COMPLEX NEEDS SUPPORT SPECIALISTS

CNSS

Personal and Professional Development

To meet the complex needs of people supported such as:

- **S**ocial Reform
- **S**ubstances Recovery
- **S**icknesses Prevention
- **S**afety
- **S**ecurity
- **S**kills (Life)
- **S**marts
- **S**elf Development
- **S**atisfactory Life

A Centre for Conscious Care

Part 8A – Fetal Alcohol Spectrum Disorder

Fetal Alcohol Spectrum Disorder

Primary Disabilities

and

Secondary Adverse Outcomes

Primary Disabilities

- **Are defined as those disabilities that a child was born with and are a direct result of the damage done to the brain by alcohol.**

- **Two types of Primary Disabilities:**
  - **Damage to the brain**
  - **Damage to organs in the body.**

What is Fetal Alcohol Spectrum Disorder?

- FASD is a diagnostic term used to describe impacts on the brain and body of individuals prenatally exposed to alcohol.
- FASD is a lifelong disability.
- Each individual with FASD is unique and has areas of both strengths and challenges.

CanFASD July 2019

Typical Vs. FASD

TYPICAL INDIVIDUAL

INDIVIDUAL WITH FASD

Imagine going through a day:

Where it takes you 10 seconds to process what others have processed in 1 second…

Where every transition is a challenge…

Where the physical environment can overwhelm you…

Where your ability to predict is impaired…

Where your memory is impaired…

Where your ability to generalize is impaired…

How would you manage this?

FASD terms

New and old Acronyms for

Fetal Alcohol Spectrum Disorder

New Diagnostic Terms

FASD with sentinel facial features

FASD **without** sentinel facial features

At Risk for Neurodevelopmental disorder and FASD (full diagnosis cannot yet be confirmed)

