

Take some time to list the current supports in your life (i.e., family, friends, agencies, associations, clubs, teams, support workers, etc.)

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CHILD'S CURRENT SUPPORT SYSTEM AND ATTACHMENTS

Take some time to list the current supports in your child's life (i.e., family, friends, agencies, associations, clubs, teams, support workers, etc.)

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