"support, kindness, collaboration - parents are partners"

"It helped to have TIME with the pediatrician."

"Doctors who smooth our way are gold"

Who I am…

- I was born in Venezuela, and lived in S America most of my childhood
- I speak Spanish and English
- I was a teacher for a few years, then became a mom, then a single mom
- I started med school at 32, have been independently practicing since 2017
- I work at:
  - My clinic, a shared practice with a family NP
  - As a qualified specialist to do autism assessments at BCAAN
  - Do sessional work through Neuropsychiatry at BCCH at the SIB Clinic
- I am a UBC Wall Scholar, where I'm spending this year looking at sustainers of health inequity

Overview

- This talk is being sponsored by Takeda
- Will likely go to 1H mark, there is too much to cover in 45minutes

- Goals
  - To understand a bit more about behavioural complexity,
    - to understand common comorbidities, their treatment, and supports
    - To recognize the impact on the family
  - To feel more comfortable in the clinic when you don't know what to do

Zoom interactivity… (new to me ☺)

I will be trialing zoom options for participation:

- View Options → annotate
- Text
- Stamp option for what you like

Please use hand up option for any comments/ questions at any point in the presentation

- Feel free to use the chat function as well

Land acknowledgement

ISP Self Assessment Tool

https://aboriginal-2018.sites.olt.ubc.ca/files/2021/06/UBC-ISP-Self-Assessment-Tool_06072021.pdf

What is hardest about a patient with behavioural complexity?

(Please type answers – they are anonymous)

What are common co-morbidities in kids with behavioural complexity?

(type a single word answer or stamp something you agree with)

What is **behavioural complexity**?

She hears her child bang their head into the wall one more time, but this time she simply can't get up, she curls up into a ball, covers her ears, just waits for it to end. But it happens again, again and again. She knows the repetitive banging hits the spot she's patched repeatedly and is covered by a soft helmet. She hopes the neighbours don't hear her cry because she knows they hear the banging.

What percentage of kids with ASD exhibit SIB?

(put a stamp by your guess)

twinkl.com

Scope of the problem

Original Paper | Open Access | Published: 15 April 2020

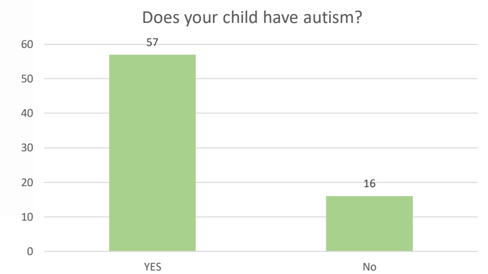
The Prevalence of Self-injurious Behaviour in Autism: A Meta-analytic Study

Catherine Steenfeldt-Kristensen, Chris A. Jones & Caroline Richards

Journal of Autism and Developmental Disorders **50**, 3857–3873 (2020) | Cite this article

4695 Accesses | **12** Citations | **24** Altmetric | Metrics

- 37 papers, 14,379 Individuals
- 42 % of individuals with autism engaged in SIB



A provincial survey of families of children with SIB was conducted this year to characterize the problem. Data will be presented throughout the presentation.

Over 20% of respondent's children did not have a diagnosis of autism.

Brief overview of Autism

"ABA only made him more frustrated and many of the sensory based approaches were only helpful when used with an OT to adapt things to his specific needs"

- Defined by the DSM-5
- Deficits in 2 areas
  - Social Communication (SC) *** this is where ABA focuses
  - Restrictive, Repetitive Behaviours (RRB) *** this is where aggression and SIB live

Dr Stephen Shore (an advocate on the spectrum) said:

"If you've met one person with autism, you've met one person with autism"

Profound autism… new category

- Intellectual impairment
- Non-verbal

THE LANCET COMMISSIONS | VOLUME 399, ISSUE 10321, P271-334, JANUARY 15, 2022

The *Lancet* Commission on the future of care and clinical research in autism

Prof Catherine Lord, PhD † • Prof Tony Charman, PhD † • Alexandra Havdahl, PhD • Prof Paul Carbone, MD • Prof Evdokia Anagnostou, MD • Prof Brian Boyd, PhD • et al. Show all authors • Show footnotes

What is the most important support?

(pls stamp the support, or add one if missing - anonymous)

