
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)



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CCS Contributing and/or Trained Organizations & Agencies

- | | |
|--|--|
| ▪ Autism Ontario | ▪ Sunbeam Community & Developmental Services |
| ▪ Community Living Ontario | ▪ Crest Support Services |
| ▪ L'Arche Daybreak | ▪ Norfolk Association for Community Living |
| ▪ OASIS (Ontario Agencies Supporting Individuals with Special Needs) | ▪ Community Living Kincardine |
| ▪ Community Living Windsor | ▪ Durham Association for Family Respite Services |
| ▪ Community Living Cambridge | ▪ Christian Horizons |
| ▪ Rygiel Supports for Community Living | ▪ Community Living Burlington |
| ▪ Community Living Oakville | ▪ Parents for Community Living |
| ▪ London Health Sciences Centre | ▪ Extend-A-Family Toronto and Waterloo |
| ▪ McMaster University | ▪ Community Living Welland Pelham |
| ▪ University of Toronto | ▪ Community Living St. Marys and Area |
| ▪ Kerry's Place | ▪ Community Living Chatham-Kent |
| ▪ Ministry of Education Special Needs Division | ▪ Community Living Stratford and Area |
| ▪ Ongwanada | ▪ Windsor-Essex Family Network |
| | ▪ Community Living Prince Edward |

Quotes by Shinzen Young - Harvard Medical School Researcher From the Foreword of The Conscious Care & Support Book



"The Practical Tools and the 5 Essential Mindfulness Based Human Competencies that Peter has developed are examples of an excellent blending of Science and Heart. The results are improved levels of compassionate services while offering best practices."



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Conscious Care and Support First Principles



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



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Facts About Autism and Other Developmental Disabilities



*The American Academy of Pediatrics
dedicated to the health of all children.*

"Autism behaviours have been adopted as unofficial criteria in the assessment of Autism, but there is no evidence 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.

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Autism Study Finds High Rates of Unmet Healthcare Needs; Suggests Public Policy Solutions

Complex Healthcare Needs

According to the national survey, 93 percent of children with autism have one or more co-occurring health conditions. This finding is backed by considerable research associating autism with high rates of many medical and mental health issues, including seizures (epilepsy), digestive disorders, disrupted sleep, anxiety and depression, among others.

See "Autism and Health: A special report by Autism Speaks", 2017



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Dr. Theresa Hamlin, Associate Executive Director at The Center for Discovery

It's well documented, but not well understood that people with Autism suffer from a whole host of chronic problems such as:

- brain and body inflammation
- gastrointestinal and metabolic problems
- seizures
- sleep problems
- high levels of chronic stress and anxiety
- general dysregulation of the emotional and psychological body systems
- immune and autoimmune problems

e.g. Harvard study examining medical problems occurring in 14,000 individuals with Autism (Kohane et al. 2012)



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The Kilee Patchell-Evans Autism Research Group, University of Western Ontario

Collectively, this suggests alterations in gut function, energy production and the immune system, a variety of environmental factors, possibly stemming from chemicals produced by gut bacteria, that may contribute to Autism associated behaviour.

It appears that these biological compounds, largely stemming from the digestive track but also present in diet, are, either directly or indirectly altering brain function at a variety of levels.

This has profound implications in identification prevention and treatment (of people with developmental disabilities).



Associated Medical & Mental Health Conditions

Children with autism are nearly eight times more likely to suffer from one or more chronic gastrointestinal disorders than are other children.

Autism and Sensory Processing Disorders

Recent estimates of the prevalence of the symptoms of sensory processing disorder of people with Autism range from 69% – 93% in children and adults (Baranek et al., 2006; Billstedt et al., 2007; Klintwall et al., 2011; Leekam et al., 2007) and were recently added as a diagnostic criteria of ASD in the diagnostic and statistical manual of mental health disorders (American Psychiatric Association) 2013.

Dr. Theresa Hamlin,

Associate Executive Director at The Center for Discovery (continued)

“Adrenaline (that is released when the person is stressed) causes a rapid release of glucose and fatty acids into the blood stream, causing our senses to become keener and less sensitive to pain and muscles to become activated. When all of this occurs together we are in metabolic overdrive.”

- Chronic stress causing increased activation of cortisol in the body and brain can be a major problem. Particularly susceptible to damage from cortisol is the hippocampus that is critical for learning and memory.



Dr. Martha Herbert,

Assistant Professor of Neurology at Harvard Medical School and Pediatric Neurologist at Massachusetts General Hospital

"Over time I gathered more and more evidence to support the idea that Autism is not about having a 'broken brain' but about having a brain that is having a hard time regulating its self."

So what kind of things can dysregulate a brain?

- insomnia
- pesticides and fumes from automobiles or household chemicals
- poor nutrition e.g. low zinc or magnesium or other vital nutrients
- too much sugar or additives or other junk
- gut inflammation and irritability that can not absorb nutrients well
- EMFs/RFs that degrade optimal chemical/electrical functions thereby detuning our brains and nervous system



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Associated Medical & Mental Health Conditions

- Autism can affect the whole body.
- Attention Deficient Hyperactivity Disorder (ADHD) affects an estimated 30 to 61 percent of children with autism.
- More than half of children with autism have one or more chronic sleep problems.
- Anxiety disorders affect an estimated 11 to 40 percent of children and teens on the autism spectrum.
- Depression affects an estimated 7% of children and 26% of adults with autism.
- As many as one-third of people with autism have epilepsy (seizure disorder).



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Ontario Association for Behaviour Analysis (ONTABA)

CCC acknowledges ONTABA as an important contributor to the objectives of Conscious Care & Support. In January 2019 the following vitally important study was published by (ONTABA).

Evidence-Based Practices for the Treatment of Challenging Behaviour in Intellectual and Developmental Disabilities: Recommendations for Caregivers, Practitioners, and Policy Makers – Report of The Ontario Scientific Expert Task Force for The Treatment of Challenging Behaviour.



