CONSCIOUS CARE & SUPPORT



Conscious Care and Support

Developing

Emotionally Self-Regulated & Kind Supporters

Facilitating

Comprehensive Biomedical Support & Treatment



Session I — Resource 1

Contributors to Conscious Care and Support

Conscious Care and Support has been developed while supporting, training or in direct consultation with:

- Approximately 3,000 Moms, Dads, and Support Professionals.
- Dr. John Ratey, Associate Clinical Professor of Psychiatry at Harvard Medical School (reference 8 books on mental health and autism and other developmental disabilities including 'Spark' and 'Shadow Syndromes').
- Dr. Theresa Hamlin, Associate Executive Director of The Center for Discovery and her staff. Dr. Hamlin is the author of 'Autism and the Stress Effect'.
- Dr. Martha Herbert, Assistant Professor of Neurology at Harvard Medical School and a Pediatric Neurologist at Massachusetts General Hospital, where she is Director of the Transcend Research Program. She sits on the Scientific Advisory Committee for Autism Speaks (reference 'The Autism Revolution').
- Dr. Shinzen Young, Mindfulness Research Consultant, Harvard Medical School.
- Universities of Toronto and Western Ontario/London Health Sciences Centre and Centre for Addiction and Mental Health (CAMH)



CCS Contributing and/or Trained Organizations & Agencies

- Autism Ontario
- Community Living Ontario
- L'Arche Daybreak
- OASIS (Ontario Agencies Supporting Individuals with Special Needs)
- Community Living Windsor
- Community Living Cambridge
- Rygiel Supports for Community Living
- Community Living Oakville
- London Health Sciences Centre
- McMaster University
- University of Toronto
- Kerry's Place
- Ministry of Education Special Needs Division
- Ongwanada
- Community Living Kincardine & District
- CREST

- Community Living Trent Highlands
- Participation House
- Community Living Owen Sound & District
- Durham Association for Family Respite Services
- Christian Horizons
- Community Living Burlington
- Parents for Community Living
- Extend-A-Family Toronto and Waterloo
- Community Living Walkerton & District
- Community Living Welland Pelham
- Community Living St. Marys and Area
- Community Living Chatham-Kent
- Community Living Stratford and Area
- Community Living Kingston & District
- Windsor-Essex Family Network
- Community Living Prince Edward
- Norfolk Association for Community Living



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Facts About Autism and Other Developmental Disabilities



"Autism <u>behaviours</u> have been adopted as unofficial criteria in the assessment of Autism, but there is <u>no evidence</u> supporting the attribution of behaviours such as head banging, aggression and night waking to the pathophysiology of Autism. Parents and supporters should be aware that these maybe the primary or sole symptom of underlying (bio) medical conditions." (Buie et al, 2010)

(Buie, T., Harvard Medical School – Professional of the Year, Autism Society of America, 2009) (Reference: Evaluation, Diagnosis and Treatment of Gastrointestinal Disorders in Individuals with ASD; A Consensus Report)

peter.mindfullivina@amail.com

Examples of Prevalence (30% - 88%) of Co-occurring Conditions* in PwDD with Complex Needs Contributing to Anxiety, Self-Injurious Behaviour & Aggression

Gastrointestinal Sensory Integration and Processing П - infections - hyper/hypo activation - intolerances - imbalances (e.g. vit/min) **Human Energy** - physical pain - sensitivities (e.g. EMF/ RWF) - intolerances **Mental & Neurological** П Cellular e.g. seizures and mood disorders - mitochondria dysfunction **Brain Imbalances Emotional** - inflammations - fears and phobias - coherence (lack of) - under development **Adrenal Glands** П - motor planning problems - over production of cortisol

"Autism itself does not cause challenging behaviour" - Autism Speaks 2012

^{*}Reference Hamlin, T. Autism and The Stress Effect (The Centre for Discovery)