Respite

Occupational therapy

Peer support

Behavioural intervention

Speech and Language

Behavioural consultant

Medical/ Dr/ specialists

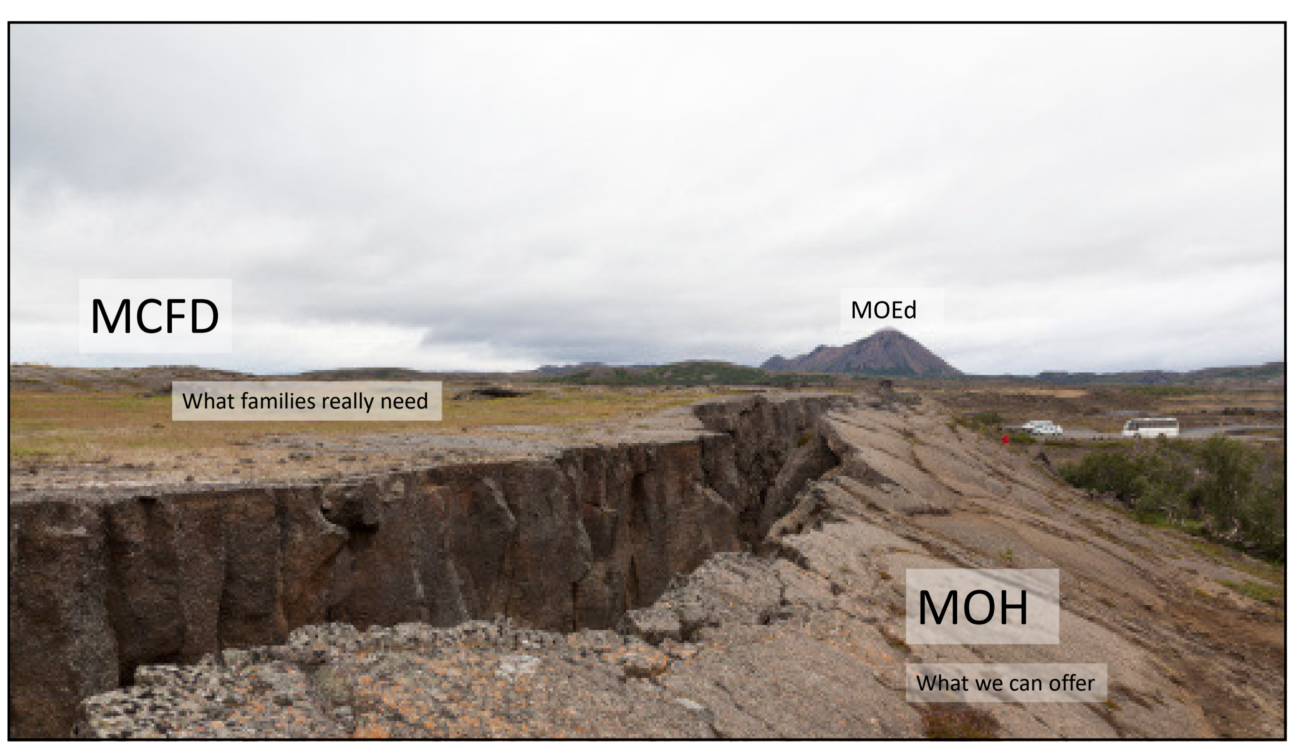
BCBA

Autism treatment and supports

Remember no autism = no supports

"Our family life was was in disarray and many times terrifying as he got older and stronger. In the end 2 things worked - ABA program with Katie Allen and Psych medications to mitigate the intensity of his behaviours."

- Not all interventionists are equal
- Board Certified Behavioural Analyst (BCBA) should be involved
- "Behavioural Consultant" is not a term, it is a self declared title, similar to a 'nutritionist' versus a 'registered dietitian' (RD)
  - Not all BCBA's are equal, if something is not working, families need to move on, especially when related to SIB and behavioural complexity
- OT is fantastic support, as it works on sensory issues
- SLP likely needs to be working with AAC (Augmentative and Alternative Communication – Touch Chat, Proloquo2go) with BCBA



“When it comes to reaching out to MCFD, parents may not express their family needs, because they are afraid of losing their children to the ministry's custody. These two systems are capable of breaking the strongest self-advocates! So, don't leave parents alone, and please *offer* your kind help, especially if you are dealing with families that are vulnerable to inequities.”

Ministry of Children and Family Development

CYSN: Social Worker (get to know them, ask parents for their name and contact information, send a greetings email)
TL: Team Leader (supervisor for a group of SW)
DO: Director of Operations (above TL)

ICM: Integrated Case Management

- Should be an opportunity for the family to talk to their SW, you can attend (Case Conference 1Hx4/yr)
- Tend to book these “tomorrow” for 3H; advocate for your time to attend, this is the families meeting, not the SW
- Attend school based meetings as well, if possible

Remember MCFD also has CPS housed under the same roof, files do get transferred.

> “Since that meeting where [CYSN SW] first told me that if there were further thoughts of self harm from me, reported to MCFD, she may have to have child protection apprehend [child], I have been scared to report anything to MCFD, including increasing severity of [child’s] behaviour, because I didn't know what would trigger apprehension, and I want to protect [child] from foster care that would devastate and disorient him beyond recovery.”

MCFD…

POTENTIAL SUPPORTS OFFERED

- Respite
  - Baseline is $256/month to be distributed by parents (they need to find the respite provider, hard in rural communities
  - MCFD considers $15/H an appropriate wage, so they calculate "hours" based on this rate
    - They may offer a family 30H per month, but this really only means about 20H when calculating an actual wage
- Services that are only accessible through MCFD (Counselling, family therapy, groups…)
- Resourced home "Out of home" respite
  - VARIABLE homes available (not all are built alike
    - ARCUS is the only home with a medical (RN) support
    - ARCUS is the only home with BCBA support
  - All other homes do not provide ANY behavioural intervention (OT, BCBA, SLP, BI)
    - Provide a generic 'safety plan'
    - 'contract' out to a BC service with no understanding of behavioural complexity

---

- CYSN is "a voluntary service provided for families" which means that families need to call then to ask for help. They do not reach out to families

- AFU (AUTISM FUNDING UNITS)
- Need to be applied to RASP list registrants
- After 15y can be applied at parents' discretion
- 20% can go towards supplies (I get parents to fill out the form and sign) or parent education

- AHP
- - Need to require supports in ¾ ADLs, 4/4 get both respite and medical

When it is too much to handle…

Voluntary Care Agreement (VCA) – over 14 days in resourced home

Special Needs Agreement (SNA) – up to 14 days of respite per month

There is complete lack of transparency within CYSN/ MCFD; some families get in home 24H per day supports, others lose their vision while waiting for 1H per week.

Patient referral…

RFR: 6yo M, has not been sleeping, taking 10mg of melatonin mom is tired. Has autism.