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Scientific Expert Task Force Report - Quotations

"All individuals who engage in challenging behaviour should receive a medical assessment to rule out the possibility that the behaviour is occurring due to an underlying medical condition."

"The Canadian Consensus Guidelines (CCG) for the Primary Care of Adults with Intellectual and Developmental Disabilities (Sullivan et al., 2018) provide a comprehensive set of recommendations." (Reference The College of Family Physicians of Canada)

"These guidelines also identify a number of common medical issues that may contribute to the onset of challenging behaviour."



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Scientific Expert Task Force Report – Quotations continued

“If medical concerns have been ruled out as a cause for challenging behaviour, subsequent assessment strategies should be employed.”

– Reference page 20.

“The bio-behavioural model of challenging behaviour indicates that both biological and environmental factors must be considered during assessment and addressed in treatment.”

– Reference page 6.

Behaviour Analyst Certification Board (BACB) Standards

BACB 2019, 3.02:

“Behaviour analysts recommend seeking a medical consultation if there is any reasonable possibility that a referred behaviour is influenced by medical or biological variables.”

Anxiety and Pain → Aggression → Calm

- Unmet regulation needs result in physical and emotional pain e.g. anxiety and stress.
- This often results in cycles of increased frequency and intensity of chronic and acute self injurious behaviours and aggressions.
- This is very often because the behaviours reduce the person's feelings of anxiety.
- This eventually results in temporary calm.



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

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

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

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Anxiety is Counterproductive

Support interventions that increase anxiety and stress are counterproductive and often increase challenging behaviours and the eventual compromise of the sympathetic nervous system's regulation.

"For us to live our life to the fullest, we must prevent and better manage our fears."

Temple Grandin



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Behavioural Interventions Are Often Necessary

- Behavioural interventions such as ABA and IBI that follow the Behaviour Analyst Board Standards for Certification are useful and often necessary complements to the fully integrated biomedical support and supporter development process.
- The more complete the integrated process, the greater the potential for ABA/IBI to enhance well-being and prevent and manage anxiety and aggression.



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From 0-60 mph in Seconds?

"Individuals with Autism live in a challenging state of hyperarousal. Many live in pre-panic states day in and day out."

"Anger can be a strangely soothing emotion – Rage is organizing: When we have worked ourselves up into a fury, we are completely focused, involved and unified....."

(Our fear is replaced by anger – a much more 'user friendly' emotion).

Shadow Syndrome

John Ratey M.D.

Associate Clinical Professor, Harvard Medical School

Author and Co-author of 8 Books

Over 60 Peer Reviewed Papers

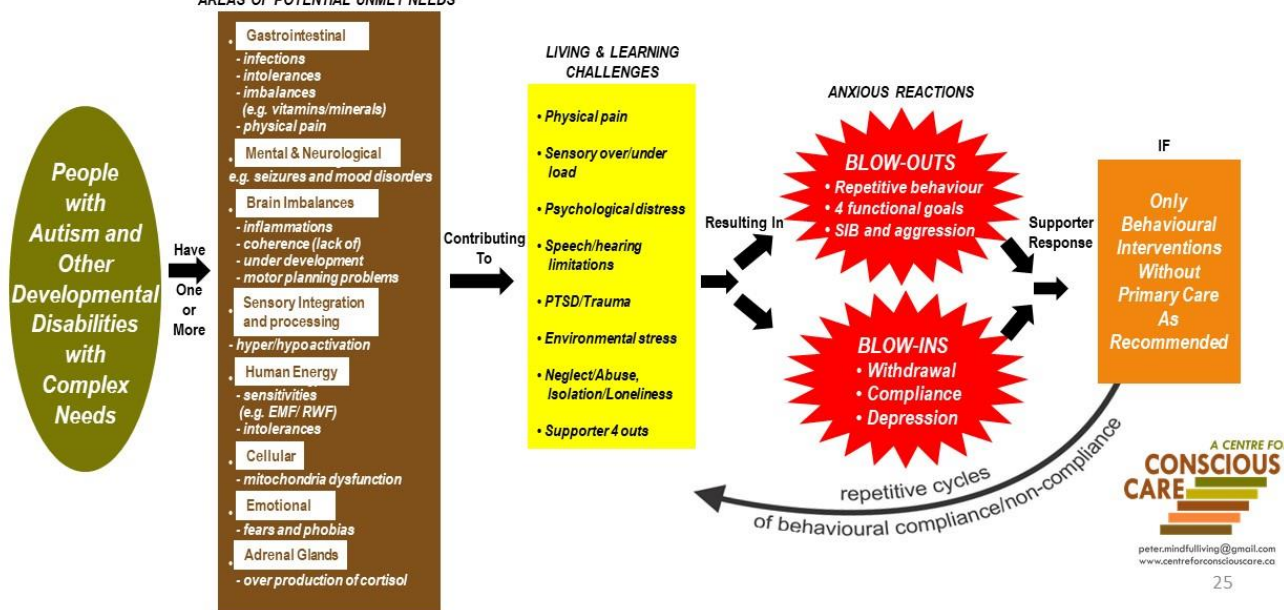


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The Recurring Cycles of Behaviour to Compliance to Behaviour