The Recurring Cycles of **Behaviour to Compliance to Behaviour**

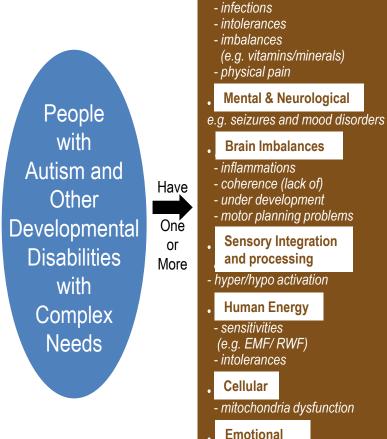
CO-OCCURRING CONDITIONS' AND AREAS OF POTENTIAL UNMET NEEDS

Gastrointestinal

- fears and phobias

Adrenal Glands

- over production of cortisol

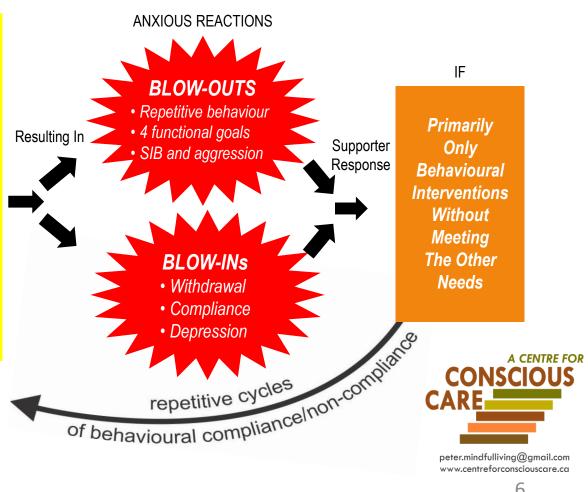


LIVING & LEARNING **CHALLENGES**

- Physical pain
- Sensory over/under load
- Psychological distress
- Speech/hearing limitations

Contributing

- PTSD/Trauma
- Environmental stress
- Neglect/Abuse, Isolation/Loneliness
- Supporter 4 outs



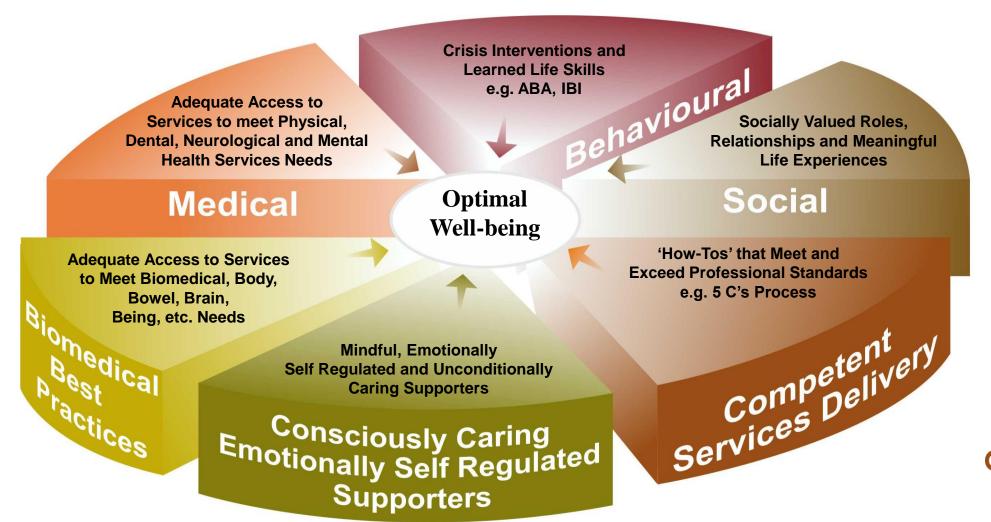
Successful Prevention and Treatment

The majority of unmet regulatory causes for the lack of wellbeing, self injury and aggression can be successfully prevented and treated however only with a more complete Biological, Psychological and Social Support process.

(As directed by the Behavior Analyst Certification Board BACB – 2016, 3.02 and 4.07 (a)



Evidence Based CCS Components for Well-being and the Prevention and De-escalation of Challenging Behaviours*

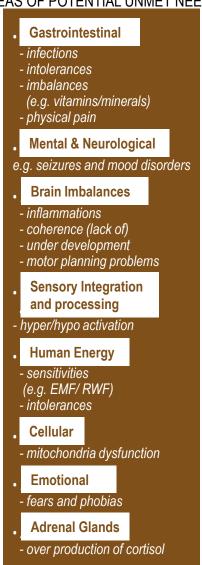


^{*} CCS reduces challenging behaviours by 50%-75% compared to MCSS current 'must use' crisis protocols alone.

peter.mindfulliving@gmail.com www.centreforconsciouscare.ca

Breaking the Recurring Cycles of Behaviour to Compliance to Behaviour

CO-OCCURRING CONDITIONS' AND AREAS OF POTENTIAL UNMET NEEDS





Note: living and learning challenges become less, directly proportionate to the implementation of CCS interventions resulting in enhanced optimal learning conditions.