Sleep and neurodiversity

- 50-80% of neurodiverse kids (and parents) have poor sleep
- Impacts health and daytime wellbeing

RESEARCH ARTICLE

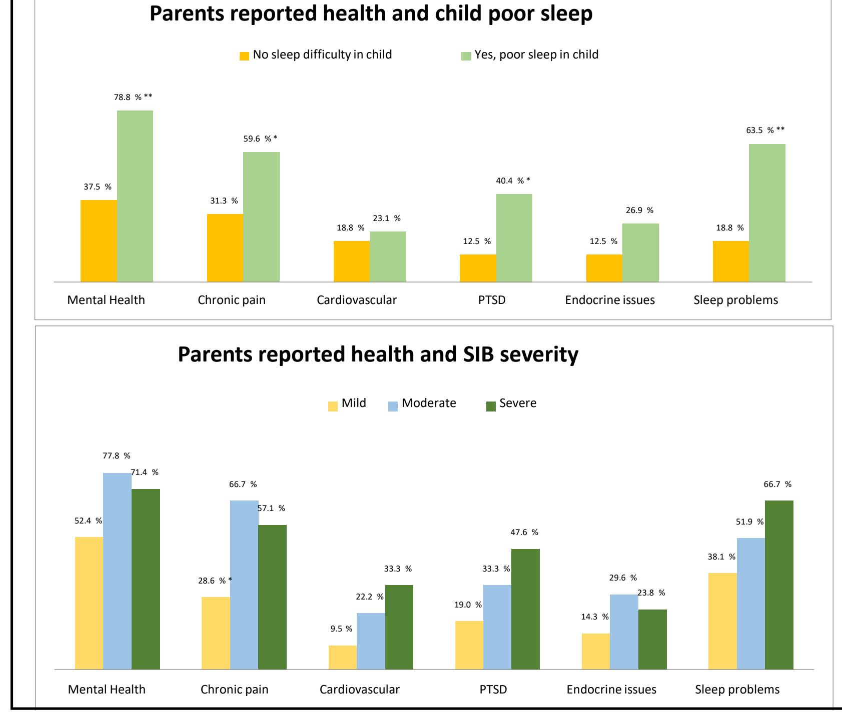
Sleep patterns predictive of daytime challenging behavior in individuals with low-functioning autism

Simonne Cohen, Ben D. Fulcher, Shantha M. W. Rajaratnam, Russell Conduit, Jason P. Sullivan, Melissa A. St Hilaire, Andrew J. K. Phillips, Tobias Loddenkemper, Sanjeev V. Kothare ... See all authors

First published: 01 December 2017 | https://doi.org/10.1002/aur.1899 | Citations: 40

Analyzed data points for 20,000 sleep observations and matched to daytime behaviour in 67 individuals with profound autism

81% predictability based on preceding poor nights sleep



As part of the provincial survey, I asked parents to self report their health – categories were selected based on known health impact of living in chronic and toxic stress

(*p-value </= 0.05, **p-value</=0.01).
Population data examples:

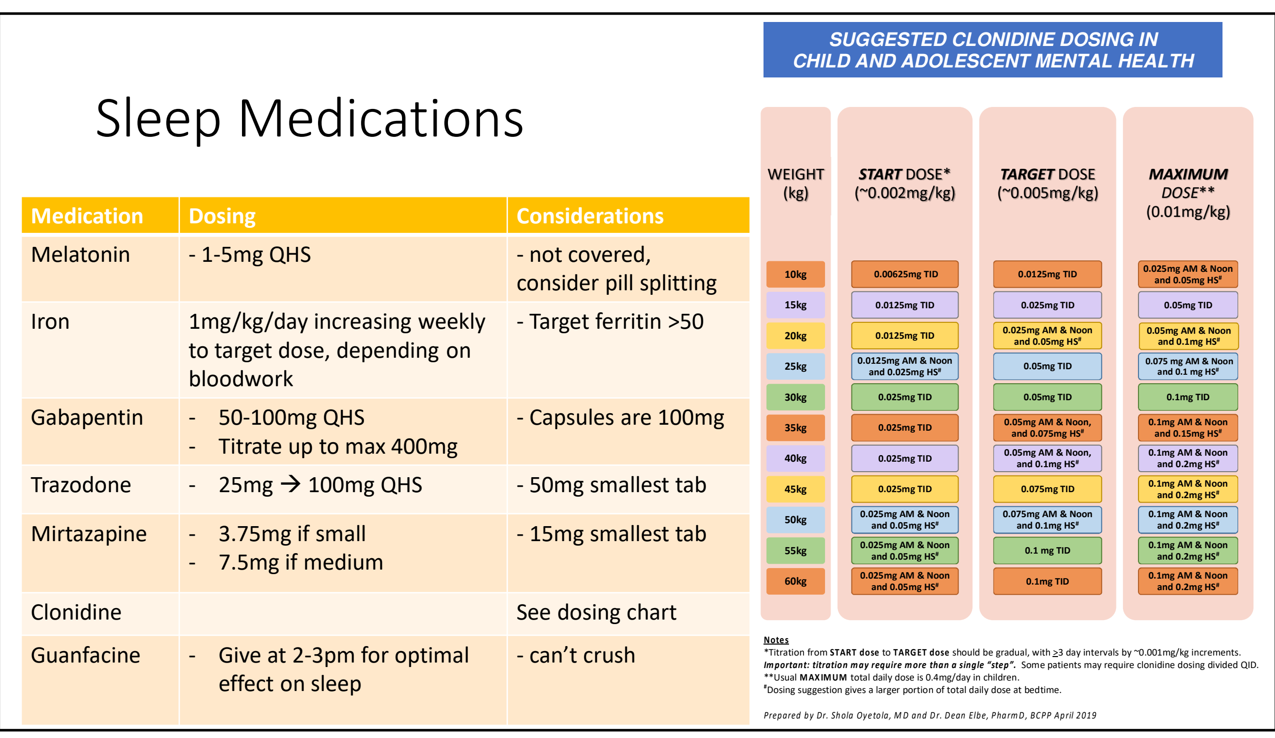
- Canadian Mental Health Association 17% of adults in BC
- Insomnia 22%
- chronic pain 22%
- PTSD in Canada 9.2%

Sleep matters

- Take a detailed history
- Bedtime, routine, sleep time, medication time, when do they wake up, does someone have to sleep with them, where do they sleep, if they wake, do they stay in their bed, napping
- Rule out medical
  - Snoring/ apnea (trial Nasonex; 1st suggest NS spray to see if tolerates)
  - Eczema
  - Restless sleep (iron deficiency/ RLS trial iron supplement, gabapentin)
  - Reflux (trial PPI)
- When parents say "wakes up early" this usually means 2-3am, so ask
  - How often? A few times a month? A week?
- For a single parent, this is extremely challenging
- Who takes the night time shift

"Medications can help to remove/ reduce the role of some of the contributors and pave the way for behavioral interventions. A parent asking for PRNs or increased doses of medication is not looking for an easy way out. They are calling for backup forces."