CO-OCCURRING CONDITIONS AND AREAS OF POTENTIAL UNMET NEEDS



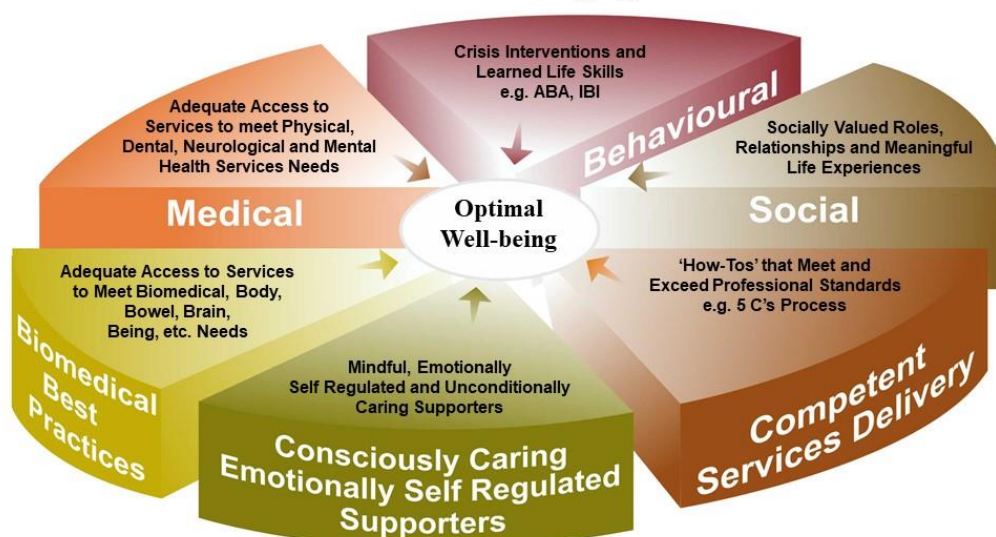
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“A counterfeit peace exists when people supported are pacified, distracted, frightened or so tired of fighting that all appears to others to be calm.”

(Adapted from Claiborne, Wilson-Hartgrove & Okoro. (2012). *Common Prayer, A Liturgy for Ordinary Rascals.*)

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 MCCSS current 'must use' crisis protocols alone.

Breaking the Recurring Cycles of Behaviour to Compliance to Behaviour

CO-OCCURRING CONDITIONS AND AREAS OF POTENTIAL UNMET NEEDS

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



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

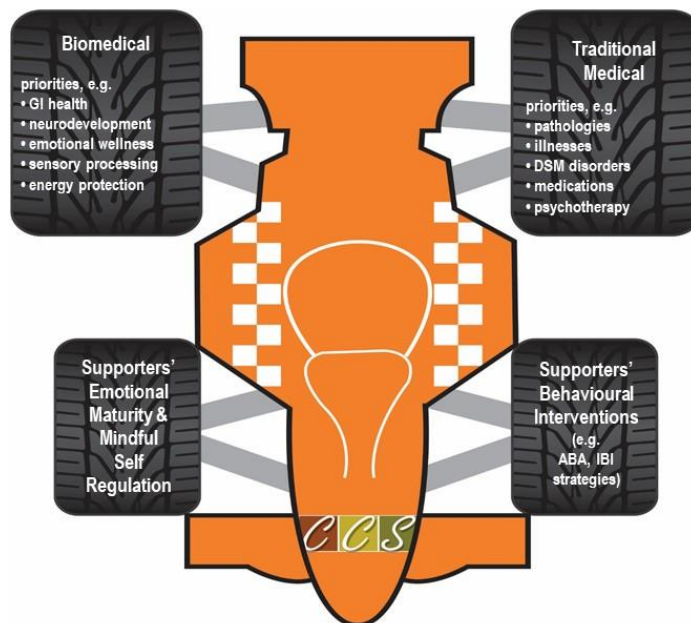
BETTER AND BETTER
OPTIMAL LIVING
CONDITIONS

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

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Comprehensive Anxiety Reduction



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CCS Well-being Facilitation Plan

Reference Session I – Resource 2

CCS Hierarchy of Service Needs

Toward A More Complete Understanding

of the hierarchy of special needs to meet
in order to facilitate optimal well-being
and to prevent and mindfully manage
anxiety, anger and aggression



Examples of CCS Tools to Enhance Self and Others' Mindful Emotional Self Regulation

- B-FIT Mindfulness (the essential tool to initiate Conscious Care and Support)
- Calming others by calming oneself – emotional contagion and mirror neurons e.g. Pain Empathy
- Bilateral, Biomeridian Awareness Based Calming (BB-ABC) e.g. Rocking and 15 Tools

All Tools must be practised during times of calm.

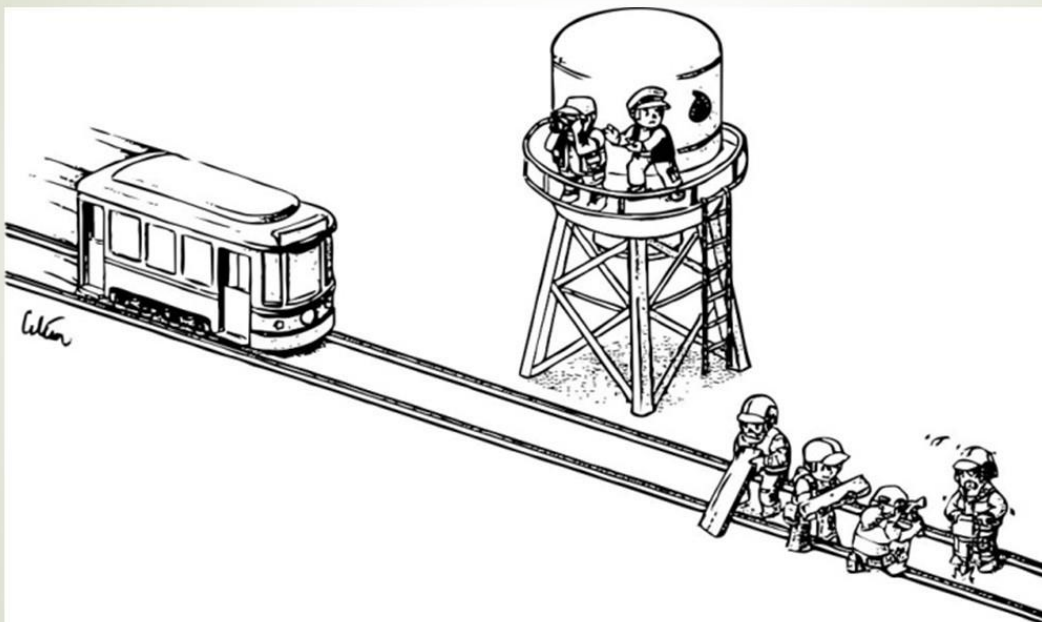
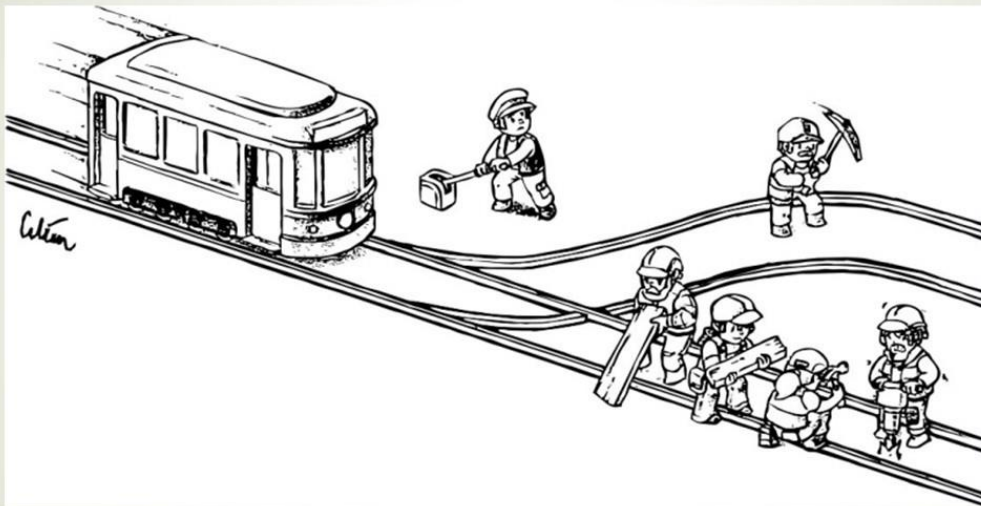