LESS AND LESS

LIVING & LEARNING CHALLENGES

- Physical pain
- Fears and phobias
- Sensory over/under load
- Psychological distress
- Speech/hearing limitations
- PTSD/Trauma
- Environmental stress
- Neglect/Abuse, Isolation/Loneliness
- Supporter 4 outs

BETTER AND BETTER

OPTIMAL LIVING CONDITIONS

Resulting In

- Self Regulated Nervous System
 - Relative Calm
- Well-being



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Physical and Emotional Well-being

CCS Hierarchy of Service Needs

Toward A More Complete Understanding

of the Hierarchy of Special Needs to Facilitate Optimal Well-being



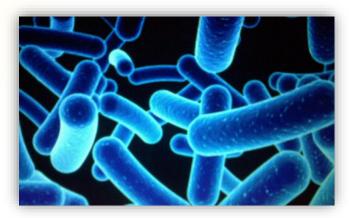
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Gastrointestinal (GI), bowel, digestive and immune systems' treatment, nutrition, pain management, dental and myofunctional disorders, illness prevention and treatment

Awareness-based calming and de-escalation skills offered by mindful, emotionally self-regulated and kind supporters

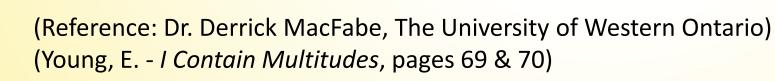
Needs for GI and Bowel Management and Holistic Treatment

Distressed Gut Microbes – produce Mind/Body Agitation, Pain and Anxiety which often leads to aggression.



1% Human 99 % Bacterial and Fungal

- Some Microbes found in the gut of individuals with Autism, when introduced into healthy rodents, create numerous Autistic like symptoms.
 e.g.
 - Repetitive behaviours
 - Social aversion
 - Easy to startle





Microbes, Anxiety and Aggression

Chronic anxiety means excessive toxic cortisol in the body.

To neutralize this toxin, the body uses up basic building blocks like amino acids that are needed to:

- digest food
- build the immune system
- produce calming neurotransmitters

This depletion causes anxiety leading to aggression



CCS GI and Bowel Management and Holistic Treatments

Engage a qualified holistic GI specialist, e.g. qualified and <u>available</u> MD, ND or nutritionist who will for example:

- 1. Complete a comprehensive biomedical assessment e.g. Organic Acid Test
- 2. Remove food toxins/allergens and metals
- 3. Balance minerals, vitamins and neurotransmitters
- 4. Implement holistic bowel management
- 5. Optimize nutrition
- 6. Optimize sleep



Physical and Emotional Well-being

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Emotional Wellness:

- mental and neurological health and disorders' treatment
- trauma desensitization and triggers' elimination
- psychological well-being
- medication side effects
- ABA behavioural interventions

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Brain development, coherence balancing and inflammation regulation

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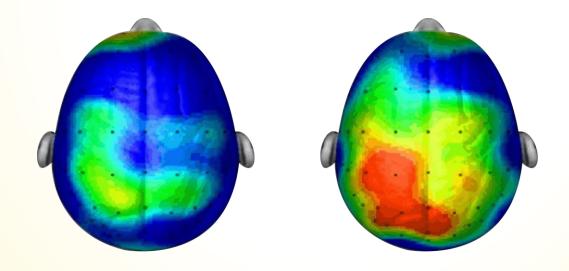


Brain Coherence

i.e. Many Parts of the Brian 'Talking' to Each Other

"Like you, I need to be able to understand and process information". This requires optimal Brain Functioning e.g.

- neurogenesis (new neurons)
- neuroplasticity (more complete neuro networks)
- neuro electrical stimulation (brain firing)
- neurochemicals production (endorphins, dopamine, serotonin, oxytocin)
- Hertz e.g. Beta, Alpha, Theta, Delta





Neuroscience also near unanimously concurs that neurogenesis, neuroelectric stimulation, neurochemicals' production, and neuroplasticity are, with appropriate training and conditioning, not only possible but highly predictable to measurably enhance cognition, empathy and emotional self regulation.