Previous Diagnostic Terms

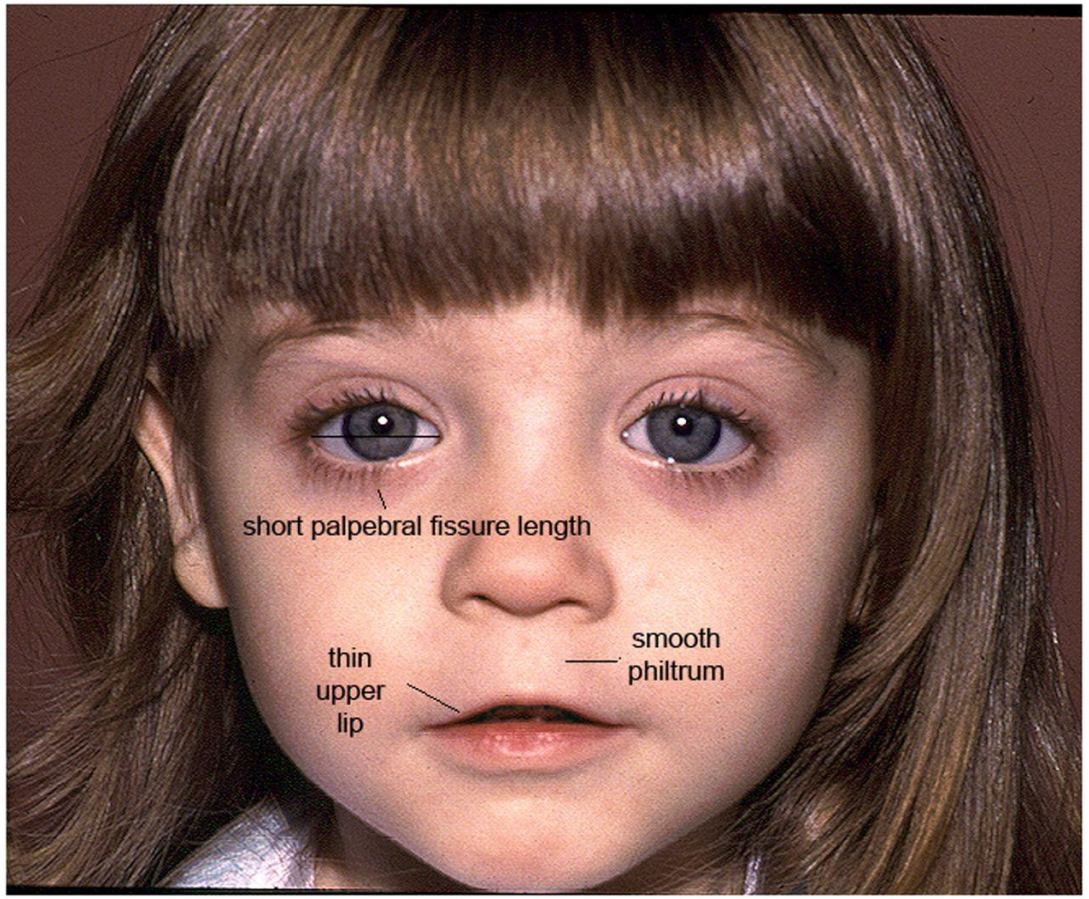
FAS: Fetal Alcohol Syndrome

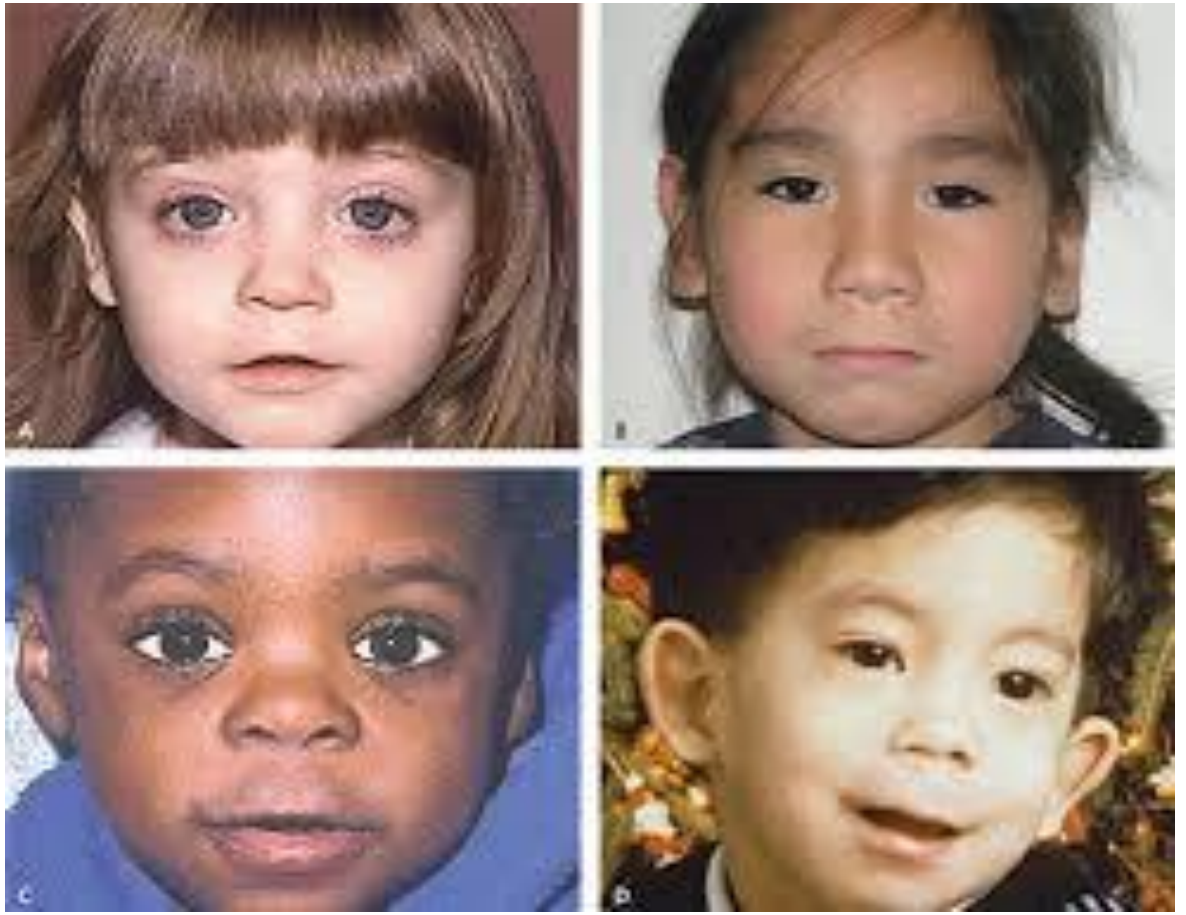
pFASD: Partial Fetal Alcohol Syndrome

ARND: Alcohol-Related Neurodevelopmental Disorder

ARBD: Alcohol-Related Birth Defects

FASD Facial Features



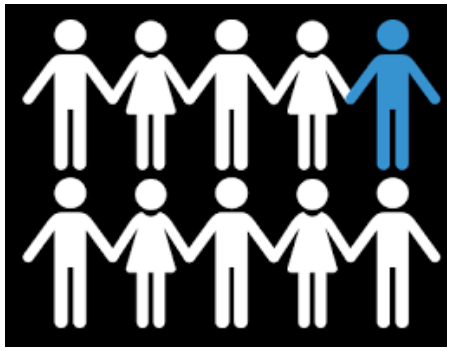


Invisibility of FASD

FASD can have three facial features:

- Small eye openings
- Flatter groove between the nose and upper lip
- Thin upper lip

Less than 1 in 10 have these facial features



IT is an INVISIBLE DISABILITY!

FASD Prevalence in Canada

Based on recent research the Canada Research Network (CanFASD) estimates the prevalence rate in Canada of FASD to be 4% (July 2018)

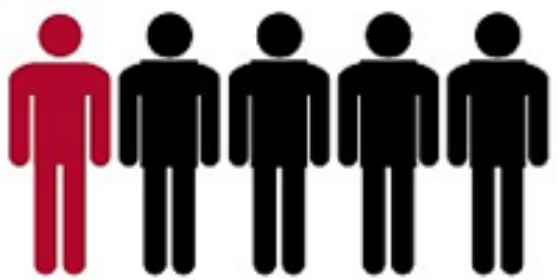
4 in 100
of the general
Canadian population.