"We experienced severe sleep deprivation due to his poor sleep habits. It had a hugely negative impact on the whole family physically and mentally. When we asked about medication for sleep, we were told that it wasn't safe for him and could impact his development, but the sleep deprivation also impacted his development."



Sleep Medications

Medication	Dosing	Considerations
Melatonin	- 1-5mg QHS	- not covered, consider pill splitting
Iron	1mg/kg/day increasing weekly to target dose, depending on bloodwork	- Target ferritin >50
Gabapentin	- 50-100mg QHS - Titrate up to max 400mg	- Capsules are 100mg
Trazodone	- 25mg → 100mg QHS	- 50mg smallest tab
Mirtazapine	- 3.75mg if small - 7.5mg if medium	- 15mg smallest tab
Clonidine		See dosing chart
Guanfacine	- Give at 2-3pm for optimal effect on sleep	- can't crush

SUGGESTED CLONIDINE DOSING IN CHILD AND ADOLESCENT MENTAL HEALTH

WEIGHT (kg)	***START*** DOSE* (~0.002mg/kg)	***TARGET*** DOSE (~0.005mg/kg)	***MAXIMUM*** *DOSE*** (0.01mg/kg)
10kg	0.00625mg TID	0.0125mg TID	0.025mg AM & Noon and 0.05mg HS#
15kg	0.0125mg TID	0.025mg TID	0.05mg TID
20kg	0.0125mg TID	0.025mg AM & Noon and 0.05mg HS#	0.05mg AM & Noon and 0.1mg HS#
25kg	0.0125mg AM & Noon and 0.025mg HS#	0.05mg TID	0.075 mg AM & Noon and 0.1 mg HS#
30kg	0.025mg TID	0.05mg TID	0.1mg TID
35kg	0.025mg TID	0.05mg AM & Noon, and 0.075mg HS#	0.1mg AM & Noon and 0.15mg HS#
40kg	0.025mg TID	0.05mg AM & Noon, and 0.1mg HS#	0.1mg AM & Noon and 0.2mg HS#
45kg	0.025mg TID	0.075mg TID	0.1mg AM & Noon and 0.2mg HS#
50kg	0.025mg AM & Noon and 0.05mg HS#	0.075mg AM & Noon and 0.1mg HS#	0.1mg AM & Noon and 0.2mg HS#
55kg	0.025mg AM & Noon and 0.05mg HS#	0.1 mg TID	0.1mg AM & Noon and 0.2mg HS#
60kg	0.025mg AM & Noon and 0.05mg HS#	0.1mg TID	0.1mg AM & Noon and 0.2mg HS#

Notes
*Titration from **START dose** to **TARGET dose** should be gradual, with ≥3 day intervals by ~0.001mg/kg increments.
Important: titration may require more than a single "step". Some patients may require clonidine dosing divided QID.
Usual **MAXIMUM total daily dose is 0.4mg/day in children.
#Dosing suggestion gives a larger portion of total daily dose at bedtime.

Prepared by Dr. Shola Oyetola, MD and Dr. Dean Elbe, PharmD, BCPP April 2019

Resources - Sleep

BCCH – Sleep

- Referral to sleep clinic if you think that child has OSA/ RLS
- May want to start IN steroids previous,
- Dr. Ipsiroglu is part of the SIB clinic, you can tic his name on the referral
  - Pls ensure ferritin done and pt on iron prior to referral to streamline

BCCH – Neuropsychiatry

- Sleep Group (for parents)
- Needs referral to NP at BCCH
  - Psychiatrists (Dr. Banno, Dr. Edwards, Dr. Friedlander) offer long term follow up for the most complex patients
  - <6 will see Infant Psychiatry, then internal referral to NP if needed
  - If child has SIB, please put SIB Referral on the form, and then they will be seen by Psychiatry, who will decide if referral to NP is needed.