Reference:

- N. Doidge The Brain's Way of Healing
- D. Siegel The Mindful Brain
- D. Eagleman The Brain



CCS Brain Coherence, Balancing & Inflammation Regulating Interventions

- 1. Enhance essential brain calming elements e.g. GABA and Serotonin
- 2. Prevent excess of excitatory elements e.g. Cortisol, Glutamate, PPA
- **3.** Balance anxiety producing vitamins and minerals e.g. Magnesium, Vitamin B6, Histamine reduction, Vitamin B12
- **4.** Cerebellum activation e.g. 20 minutes of bouncing and balancing, and neurofeedback
- **5.** Maintain adequate glutathione levels to prevent brain inflammation e.g. NAC



6. Keep the Mitochondria Cell System Healthy:

- Mitochondria are known as the powerhouse of each cell
- They give cells their energy to do their work such as maintaining healthy brain functioning

Controllable Mitochondria Killers:

- Sugar and Simple Carbohydrates
- Oxidative Stress causing Brain Inflammation low glutathione
- Medications such as Antibiotics and Antipsychotics
- Vitamins and Minerals Imbalance low B vitamins, folic acid,
 magnesium, vitamin D



7. Cardio Exercise:

 Cardio exercise, especially bouncing and balancing, increases brain wave activity (e.g. cerebellum) to give better brain coherence for optimal functioning.

- Improved coherence results in thoughts becoming more organized and focused.
- This results in less fear and therefore more calm.



8. Neurofeedback

From Stick People to Clearly Defined Human Beings

After four months of neurofeedback, a ten-year-old boy's family drawings show the equivalent of six years of mental development.



Physical and Emotional Well-being

CCS Hierarchy of Service Needs

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Human energy system – building, balancing and protecting from wireless radiation and electromagnetic fields (EMF)

Brain development, coherence balancing and inflammation regulation

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Human Energy – Building, Balancing and Protection

Protection from Environmental Toxins

- e.g. reduce electromagnetic energy fields (EMF) (a.k.a. dirty electricity)
 - reduce Wi-Fi and cell phone radiation



The Bioinitiative Report 2012 links EMF Exposure to Autism concluding: Based on strong evidence for vulnerable biology, in Autism, EMF/ Radio Frequency Radiation (RFR) can plausibly increase Autism risk and symptoms. "While we aggressively investigate the links between Autism disorders and wireless technologies, we should minimize wireless and EMF exposures for people with Autism disorders, children of all ages, people planning a baby, and during pregnancy," says Martha Herbert, MD, PhD, Pediatric Neurologist Harvard Medical School.

Physical and Emotional Well-being

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Sensory integration and processing

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Hyperactive Senses Lead to Challenging Behaviours

Hyperactive Senses means that people, objects and places can be: e.g. too loud too fast too scratchy too tight too bright too off balance too confusing too chaotic

N

Agitation, Anger and/or Aggression

e.g.

- repetitive behaviour
- challenging behaviour
- Injury to self or others

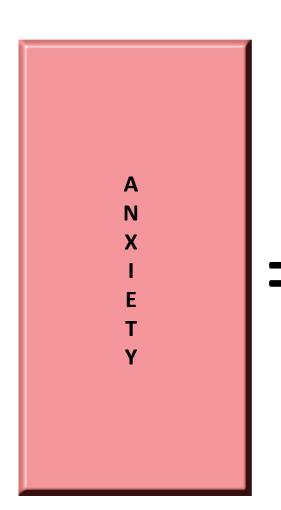


Hypoactive Senses Lead to Challenging Behaviours

Hypoactive Senses means that people, objects and places can be: e.g. too quiet too slow too dark too loose too tickly

too confusing

too chaotic



Agitation, Anger and/or Aggression

e.g.

- low energy
- low motivation
- quiet/withdrawn

Eventually -

- repetitive behaviour
- challenging behaviour
- Injury to self or others



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Physical and Emotional Well-being

Environmental – supporter's accommodations, behaviour (ABA learning), social interactions and contributing to others' well-being

Sensory integration and processing

Human energy system – building, balancing and protecting from wireless radiation and electromagnetic fields (EMF)

Brain development, coherence balancing and inflammation regulation

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To Consistently Deliver Optimal Support – The Supporter Needs Three Key Professional and Intrapersonal Qualities





Supporter's Optimal Solutions: Screening for Sensory Irregularities

- 1. Use the following tool to screen each PwDD to determine if an occupational therapist should assess the needs for a sensory-integration treatment plan.
- 2. List the activities that are highly preferred and help the PwDD do these activities on a near-daily basis.
- 3. List the activities that are strongly resisted and, as much as possible, eliminate these concerns.
- 4. Follow the occupational therapists' recommendations as much as possible each day.