= 1.45m
Canadians are
living with FASD

Justice FASD Prevalence

It is estimated that between
1 in 10 to 1 in 5 offenders
involved in the Justice system have FASD

TO



CanFASD August 2018

Types of Justice Involvement

- Risk of harm to themselves
- Verbal and Physical aggression
- Sexualized behaviours
- Excessive substance use
- Property damage
- Shoplifting
- Break and enter
- Trespassing
- Stolen vehicles
- Victims of others
- Breaches
- Failure to appear
- Mischief

Recognizing FASD Primary Disabilities

- **Academic achievement** -may have Learning Disabilities.
- **Adaptive Behaviour and Social Skills** –can act younger than their age, have trouble making and keeping friends, do not understand personal boundaries, problems with personal hygiene.
- **Affect Regulation** – struggle to regulate their emotions.
- **Attention/Hyperactivity** -more impulsive-crimes are less planned.
- **Cognition** –difficulty making a plan and following it through, struggle to understand abstract concepts and another's perspective, seem to lack remorse because of problems with reasoning.

Cook, JL, et al 2015

Recognizing FASD Primary Disabilities

- **Executive Functioning Skills** -poor impulse control, difficulty with math, money, time, ownership, consequences. Struggle to understand cause and effect in a situation.
- **Language and Communication** -can come across as uncooperative when they don't understand, may not understand subtle jokes and can take things very literally.
- **Learning and Memory-encoding and working memory** -have memory gaps, have trouble retrieving information from their memory, may understand something one day and not the next.
- **Motor Skills** -trouble with coordination, balance and control.
- **Sensory Integration** -low or high pain tolerance, sensitivity to light, sound, texture and touch.

Cook, JL, et al, 2015

Recognizing FASD Adverse Outcomes as FASD Indicators

- Disrupted school experience.
- Involvement with Child Welfare.
- High risk of being neglected and abused (physically, sexually, and/or emotionally).
- Multiple Mental health comorbid diagnosis-ADHD, ODD, OCD, Anxiety, Depression, etc.
- Getting into trouble with the police.
- Homelessness-often losing accommodations or residency

Streissguth, A., et al, 2004, McLachlin, K, 2017

Recognizing FASD Adverse Outcomes as FASD Indicators

- Being confined in prison, substance use treatment centres, psychiatric treatment centres, or residential care.
- Frustration, irritability, tantrums, and acting out.
- Inappropriate sexual behaviour.
- Problems with employment.
- Substance use problems.

Streissguth, A., et al, 2004, McLachlin, K, 2017

Secondary Adverse Outcomes

- 90% experienced mental health problems
- 60% had been in trouble with the law
- 50% had experienced confinement (either inpatient treatment for alcohol and other drugs dependency or incarceration for a crime)
- 50% of the group had been reported for repeated inappropriate sexual behaviour, or referred for offender treatment
- 60% had a disrupted school experience
- 30% had experienced problematic alcohol and other drug use

FASD Handbook for Professionals; 2016

Secondary Adverse Outcomes (cont.)

Their protective reactions to frustration and continued failure:

- **Inappropriate humour**
- **Fatigue, irritability, resistance and/or argumentative behaviour**
- **Anxiety, fearfulness and/or felling chronically overwhelmed**
- **Poor self-concept, often masked by unrealistic goals**
- **Isolation, having few friends and likely experiencing bullying**
- **Family or school problems, including fighting, suspensions, etc.**
- **Running away**
- **Trouble with the law**
- **Problematic alcohol and drug use**
- **Depression, self destructive and/or suicidal behaviour**

Diane Malbin, 2005

Profile of an Individual with FASD at 18 and 25 Years

Developmental Dysmaturity

Streissguth, et al, 1994, and Malbin, 2002

Skill/Ability	Developmental Ability
Expressive Language	20 years
Physical Maturity	18 years
Reading ability	16 years
Living skills	11 years
Money and time concepts	8 years
Social Skills	7 years (6 years at age 25)
Comprehension	6 years
Emotional maturity	6 years

Intervention: Paradigm Shift

From Seeing as:	To Understanding as:
Won't	Can't
Bad	Frustrated, Challenged
Lazy	Tries hard
Lies	Confabulates/fills in
Doesn't Try	Exhausted/Can't start
Mean	Defensive and/or hurt
Doesn't Care, Shuts down	Struggles to articulate their needs/feelings
Is a problem	Has a problem
Acts immature	Is dysmature

Malbin, D, 2002

How to Think about Challenging Behaviours

- Do not assume deliberate malice
- Assume confusion, uncertainty or inability to understand expectations
- Assume distraction or forgetfulness
- Assume a learning dysfunction, lack of training, or accommodations
- Assume difficulty with exercising self-control and the need for external structure

Only when these are ruled out, should you consider the behaviour to be deliberate!