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Mindfulness Benefits for Individuals with Developmental Disabilities

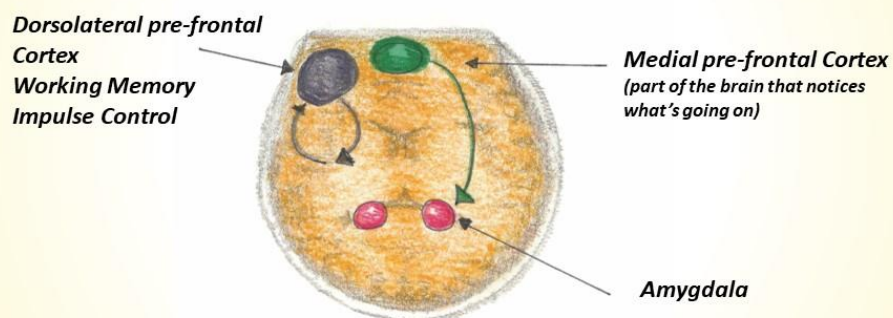


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Mindful Emotional Self Regulation

The main way we can consciously access the emotional brain is through self awareness*, i.e. becoming mindful. Mindfulness increases connections in the medial pre-frontal cortex. This reduces anxiety for the Supporter and the Person Supported.



(*Research reference: J. LeDoux, "Emotion Circuits in the Brain", Journal of Neuroscience 33, no. 9 (2013) 3815-23)

According to many published Neuroscientists, including Dr. Daniel Siegel (UCLA) in his book called **The Mindful Brain** (page 42 and 43) the following brain, body and being functions correlate with the activity of medial areas of the prefrontal cortex:

1. **Body regulation** – the emotional brakes and accelerator functions.
2. **Attuned communication** involves the coordination of the input from another person with the activity of one's own (as with mirror neurons).
3. **Emotional balance** to have enough activation so that life has meaning and vitality but not so much that life becomes chaotic.
4. **Response flexibility** is the capacity to pause before action.
5. **Empathy** – knowing what might be going on inside someone else.
6. **Insight or self-knowing** awareness to be able to link the past, present and future.
7. **Fear modulation** that may be carried out by the release of the inhibitory neurotransmitter GABA.
8. **Intuition** – a neural mechanism by which we process deep ways of knowing via our body i.e. 'somatic intelligence'.
9. **Morality** – taking into consideration the larger picture, to image what is best for the whole not just one's self, even when alone.

The You

Who is Listening to Me

Did Not Make the Choice

To Push or Not!

(Unless you were mindful/conscious)



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Definitions to Better Understand the 'Set-up'

Over each 24 hour period, we can be experiencing consciousness on a 1-10 continuum.

Unconscious: (1)

- like when we are asleep in our bed.

Semiconscious: (autopilot) (5)

- like how we typically drive our car, relate to people and do most 'doings'.

Fully Conscious: (self aware) (10)

- like when we are paying attention – noticing **what** we are doing e.g. how we drive when a police car is following us;
- knowing **that** we are doing it and
- knowing **how** our **body's sensations, feelings and thoughts** are reacting to what is happening.

Subconscious:

- our data bank of 'files' that we inherit and develop.



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The Role of Early Educational Interventions



Physician Handbook



Studies have shown that early intensive educational interventions result in improved outcomes for the child and family. Initial strategies may include teaching the child to notice what is going on in their environment, to be able to pay attention.

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CCS Hierarchy of Service Needs

Toward A More Complete Understanding

of the hierarchy of special needs to meet in order to facilitate optimal well-being and to prevent and mindfully manage anxiety, anger and aggression

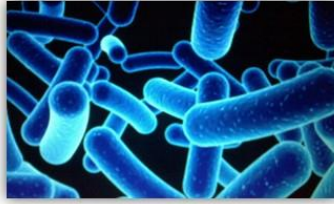


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Needs for GI and Bowel Management and Holistic Treatment

- 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

(Reference: Dr. Derrick MacFabe, The University of Western Ontario)
(Young, E. - *I Contain Multitudes*, pages 69 & 70)

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 challenging behaviour.