- https://ndd.betternightsbetterdays.ca/can-i-participate-0

Better Nights Better Days

Bonnes nuits Jours meilleurs

Better Nights, Better Days for children with Neurodevelopmental Disorders

Patient referral…

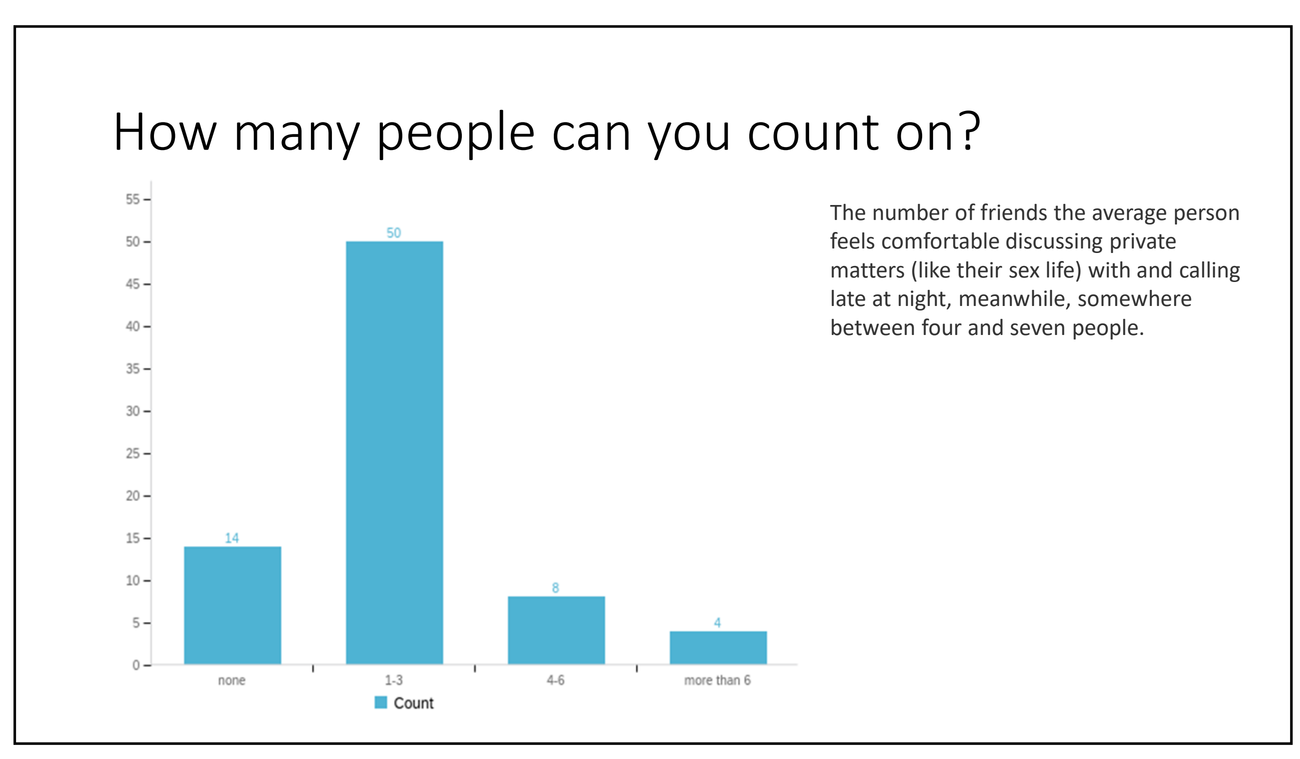
- 8yo, severe autism, not able to attend school due to worsening behaviours, parents worried about PANS?