Ory, N, 2007

Useful tips for Intervention

- Ask one question and wait (allow time to process)
- Patience, allowing time to calm
- Simple language
- Think younger
- Don't personalize behaviours
- Be Concrete
- Be Consistent
- Repetition

"10 second person in a 1 second world"

Useful Tips for Intervention

- Ensure close Supervision
- Think Brain Dysfunction
- Successful Dependence
- Follow a Routine
- Provide structure
- Keep it simple
- Be specific

SUCCESS is about The ENVIRONMENT And The INDIVIDUAL

The 8 Magic Keys

Be Concrete:

- Use concrete words (“we can do that in 5 minutes” rather than “wait a minute”)
- Don’t use words with double meanings
- Think younger than their chronological age

Be Consistent:

- The fewer changes the better
- Talk the same way, give instructions the same
- Everyone in their life uses the same phrases (caregivers, teachers, coaches, etc.)

The 8 Magic Keys

Repetition:

- You need to repeat things in the same way day after day in order for it to get into long term memory
- Repeat instructions, requests or directions as necessary

Routine:

- Stable routines that do not change from day to day are best for learning and lower anxiety
- This way they know what to expect next
- The routines we set now are the routines that will be used for a long time

The 8 Magic Keys

Keep it Simple:

- Keep the environment simple to not over stimulate
- Keep the directions short and simple

Be Specific:

- Say exactly what you mean
- FASD people are not good with abstract

The 8 Magic Keys

Structure:

- Structure is very important
- Structure organizes the environment so success can happen
- They cannot figure out what comes next

Supervision:

- Appropriate supervision is required to keep them safe, and others safe

Resources
Websites for Information

Helpful Websites

CanFASD https://canfasd.ca/

FASD Ontario www.fasdon.ca

KnowFASD http://www.knowfasd.ca/

Contact Hamilton https://contacthamilton.ca

Developmental Services Ontario
http://dsohnr.ca/en/

Partners for Planning
http://www.planningnetwork.ca/en-ca

Be Safe: Have an alcohol-free pregnancy
https://www.alcoholfreepregnancy.ca/

Hamilton FASD Collaborative

Hamilton Community Agencies have been working together since 2005 to develop awareness and supports in regards to FASD.

There are currently 15 Hamilton Agencies Involved in the Collaborative. The Collaborative includes the Leadership team and the Resource Team.

Hamilton COLLABORATIVE FASD FETAL ALCOHOL SPECTRUM DISORDER

Hamilton FASD Resource Team

The Resource Team has received FASD Best Practice Training and provides the following services:

- Community FASD Education Training
- In Service FASD Training
- FASD Case Conferences

Personal and Professional Development

To meet the complex needs of people supported such as:

- **S**ocial Reform
- **S**ubstances Recovery
- **S**icknesses Prevention
- **S**afety
- **S**ecurity
- **S**kills (Life)
- **S**marts
- **S**elf Development
- **S**atisfactory Life

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Part 8B – CCS FASD Evidence Based Support Interventions

WARNING

In the Absence of Consistent Application of the Following Support Guidelines, The Following Is Highly Predicable:

- **Ongoing power struggles leading to the need to implement safety interventions.**
- **Ongoing need for safety interventions, e.g. today's physical redirect will be tomorrow's challenging behaviours.**
- **Low to no growth in the person's social independence.**

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WARNING -

continued

- **Unnecessarily high risk of incarceration (60% of people who are incarcerated have developmental disabilities).**
- **Unnecessarily high risk of being sexually trafficked / venereal disease.**
- **Unnecessarily high risk of addictions and overdose.**

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1. Build Trusting Relationships with FASD Adolescents and Adults

- Mindfully commit to build good relationships.
- Speech should be useful, truthful, kind and timely.
- Acknowledge and validate their successes.
- Acknowledge your mistakes.
- Acknowledge not knowing something.
- Follow through on commitments.
- Do not take anything personal.
- Eliminate resentments and be forgiving.
- Avoid power struggles.
- Only give ‘teaching’ consequences when the person is calm.
- Help them have wins.
- Catch them being good.