Use the following tool to screen for sensory issues and then if appropriate engage an occupational therapist for assessment and treatment.

Rating: 1 not applicable/seldom

2

3 several times per week

4

5 nearly daily

Things to consider as you make your rating:

- Everyone has some sensory integration problems now and then, because no one is well regulated all the time. All kinds of stimuli can temporarily disrupt normal functioning of the brain, either by overloading it with, or by depriving it of, sensory stimulation. Screen for trends
- Gut health is an extremely important consideration for sensory integration. Poor GI function limits production of necessary neurotransmitters required to interpret and regulate sensory messages. Regulation often requires improved GI, bowel and digestive symptoms management.
- Once the screening indicates some concerns (e.g. two to three items at ratings of three and above), a qualified occupational therapist should be retained to assess, develop a plan and train supporters to implement the plan.

Signs of Tactile Dysfunction:

The tactile sense is the input received from the skin receptors about touch, pressure, temperature, pain, and movement of the hairs on the skin.

Hypersensitivity to Touch (tactile defensiveness)

- becomes fearful, anxious or aggressive with unexpected touch
- appears fearful of, or avoids standing in close proximity to other people or peers (especially in lines)
- becomes frightened when touched from behind or by someone/something they cannot see
- bothered by rough bed sheets (i.e. if old and "bumpy")
- avoids group situations for fear of the unexpected touch
- resists friendly or affectionate touch from anyone besides parents or siblings (and sometimes them too!)
- may overreact to minor cuts, scrapes and or bug bites
- avoids touching certain textures of material (blankets, rugs, stuffed animals)
- refuses to wear new or stiff clothes, clothes with rough textures, turtlenecks, jeans, hats, or belts, etc.
- avoids/dislikes/aversive to "messy play", i.e. sand, mud, water, glue, glitter, playdoh, slime, shaving cream/funny foam etc.
- will be distressed by dirty hands and want to wipe or wash them frequently
- excessively ticklish
- distressed by seams in socks and may refuse to wear them
- resists brushing teeth and is extremely fearful of the dentist
- can be a picky eater, only eating certain tastes and textures; mixed textures tend to be avoided as well as hot or cold foods; resists trying new foods
- may refuse to walk barefoot on grass or sand
- may walk on toes only

Hyposensitivity to Touch (under-responsive):

- may crave touch, needs to firmly touch everything and everyone
- is not aware of being touched/bumped unless done with extreme force or intensity
- is not bothered by injuries, like cuts and bruises, and shows no distress with shots (may even say they love getting shots!)
- may not be aware that hands or face are dirty or feel his/her nose running
- may be self-abusive; inching, biting, or banging his/her own head
- mouths objects excessively
- repeatedly touches surfaces or objects that are soothing (i.e. blanket)
- seeks out surfaces and textures that provide strong tactile feedback
- thoroughly enjoys and seeks out messy activities
- craves vibrating or strong sensory input
- has a preference and craving for excessively spicy, sweet, sour, or salty foods

Signs of Vestibular/Balance Dysfunction:

The balance sense provides input from the inner ear about equilibrium, gravitational changes, and movement experiences.

Hypersensitivity to Movement (over-responsive):

- climbs stairs one at a time
- avoids/dislikes playground equipment; i.e. swings, ladders, slides, or merry-go-rounds
- prefers sedentary tasks, moves slowly and cautiously, avoids taking risks, and may appear "wimpy"
- avoids/dislikes elevators and escalators; may prefer sitting while they are on them or, actually get motion sickness from them
- may physically cling to an adult they trust
- may appear terrified of falling even when there is no real risk of it
- afraid of heights, even the height of a curb or step
- fearful of feet leaving the ground
- fearful of going up or down stairs or walking on uneven surfaces
- afraid of being tipped upside down, sideways or backwards; will strongly resist getting hair washed over the sink
- startles if someone else moves them; i.e. pushing his/her chair closer to the table
- may be fearful of and have difficulty riding a bike, jumping, hopping, or balancing on one foot (especially if eyes are closed)
- loses balance easily and may appear clumsy
- fearful of activities which require good balance
- avoids rapid or rotating movements

Hyposensitivity to Movement (under-responsive):