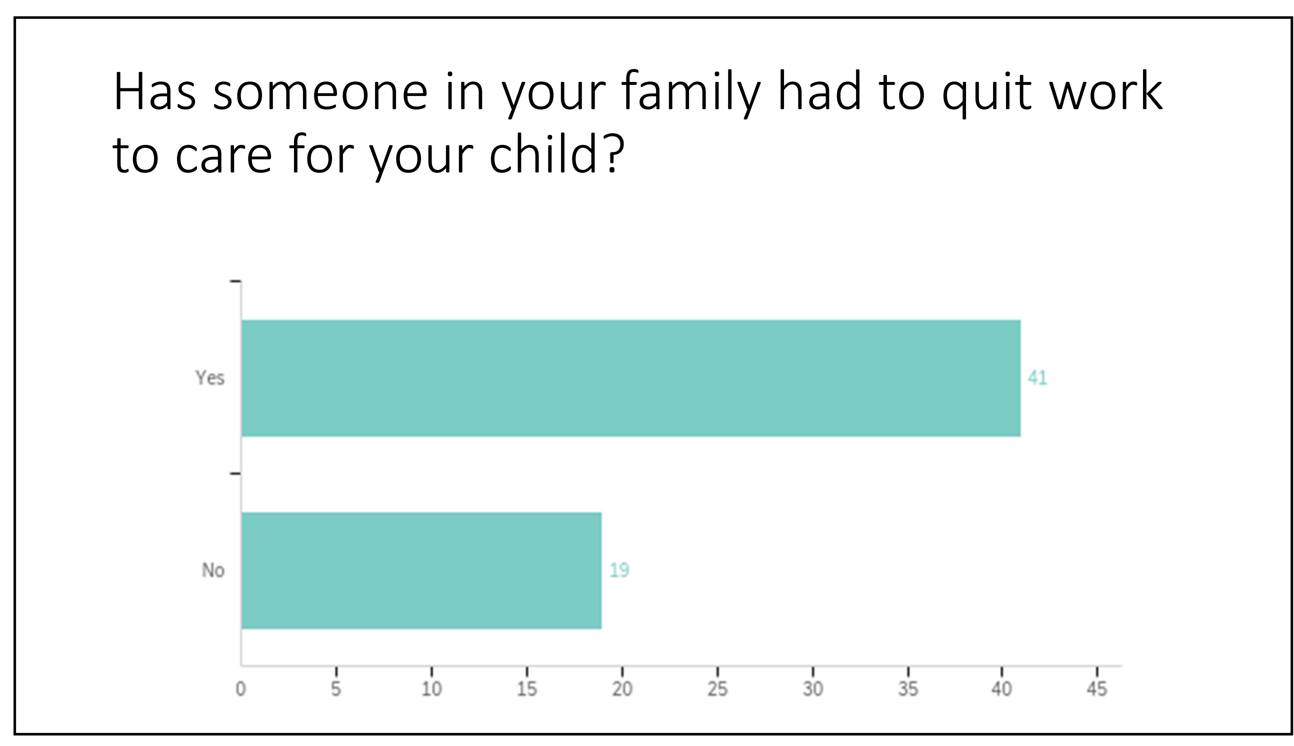
When understandings differ…

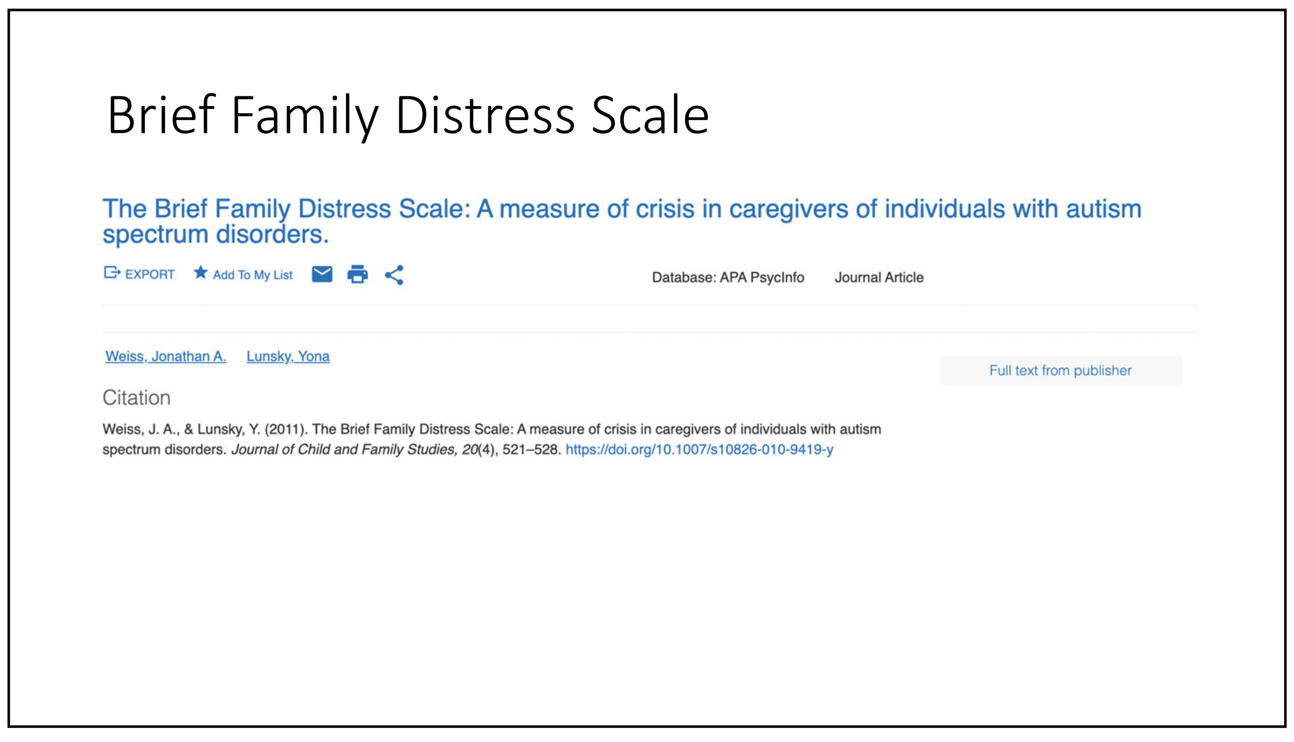
“No doctor was willing to acknowledge the life-changing surgery our daughter underwent. They always disregarded our experience and facts and jumped straight to autism diagnosis I went to numerous doctors walk in clinics and even moved province’s. Each time was the same the doctor would listen and then respond as if they never heard me”

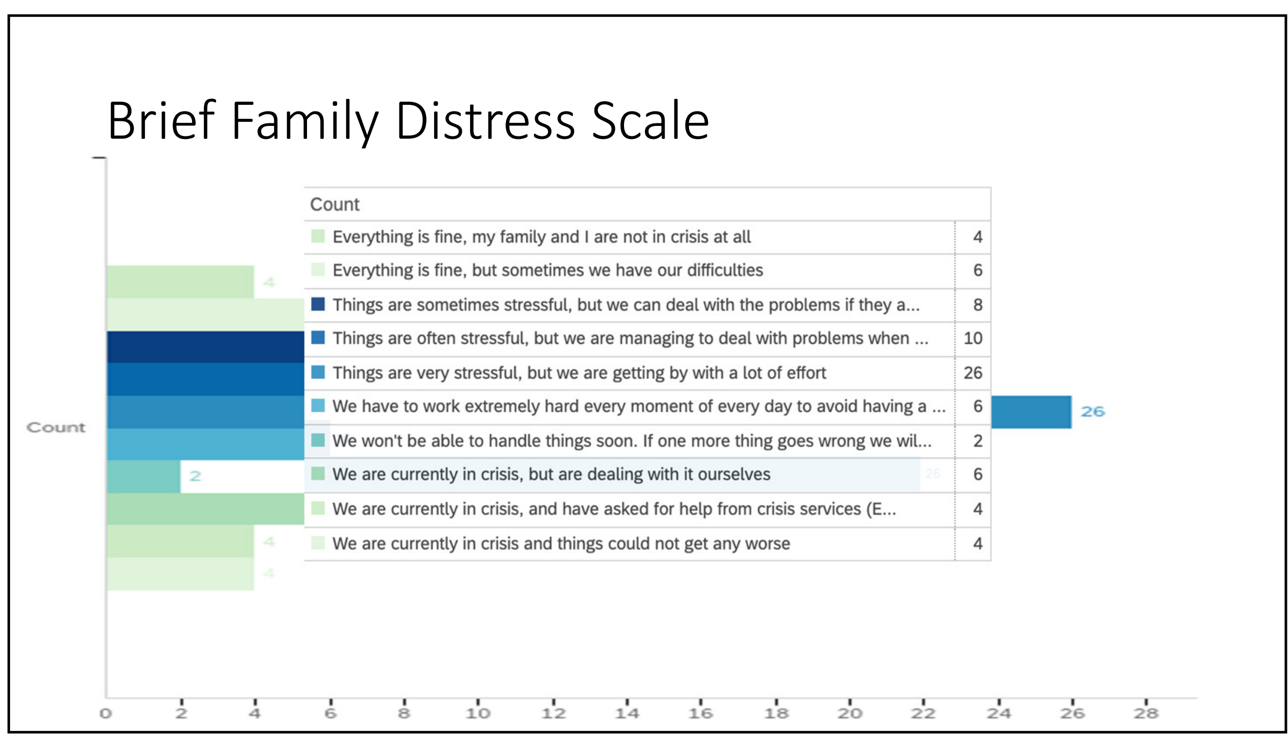
"Looking for the root cause of the behaviour, including ensuring that they are not in pain or that there is not health concerns. Working with an ND to looking gut issues, Lyme disease, or any viruses that cause behaviours. Looking at food to ensure there are no food issues. Rule out epilepsy, migraines, brain issues, gut issues, that can all lead to behavioural challenges."