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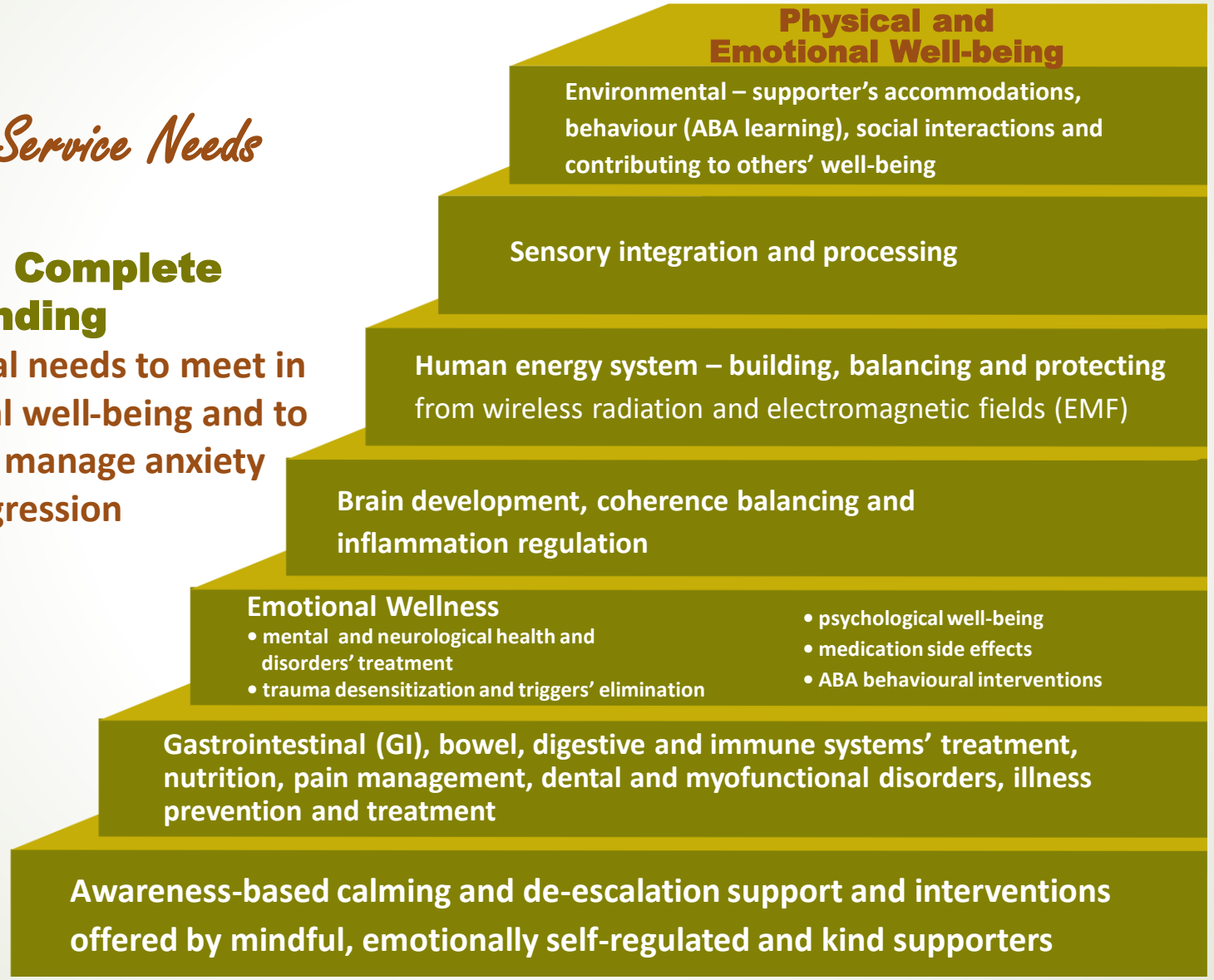
2. Assess and Treat all Hierarchy of Needs

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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3. Assess and Treat all Biomedical Comorbidities

Systems	***Examples of Potential Comorbid Variables that can Contribute to Compromised Well-Being and often Leads to Challenging Behaviours***
Gastrointestinal (GI)	• poor nutrition e.g. excessive sugar, processed food, preservatives • infections – candida and clostridium (PPA), fungi • intolerances – casein, gluten, lectins, antibiotics • digestion – e.g. constipation, diarrhea • vitamin and mineral imbalances e.g. - low magnesium, zinc, chromium, calcium - high copper, mercury, lead - low omega^3, fatty acids, vitamin A, C, D^3 • *hypoglycemia/hyperglycemia*
Immune	Immune Deficiency or Dysfunction: • hypersensitivity, e.g. over reaction to toxins • autoimmunity, e.g. inappropriate reactions to one's own cells • inflammation, e.g. too aggressive an attack against infections

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3. Assess and Treat all Biomedical Comorbidities

Systems	*Examples of Potential Comorbid Variables that can Contribute to Compromised Well-Being and often Leads to Challenging Behaviours*
Dental Myofunctional	• pain from tooth decay • bacterial infections leading to bacterial pneumonia
Emotional Wellness/Psychological	• faulty filters' activation e.g. control, entitlement • seeking attention, avoiding tasks, seeking tangibles, sensory stimulation • perceived or actual threats
Mental Health	• excessive stimulating neurotransmitters e.g. norepinephrine and glutamate from low B6, MSG, grains, dairy, processed foods etc. • low levels of calming neurotransmitters e.g. GABA, serotonin • excessive stimulating hormones e.g. cortisol • unresolved trauma and phobias • untreated or undertreated mental health disorders e.g. depression • side effects of some medications e.g. antipsychotics • chronic non-restorative sleep

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3. Assess and Treat all Biomedical Comorbidities