CCS GI and Bowel Management and Holistic Treatments

Engage a qualified holistic GI specialist, e.g. qualified and available 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



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Dental and Myofunctional Needs

10 Observations to Identify Oral Health Problems that Could be Causing Pain and therefore Challenging Behaviours (reference OHTH*)

1. Noticed any changes in their eating and/or drinking?
2. Noticed any changes in their behaviour - more aggressive to themselves or others, more excited or more withdrawn?
3. Noticed any changes in their sleeping pattern?
4. Noticed an increase in teeth grinding, clenching or drooling?
5. Are they recently avoiding daily oral care?
6. Noticed any facial swelling or redness on one side, possibly with a fever?
7. Are their lips apart at rest and/or snoring at night?
8. Do they have really bad breath?
9. Look in the mouth: Red inflamed gums that bleed on looking or touching with a toothbrush, broken teeth, holes in teeth, pimples/boils/ swellings on the gums?
10. Need for more medications such as PRN medications for pain or behaviour?



Website: www.ohth.ca



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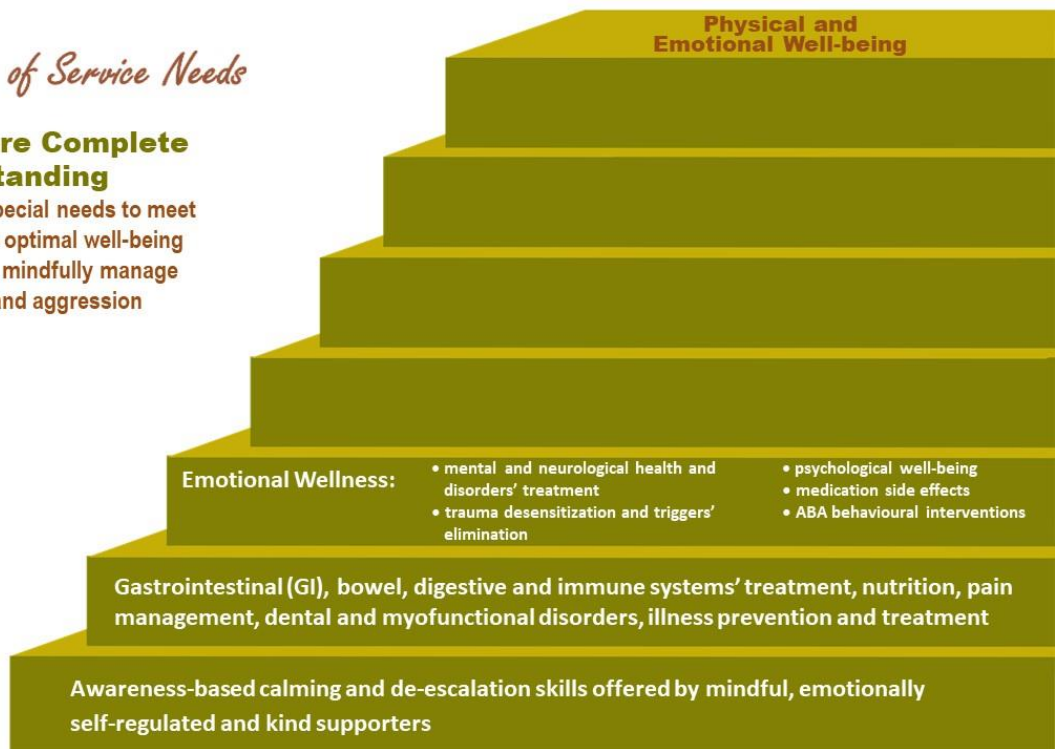
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Mental and Neurological Health

- Ensure accurate tracking of symptoms and report to the Primary Care Physician.
- Behaviour check lists must be an accurate reflection of the supported person's behaviour – not contaminated with the supporter's inadvertent 'Challenging Behaviour'



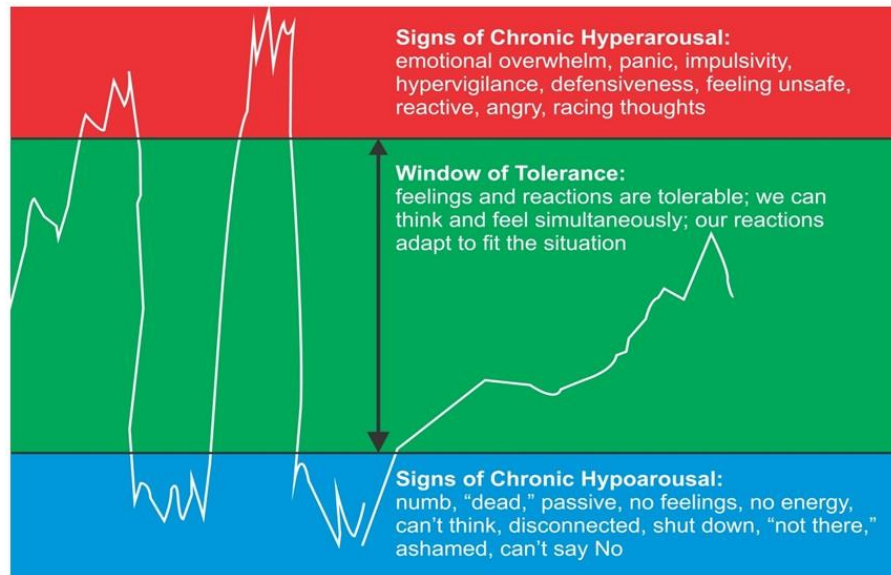
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Mental and Neurological Health

- **Benefits and Risks of Psychotropic Medications:**
 - Anti-psychotics
 - Anti-anxiety
 - Anti-depressants
- **Questions for the Primary Care Physician:**
 - How will we know that it is effective and helpful?
 - What will we observe if there are unacceptable side effects or risks e.g. Akathisia?