- in constant motion, can't seem to sit still
- craves fast, spinning, and/or intense movement experiences
- could spin for hours and never appear to be dizzy
- loves the fast, intense, and/or scary rides at amusement parks
- always jumping on furniture, trampolines, spinning in a swivel chair, or getting into upside down positions
- loves to swing as high as possible and for long periods of time
- is a "thrill-seeker;" dangerous at times
- always running, jumping, hopping etc. instead of walking
- rocks body, shakes leg, or head while sitting
- likes sudden or quick movements, such as, going over a big bump in the car or on a bike

Signs of Proprioceptive/Awareness of Body and Space Dysfunction:

The proprioceptive sense provides input from the muscles and joints about body position, weight, pressure, stretch, movement, and changes in position in space.

Sensory-Seeking Behaviour: (hyposensitive proprioceptive functioning):

- seeks out jumping, bumping, and crashing activities
- stomps feet when walking
- kick his/her feet on floor or chair while sitting at desk/table
- bites or sucks on fingers and/or frequently cracks his/her knuckles
- loves to be tightly wrapped in many or weighted blankets, especially at bedtime
- prefers clothes (and belts, hoods, shoelaces) to be as tight as possible
- loves/seeks out "squishing" activities
- enjoys bear hugs
- excessive banging on/with toys and objects
- loves "roughhousing" and tackling/wrestling games
- frequently falls on floor intentionally
- would jump on a trampoline for hours on end
- grinds his/her teeth throughout the day
- loves pushing/pulling/dragging objects
- loves jumping off furniture or from high places
- frequently hits, bumps or pushes other people
- chews on pens, straws, shirt sleeves etc.

Difficulty with Grading of Movement:

- misjudges how much to flex and extend muscles during tasks/activities (i.e. putting arms into sleeves or climbing)
- difficulty regulating pressure when writing/drawing; may be too light to see or so hard the tip of writing utensil breaks
- written work is messy and he/she often rips the paper when erasing
- always seems to be breaking objects and toys
- misjudges the weight of an object, such as a glass of juice, picking it up with too much force sending it flying or spilling, or with too little force and complaining about objects being too heavy
- may not understand the idea of "heavy" or "light"; would not be able to hold two objects and tell you which weighs more
- seems to do everything with too much force; i.e. walking, slamming doors, pressing things too hard, slamming objects down
- plays with animals with too much force, often hurting them

Signs of Auditory Dysfunction (no diagnosed hearing problem):

Hypersensitivity to Sounds (auditory defensiveness):

- distracted by sounds not normally noticed by others; i.e. humming of lights or refrigerators, fans, heaters, or clock ticking
- fearful of the sound of a flushing toilet (especially in public bathrooms), vacuum, hairdryer, squeaky shoes, or a dog barking
- startled with or distracted by loud or unexpected sounds
- bothered/distracted by background environmental sounds; i.e. lawn mowing or outside construction
- frequently asks people to be quiet; i.e. stop making noise, talking or singing
- runs away, cries and/or covers ears with loud or unexpected sounds
- may refuse to go to movie theaters, parades, skating rinks, musical concerts etc.
- may decide whether they like certain people by the sound of their voice

Hyposensitivity to Sounds (under-registers):

- often does not respond to verbal cues or to name being called
- appears to "make noise for noise's sake"
- loves excessively loud music or TV
- seems to have difficulty understanding or remembering what was said
- appears oblivious to certain sounds
- appears confused about where a sound is coming from
- talks self through a task, often out loud
- had little or no vocalizing or babbling as an infant
- needs directions repeated often, or will say, "What?" frequently

Signs of Oral Input Dysfunction (taste):

Hypersensitivity to Oral Input (oral defensiveness):

- picky eater, often with extreme food preferences; i.e. limited repertoire of foods, picky about brands, resistive to trying new foods or restaurants, and may not eat at other people's houses)
- may gag with textured foods
- has difficulty with sucking, chewing and swallowing; may choke or have a fear of choking
- resists/refuses/extremely fearful of going to the dentist or having dental work done
- may only eat hot or cold foods
- refuses to lick envelopes, stamps, or stickers because of their taste

- dislike or complains about toothpaste and mouthwash
- avoid seasoned, spicy, sweet, sour or salty food; prefers bland foods

Hyposensitivity to Oral Input (under-registers):