Systems	***Examples of Potential Comorbid Variables that can Contribute to Compromised Well-Being and often Leads to Challenging Behaviours***
Brain	• lack of brain coherence e.g. uncoordinated sensory processing • cognitive differences • under-functioning brain cerebellum • neurological disorders e.g. seizures, headaches • inflammation due in part to low levels of glutathione
Human Energy	Low Cell Energy i.e. mitochondria/methylation problems influenced by: • low B^{12}, B^{9} (folate) • low zinc, magnesium, iron • excessive sugar • excessive cortisol • oxidative stress/low GSH • chronic non-restorative sleep • low hertz (EME) • low amino acids
Sensory Integration and Processing	• hyper – too high arousal of one or more of the eight senses • hypo – too low arousal of one or more of the eight senses

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3. Assess and Treat all Biomedical Comorbidities

Systems	***Examples of Potential Comorbid Variables that can Contribute to Compromised Well-Being and often Leads to Challenging Behaviours***
Environmental and Social *(reference CCS Textbook pages 169-175)*	• supporter's anxiety and power struggles resulting from lack of mindful emotional self-regulation • feeling alone, disconnected, excluded, uncared about • environmental overwhelm e.g. noise, chaos, transitions • non-compatible social interactions e.g. introvert vs. extrovert • toxins – EMF, microwaves e.g. Wi-Fi, allergies • incomplete ABA protocols (reference 'all' ONTABA standards) • four functional goals preoccupation • no/low clear knowing of what is expected or required • change in patterns or schedules that is not adequately communicated • quick and sudden movements • slower cognitive processing (a ten-second person in a one-second world)

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4. **Teach Mindful Movement Exercises, e.g. Walking, Eating, Brain Gym**

- **Plan and complete a daily practice regime.**

- **Reference research – The Influence of Mindfulness Training on Social Functioning in Adolescents with FASD – L. Baker.**

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5. **Teach and Practise Bilateral Biomeridian Awareness Based Calming Exercises.**

- ***BB-ABC Exercise # 1: Butterfly Hug***
- ***BB-ABC Exercise # 2: Collar Bone Activation***
- ***BB-ABC Exercise # 3: Hand BB Activation by Supporter***
- ***BB-ABC Exercise #4 – Mindful Movement Awareness-Based Calming***
- ***BB-ABC Exercise #5 – Mindful Walking***

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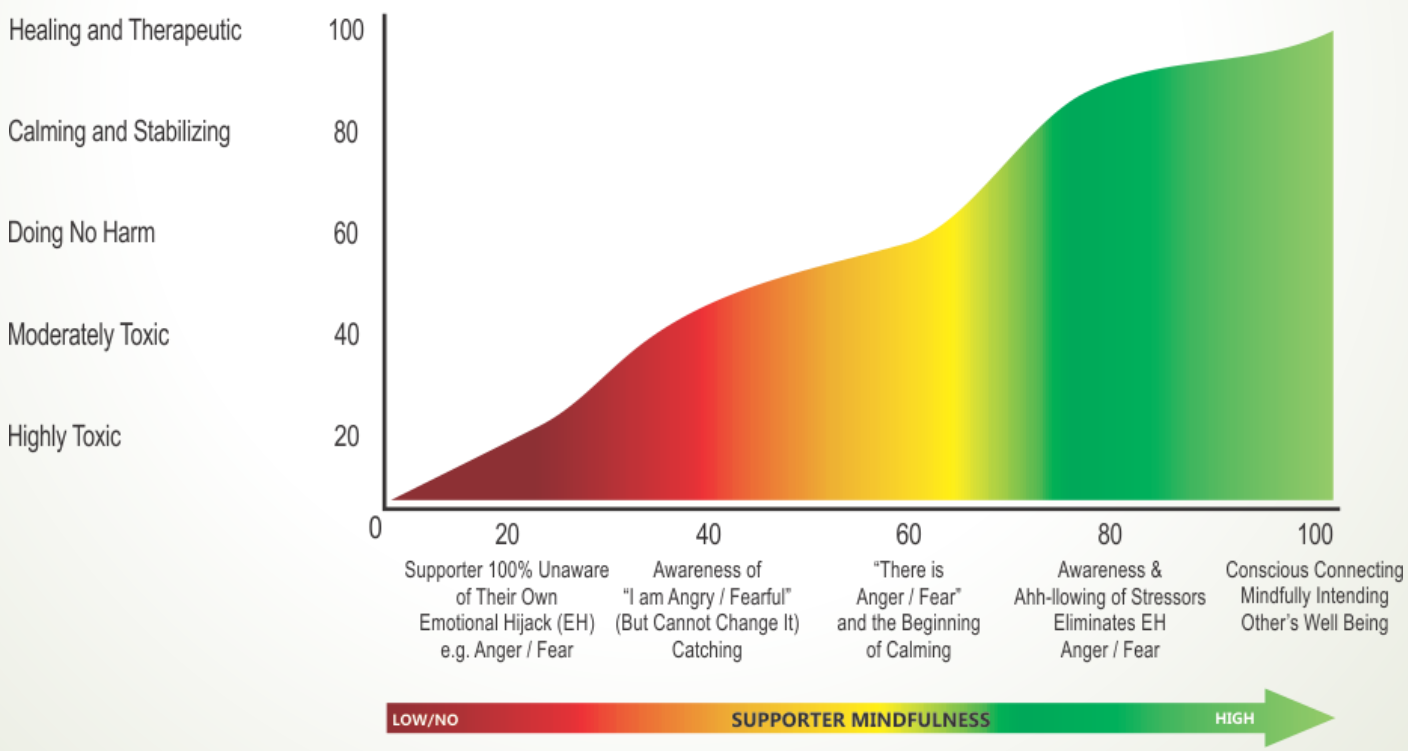
6. Mindful Emotional Self-Regulation Training for Supporters