"Doctors who don't listen, and suggest putting a behaviour plan into place without looking internally for causes. Providing medication to mask the issues. It's time for medical doctors to really start looking internally. The refusal of paediatricians to see past a diagnosis and look for the root causes of the behaviour is mind-blowing and creates years of pain and frustration. I ended up going to the States to see doctors and found out that my son has Lyme disease; and my other son has a severe yeast issue (both cause behavioural challenges - but I'm going to guess that this will also be ignored). Yeast does cause behaviours and when we treated the yeast the behaviours went away; for my other son with Lyme, as we have been treating the Lyme, the self injurious behaviours are improving. I'm tried of the medical system that refuses to learn about disabilities and refusing to partner with ND's so that they can truly help patients. For 20 years I've been helping my children and spending thousands of dollars to help my children because the Canadian medical system will not improve on what they don't know. If you fit in the box, you can get the help you need, but if you are a person with behavioural challenges, we refuse to look at the root cause. "




Has someone in your family had to quit work to care for your child?
Yes
41
No
19
0
5
10
15
20
25
30
35
40
45


Brief Family Distress Scale
The Brief Family Distress Scale: A measure of crisis in caregivers of individuals with autism spectrum disorders.
EXPORT
Add To My List
Database: APA PsycInfo
Journal Article
Weiss, Jonathan A.
Lunsky, Yona
Full text from publisher
Citation
Weiss, J. A., & Lunsky, Y. (2011). The Brief Family Distress Scale: A measure of crisis in caregivers of individuals with autism spectrum disorders. Journal of Child and Family Studies, 20(4), 521–528. https://doi.org/10.1007/s10826-010-9419-y



Brief Family Distress Scale
Count
Everything is fine, my family and I are not in crisis at all 4
Everything is fine, but sometimes we have our difficulties 6
Things are sometimes stressful, but we can deal with the problems if they a... 8
Things are often stressful, but we are managing to deal with problems when ... 10
Things are very stressful, but we are getting by with a lot of effort 26
We have to work extremely hard every moment of every day to avoid having a ... 6
We won't be able to handle things soon. If one more thing goes wrong we wil... 2
We are currently in crisis, but are dealing with it ourselves 6
We are currently in crisis, and have asked for help from crisis services (E... 4
We are currently in crisis and things could not get any worse 4
Count
0 2 4 6 8 10 12 14 16 18 20 22 24 26 28

Basic Household (rent, mortgage, hydro, etc.)
73.38
0
80
data
Other Housing (vacations, pets, etc.)
47.52
0
80
data
Transportation
69.65
0
80
data
Yes
41
No
19
0 5 10 15 20 25 30 35 40 45

When understandings differ …

- You can help and still never agree!
  - "I don't know if I agree about PANS, but I can help with…"
  - "You're right, the system is broken; how can I help?"
  - "I'm not sure we will ever know what has caused X, but I can help with…"
  - "how are *you* managing/ doing?"
- Try a "what if I'm wrong" approach (phenomenology of hesitation)
- Remember you have implicit biases
- At some point, you may want to clarify your comfort with ordering labs for other practitioners, and sometimes, after time, I do talk to families about what I consider to be predatory practices

It's ok to:

- To not do anything in an appointment
- To just listen
- To not know the answer
- Community pediatrics allows for flexibility in long term follow up, check in in 1 month, see if things have changed

Violence-informed approach

Shock and Awe: Trauma as the New Colonial Frontier

by Natalie Clark

School of Social Work, 2080 West Mall, The University of British Columbia, Vancouver, BC V6T 1T2, Canada

Academic Editor: Sonya Andermahr

Humanities **2016**, *5*(1), 14; https://doi.org/10.3390/h5010014

Received: 30 September 2015 / Revised: 23 December 2015 / Accepted: 21 January 2016 / Published: 5 February 2016

(This article belongs to the Special Issue Decolonizing Trauma Studies: Trauma and Postcolonialism)

Consider moving from "trauma informed" where the patient experiences the impact of violence, to "violence informed" where the clinician owns some responsibility for the trauma

Intersectionality – when risks pile up

"Non-judgemental support for the parent. Parenting a child with challenging behaviour can be very socially isolating for the parents and for siblings. Parents and siblings may suffer with significant anxiety/hyper-vigilance as so many "unexpected" things can trigger behaviour. Non-judgemental health-care professionals are crucial to our survival - we are often so overwhelmed that we can't implement suggestions provided, and may get conflicting advice from different professionals!"

"Awareness of the trauma that complex behaviour causes families especially when regular aggression is occurring towards family members."

Intersectionality is about fighting discrimination *within* discrimination, tackling inequalities *within* inequalities, and protecting minorities *within* minorities.

CENTER FOR INTERSECTIONAL

Hang Time

Journal of Family Therapy (2020) **0**: 1–2
doi: 10.1111/1467-6427.12293

"Witnessing requires that we situate personal suffering in its sociopolitical context and resist the individualisation and medicalisation of suffering"

Trauma and resistance: 'hang time' and other innovative responses to oppression, violence and suffering