- may lick, taste, or chew on inedible objects
- prefers foods with intense flavour; i.e. excessively spicy, sweet, sour, or salty
- frequently chews on hair, shirt, or fingers
- acts as if all foods taste the same
- can never get enough condiments or seasonings on his/her food
- loves vibrating toothbrushes and even trips to the dentist

Signs of Olfactory Dysfunction (Smells):

Hypersensitivity to Smells (over-responsive):

- reacts negatively to, or dislikes smells which do not usually bother, or get noticed, by other people
- tells other people (or talks about) how bad or funny they smell
- refuses to eat certain foods because of their smell
- offended and/or nauseated by bathroom odours or personal hygiene smells
- bothered/irritated by smell of perfume or cologne
- bothered by household or cooking smells
- decides whether he/she likes someone or some place by the way it smells

Hyposensitivity to Smells (under-responsive):

- has difficulty discriminating unpleasant odours
- may drink or eat things that are poisonous because they do not notice the noxious smell
- unable to identify smells from scratch 'n sniff stickers
- does not notice odours that others usually complain about
- fails to notice or ignores unpleasant odours
- makes excessive use of smelling when introduced to objects, people, or places
- uses smell to interact with objects

Signs of Visual Input Dysfunction (no diagnosed visual deficit):

Hypersensitivity to Visual Input (over-responsiveness):

- sensitive to bright lights; will squint, cover eyes, cry and/or get headaches from the light
- has difficulty keeping eyes focused on task/activity he/she is working on for an appropriate amount of time

- easily distracted by other visual stimuli in the room; i.e. movement, decorations, toys, windows, doorways etc.
- has difficulty in bright colourful rooms or a dimly lit room
- rubs his/her eyes, has watery eyes or gets headaches after reading or watching TV
- avoids eye contact
- enjoys playing in the dark

Hyposensitivity to Visual Input (under-responsive or difficulty with tracking, discrimination or perception):

- has difficulty telling the difference between similar printed letters or figures; for example, p and q, b and d, + and x, or square and rectangle
- has a hard time seeing the "big picture"; focuses on the details or patterns within the picture
- has difficulty locating items among other items; i.e. papers on a desk, clothes in a drawer, items on a grocery shelf, or toys in a bin/toy box
- often loses place when copying from a book or the chalkboard
- difficulty controlling eye movement to track and follow moving objects
- has difficulty telling the difference between different colours, shapes, and sizes
- often loses his/her place while reading or doing math problems
- makes reversals in words or letters when copying, or reads words backwards; for example, "was for "saw" and "no" for "on" (after first grade)
- complains about "seeing double"
- difficulty finding differences in pictures, words, symbols, or objects
- difficulty with consistent spacing and size of letters during writing and/or lining up numbers in math problems
- difficulty with jigsaw puzzles, copying shapes, and/or cutting/tracing along a line
- tends to write at a slant (up or down hill) on a page
- confuse left and right
- difficulty judging spatial relationships in the environment; bumps into objects/people or missteps on curbs and stairs

Internal Regulation (the interoceptive sense):

- becoming too hot or too cold sooner than others in the same environments; may not appear to ever get cold/hot, may not be able to maintain body temperature effectively
- difficulty in extreme temperatures or going from one extreme to another (i.e. winter, summer, going from air conditioning to outside heat, a heated house to the cold outside)
- respiration that is too fast, too slow, or cannot switch from one to the other easily as the body demands an appropriate respiratory response (heart rate variability (HRV)

- heart rate that speeds up or slows down too fast or too slow based on the demands imposed on it (HRV)
- narrow range of heartrate variability, e.g. high resting, low when exerted
- respiration and heart rate that takes longer than what is expected to slow down during or after exertion or fear (HRV)
- severe and frequent mood swings throughout the day (angry to happy in short periods of time, perhaps without visible cause)
- unpredictable state of arousal or inability to control arousal level (hyper to lethargic, quickly vacillating between the two; over-stimulated to under-stimulated, within hours or days, depending on activity and setting, etc.)
- frequent constipation or diarrhea, or mixed during the same day or over a few days
- does not seem to know when he/she has to go to the bathroom (cannot feel the necessary sensation that bowel or bladder are full)
- unable to regulate thirst; always thirsty, never thirst, or oscillates back and forth
- unable to regulate hunger; eats all the time, won't eat at all, unable to feel full/hungry
- unable to regulate appetite; has little-to-no appetite and/or will be "starving" one minute, then full two bites later, then back to hungry again (prone to eating disorders and/or failure to thrive)