(Reference one with one training with Peter)

Emotional Contagion/Entrainment

Calming of Challenging Behaviours



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Emotional Contagion - Continued

Approximately 50%* of all behavioural incidents appear to be caused or significantly influenced by supporters' power struggles that are unrelated to safety concerns

- **Reference: - Anecdotal Reports from approximately 3000 CCS trained supporters**
  - Review of approximately 2000 Behavioural Incident Reports

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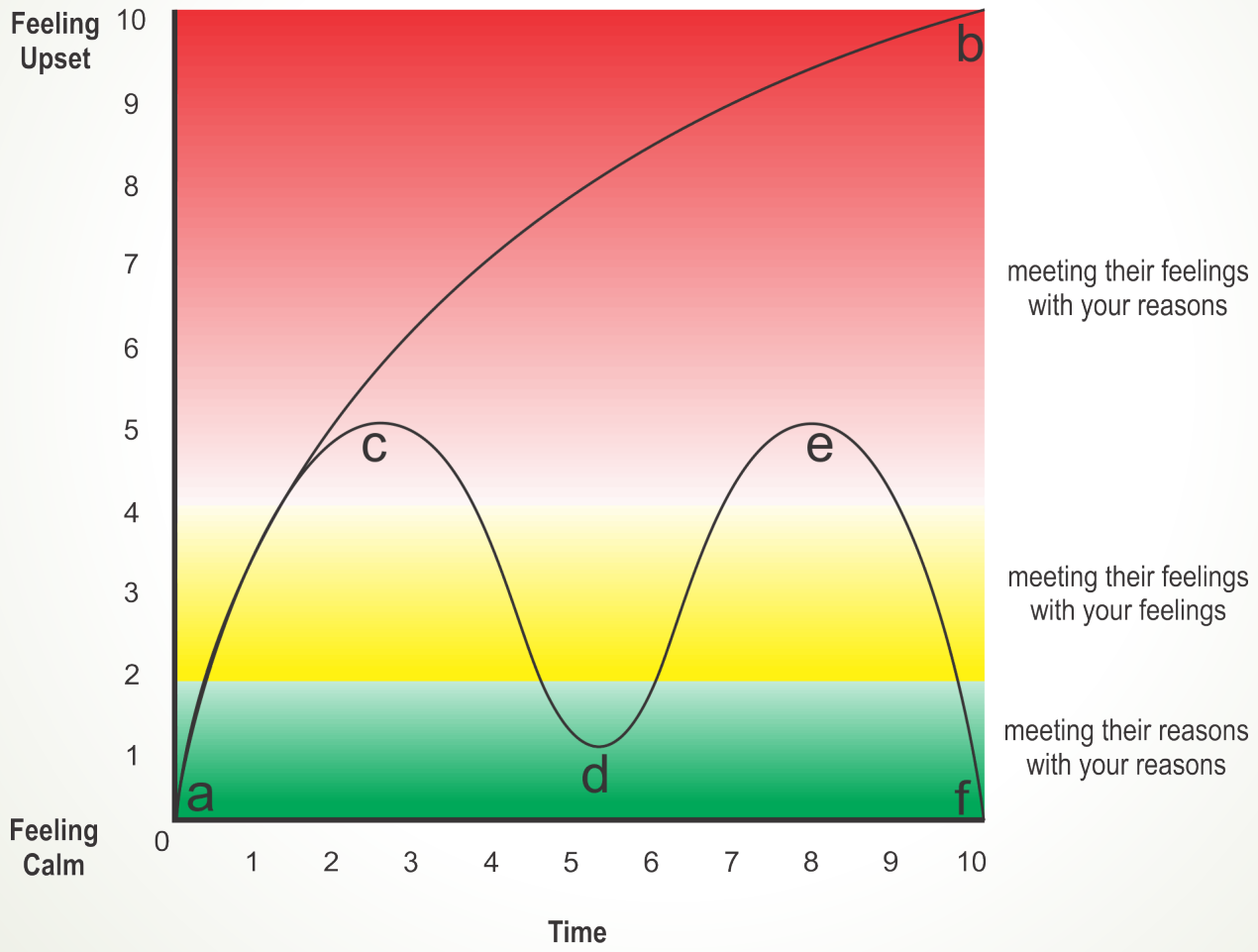
7. Feelings to Feelings and Reasons to Reasons



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8. Work to Eliminate the 3 most Prevalent Purposes and Payoffs of Behaviours of the Person with FASD

A. Need for Greater Connection, Perceived Worth and Counting for something: a Sense of Belonging with Significant Others to Avoid 'Solitary Confinement'.