Vikki Reynolds

Micro-resistance responding to micro-aggression

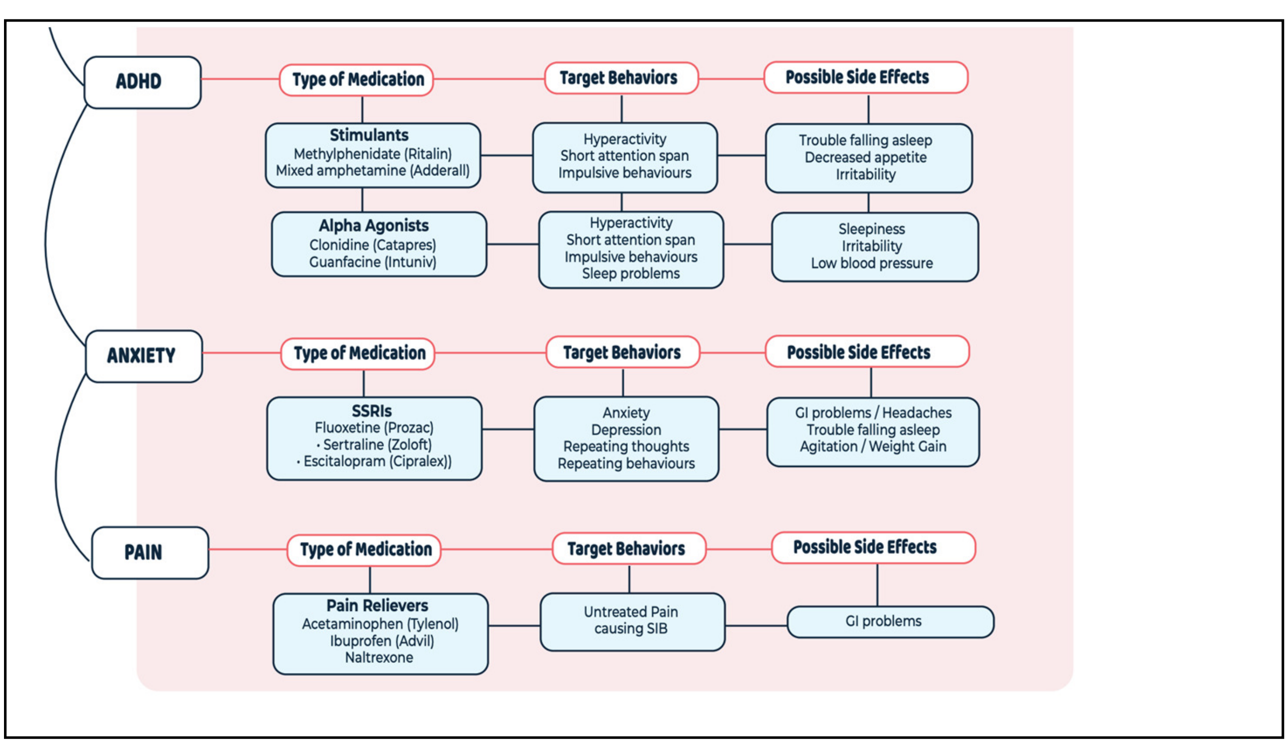
Comorbidities in Behavioural Complexity "AAA"

Avoid diagnostic overshadowing:

- when all symptoms are attributed to a psychiatric diagnosis
- "it's just autism"

Treat behaviour, or functional impairment, not diagnosis

- Tantrums ?anxiety (SSRI), ?inattention (Stimulants)
- Perseveration, tics ? OCD (SSRI)
- Try BEFORE risperidone/ aripiprazole



Investigations: necessary versus helpful

(pls type answer, or stamp if agree)

As you may only get one shot every now and then, think about:

What do I need now? What may I need later?

"A lot of the medical testing was also traumatic. They would physically confine him to poke him with needles. He is too big to do that now"

	Need now	Need later
CBC, ferritin, CRP, iron studies	Sleep, ADHD, poor nutrition	
B12, VD, albumin, T protein	If nutritionally concerned	
LFT, renal		? Medications
Lipids, prolactin		? Use of atypicals later
ECG		? QT meds (amitriptyline)
TTG, H.Pylori, lipase	If abdominal symptoms	
CGH/ FXR (male)/ PWD (picking)		
MRI/ EEG		
Abdo XR	?constipation	

EUA Project at BCCH

Coordination of investigations with sedation

- Many pediatric dental clinics will offer sedation

*** this is a great opportunity to get bloodwork

- If at BCCH, you can connect with PACNursing@cw.bc.ca, connect with them ahead of time, and they will help coordinate

-- consider ENT, Ophtho, ECG, imaging, CTU will do PE if asked in time

Patient referral:

5yo, fleet every 2-3 days, on PEG, and Ex-lax, very dysregulated behaviours, autism, non-verbal. Mom is convinced that there is something wrong with his gut. Live in town 4H north of Ft. St. John.

- Gut seems to be really impacted in ND kids, I don't think we know too much about how/why, but this is a huge where US/ ND will target
- Treatments parents are likely reading about
  - Nemechek/ Rifaximin/ SIBO
  - Leaky bowel/ inflammation
  - GAPS diet
  - microbiome
- These are presented to parents as 'curative' so…
- Constipation
  - PEG smallest does possible, daily dose, much better/ tolerated than large doses when needed
  - Senna is an excellent additive
  - Fleets/ sups happen
  - IBS supports: Procolamide, Cisapride, constella (watch for drug interactions)

Supports - Medical

- ACCESS Clinic
  - Menstrual suppression, IUD insertion, follow into adulthood
- AIMS Clinic
  - Dr. Lewis is an expert in genetics and autism, especially girls, especially if intellectual impairment as well, or if there are multiples in the family
- SIB Clinic
  - Referral to BCCH Psychiatry
- Compass Line (1-855-702-7272)
- Sleep Clinic
  - Dr. Ipsiroglu is an expert in sleep and ND
- DDMHS (Developmental Disability Mental Health Services – over 12)
- Dr. Dean Elbe – Pharmacist extraordinaire available to answer specific questions (delbe@cw.bc.ca)

Support - Community

- Family Support Institute
  - I refer almost all my patients here, have great peer-to-peer support
- Autism Community Training
- Inclusion BC (school issue)
- PARENTING GROUPS!

"Calling on other parents with experience was the best thing we did."

- POPARD (https://autismoutreach.ca/)