Trauma Closes The Window of Tolerance

After trauma, the nervous system remains prepared for danger (Ogden, Minton & Pain, 2006)



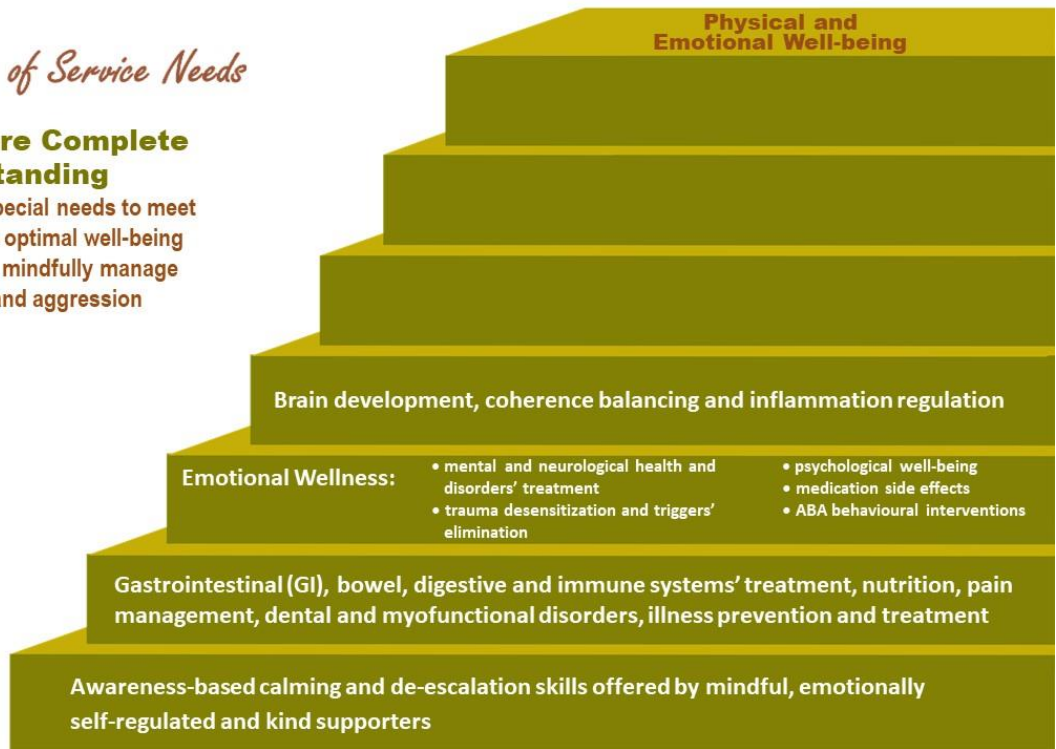
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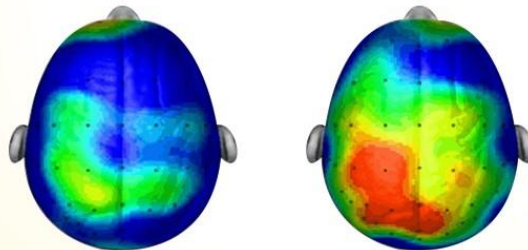


Brain Coherence

i.e. Many Parts of the Brain '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



(Brain MRIs before & after 20 minutes of exercise)



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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*

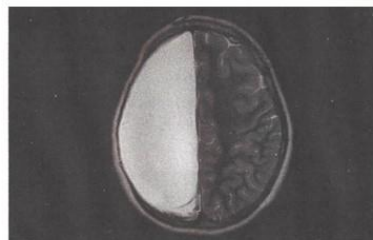


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Could This Indicate Potential for Well-being for People Supported?

In 2007, Neurosurgeons removed half of Cameron Mott's Brain

In this scan of Cameron's brain, the blank space is where half of her brain has been removed.



The Results:

Aside from some weakening on one side of her body, she is indistinguishable from her classmates. She is a good student and participates in sports.

(Reference D. Eagleman *The Brain*)



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Neuroscience and Gastrointestinal (GI) Research Conclusions

1. No evidence to suggest that the Brain and GI of people supported cannot heal, grow and develop.
2. Evidence that the Brain and GI can heal, grow and develop with appropriate (CCS type) training and conditions.

(Reference Bibliography)



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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



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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.



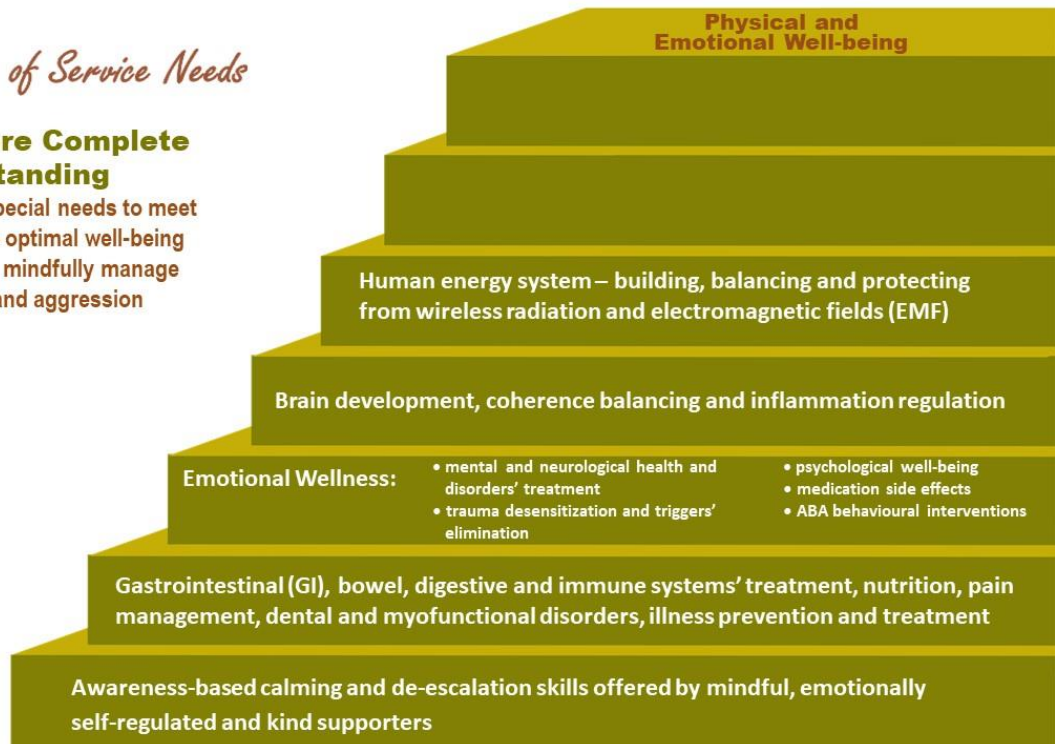


stabilization balls
and elliptical stabilization cushions

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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.