Supporters' Response to Promote Socially Useful Expression

- **Give as many positive and sincere expressions of connection to the person supported as is possible e.g. "I like the way you ……."**
- **Catch them being "good": for example, "I noticed how you _____."**
- **Be authentically grateful for their contributions to others: "Thank you for _____."**
- **Explore giving them responsibility somewhat beyond their current self-perceived level of competence: for example, ask them to volunteer as part of a support team for someone who needs physical and/or social supports.**

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8. Work to Eliminate the 3 most Prevalent Purposes and Payoffs of Behaviours of the Person with FASD - continued

B. Need to Use Angry Power Struggles to Distract Themselves from Painful Emotional Upsets such as Feeling Alone, Inferior, Insecure, Excluded, Embarrassed, Fearful, Out of Control or in Physical Pain.

Supporters' Response to Promote Socially Useful Expression:

- **When times are good, lay ground rules for communications during power struggles such as when they seem to have a need to pick a fight with you. Give them "the sign" that you value them but will ignore them so as not to be a part of this negative power struggle. Refrain from eye contact and speaking to them as previously agreed upon.**

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8. Work to Eliminate the 3 most Prevalent Purposes and Payoffs of Behaviours of the Person with FASD - continued

B. Need to Use Angry Power Struggles to Distract Themselves from Painful Emotional Upsets such as Feeling Alone, Inferior, Insecure, Excluded, Embarrassed, Fearful, Out of Control or in Physical Pain.

Supporters' Response to Promote Socially Useful Expression:

- **Leave the space (if possible) after giving "the sign."**
- **Catch and Calm yourself so as not to become emotionally hijacked into a power struggle which will result in causing challenging behaviours in others.**
- **"The sign" will acknowledge their power is stronger than yours and you need to leave.**
- **Communicate feelings to feelings versus reasons to feeling (reference above).**
- **Remember, how you behave—powerfully or respectfully—teaches and then trains the person supported how to behave.**

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8. Work to Eliminate the 3 most Prevalent Purposes and Payoffs of Behaviours of the Person with FASD - continued

C. Need to Overcome Feelings of Inadequacy.

Supporters' Response to Promote Socially Useful Expression:

- **Provide adequate ratios of qualified staff.**
- **Propose a positive task and teach it by breaking it down into bite size pieces.**
- **Connect them to a positive peer.**

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8. Work to Eliminate the 3 most Prevalent Purposes and Payoffs of Behaviours of the Person with FASD - continued

C. Need to Overcome Feelings of Inadequacy.

Supporters' Response to Promote Socially Useful Expression:

- **Role model having the courage to be imperfect yourself.**
- **Recognize their achievements.**
- **Always provide choices.**
- **As appropriate during optimal teaching moments, reduce doing for individuals what they can do for themselves to avoid teaching them that they are incapable/inadequate/not enough.**

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8. Work to Eliminate the 3 most Prevalent Purposes and Payoffs of Behaviours of the Person with FASD - continued

C. Need to Overcome Feelings of Inadequacy.

Supporters' Response to Promote Socially Useful Expression:

- **When they make a mistake, DO NOT say anything that would make them feel like a failure. Say instead, "I am sorry that it didn't work out for you," and "If you could do that/say that over again – how would you do/say it?"**
- **Be encouraging: "I like the way you _____."**

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A misbehaving person

is often a

discouraged person.

Rudolf Dreikurs

In the absence of intervention plans being developed using evidence based 'complete' systems' assessments and 'comprehensive' treatments, not only will the results be relatively ineffective but symptoms will tragically intensify and prolong the person's unnecessary painful suffering, supporters' safety risks and wasted resources.

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A Most Alarming Question

IF – as is generally acknowledged by caring supporters, between 50% to 60% of all incidents of challenging behaviours are directly caused by or significantly influenced by the supporter's lack of emotional self-regulation leading to power-struggles and increased anxiety in both the supported and the supporter.

WHAT – is the likelihood then of Behaviour Support Plans and prescribed medications alone (based on recorded incidents) accurately and effectively responding to meet the treatment needs of people supported when almost half of the causes of the reported incidents have little to do with the persons supported?

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9. **Skillful Advocacy for Optimal Medication Management** ***(reference text page 51).***

- **Ask the medication manager for specific indicators that a drug trial is effective.**
- **Ask the medication manager for a tracking tool to report back on medication efficacy.**
- **Ensure medication regime is followed in accordance with the prescription.**

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10. **With the Primary Care Physician and Naturopathic Doctor, Explore Neuro Development Nutritional Treatments to Mitigate Neuro Development Dysfunction, e.g. Omega 3 Fatty Acids (Anti-inflammatory), Magnesium, Choline, Vitamin E and NAC – (Antioxidants) can improve Learning and Memory.**

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11. Transcranial Magnetic Stimulation (TCMS)

Reference Science Direct Research- Baroda

TCMS is a well tolerated neuro-modulator to enhance brain plasticity and together with Cognitive Therapy (CT), improves social functioning outcomes in people with FASD.

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