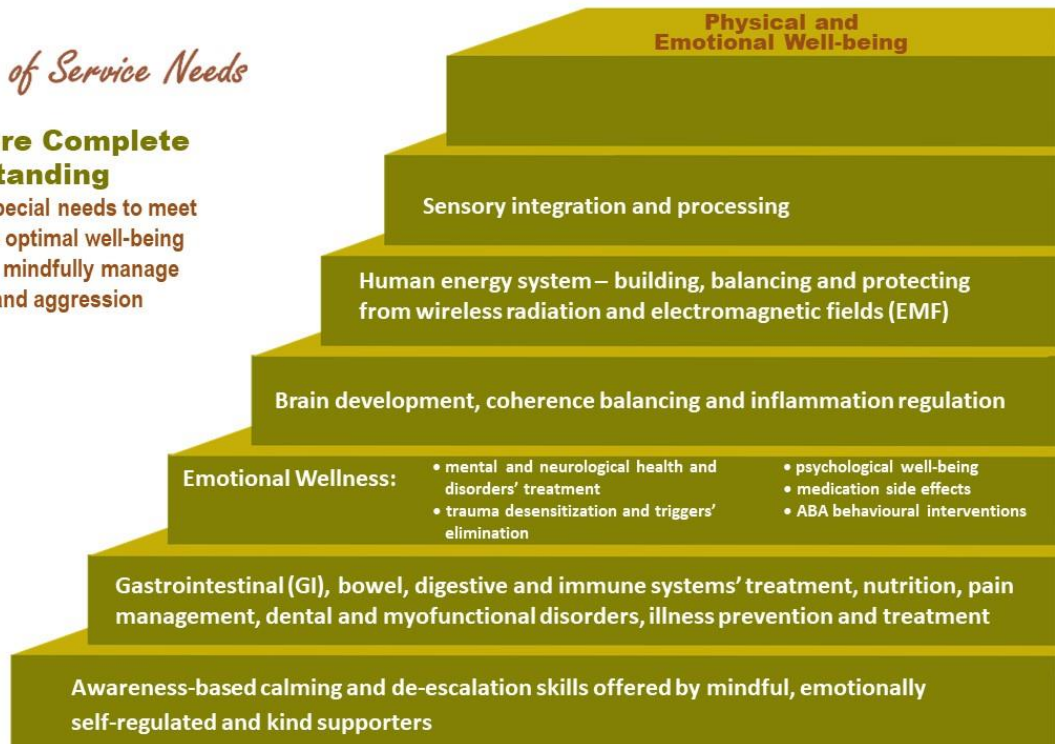


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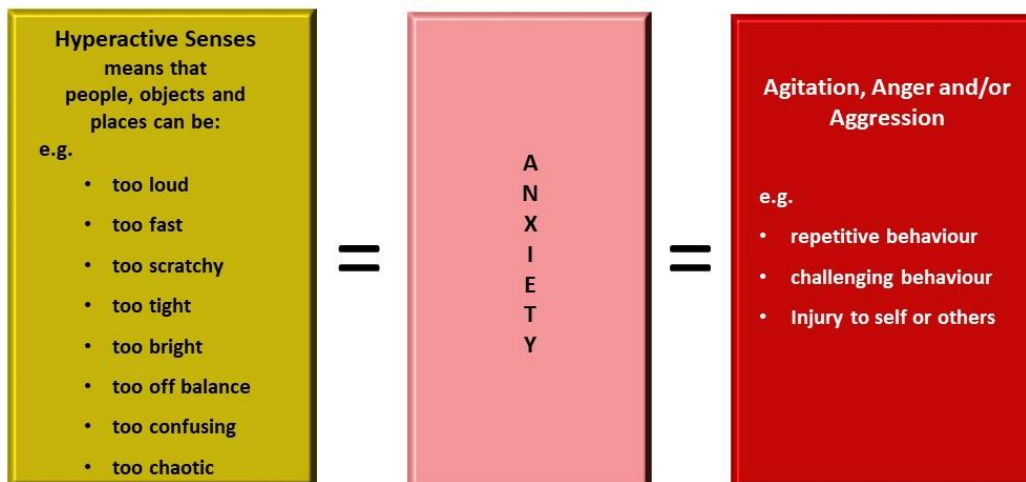
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Filling the Gap – Sensory Integration and Processing:

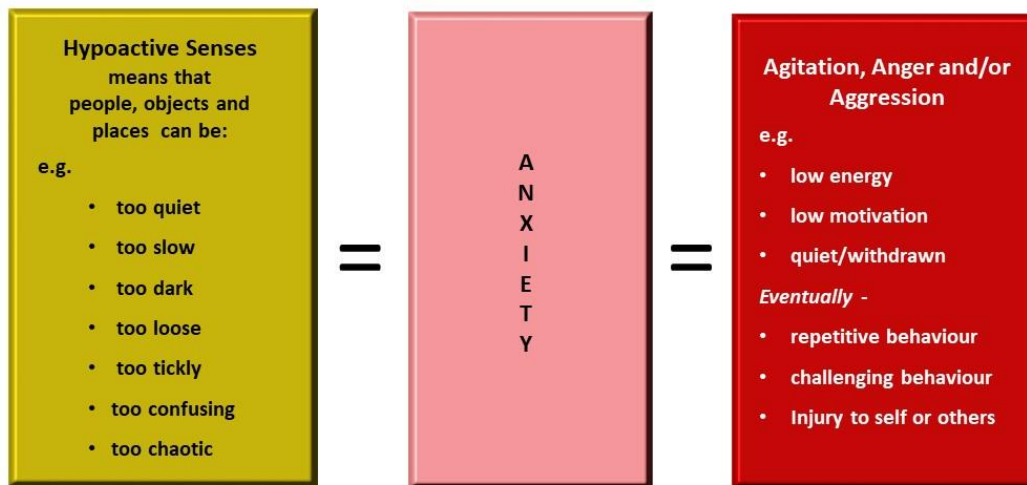
Because research indicates that there is an 80% likelihood that individuals with ASD/DD will have sensory processing and integration challenges that cause and/or greatly influence anxiety and for some aggression, CCS advocates for screening, assessments and treatments by qualified Occupational Therapists.

This treatment does not generally appear to be the case for many people supported throughout Ontario.

Hyperactive Senses Lead to Challenging Behaviours



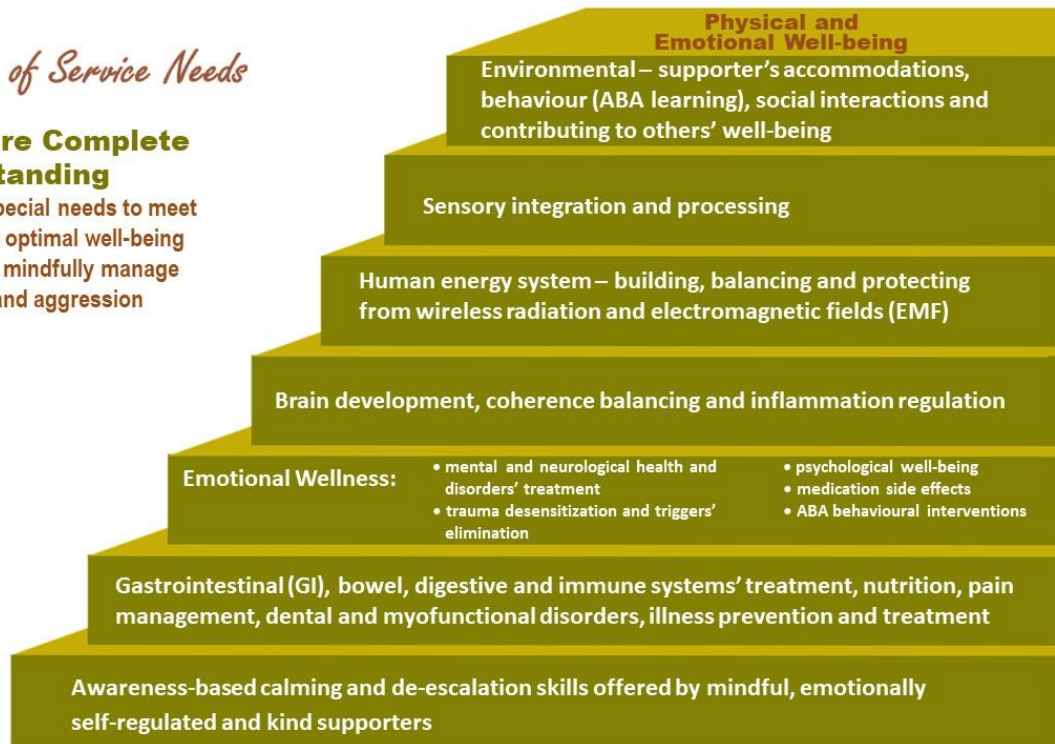
Hypoactive Senses Lead to Challenging Behaviours



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Environmental Well-being

Communications – Validate not Vet
Accommodations e.g. – Limited Choices
– Avoid 'No'

Behavioural Learning e.g. – ABA, IBI, Best Practices

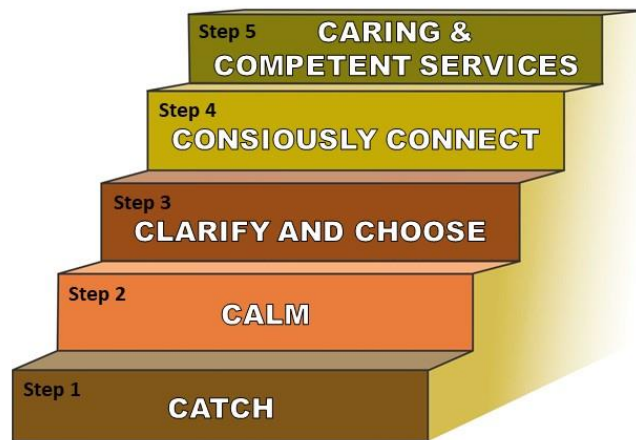
Social Interactions e.g. – “Go slow in ways I know”

Contributing to Others' Well-being e.g. – socially valued roles

Stress Inducers and Reducers

Reference CCS Textbook – Page 169 – 175

The 5 Step Conscious Care and Support Process



“My mindful words and actions are useful, truthful, timely and kind”

What My Symptoms Are Saying:

“Even though I don’t control them, most of my behavioural symptoms are messages to you. My nervous system is asking you for certain kinds of support to have its specific needs met. Please listen to what it is doing. If you don’t, I can’t stop it from becoming anxious and frightened. And the main way that it has learned to calm its fears is to get irritated, angry and even aggressive. I hate when it does that but the calm that follows my aggression makes me feel normal again. Please help me to find a better way.”

Through Substantial and Sustainable Supporters' & Leaders':

- Training in Evidence Based Best Practices;
- Development in Conscious Self-regulation;

Resulting in Competence & Commitment –

People Supported

Will

Live to Their Fullest Mind, Body and Spiritual Potential.



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