Lessons Learned: Fragile X and Trauma

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Outline:

1. Discussion of the special vulnerability of trauma related to Fragile X Syndrome
   - unique disinhibited social drive may predispose trauma vulnerability
   - neurobiology of hyperarousal compounds the impact of trauma
2. Review the tenets of trauma informed care and how these might be modified for FXS
3. Presentation of Case Study
4. Summary of recommendations from these lessons for the Fragile X community

Why a session of Trauma Informed Care?

- A topic that is challenging to discuss, yet all too real and necessary.
- This talk was inspired by the resilience of a Fragile X Family who were thrown into the world of trauma intervention following the life-altering result of traumatic events.
- We will share more on the case after we talk about some important concepts related to trauma-informed care.

What is Trauma?

- **Traumatic events** can include physical and sexual abuse, neglect, verbal abuse, emotional abuse, peer aggression, community-based violence, disaster, terrorism, and war.
  - ***acute trauma*** - Exposure to a single traumatic event
  - ***complex trauma*** - Exposure to multiple or prolonged traumatic events and their impact

http://www.samhsa.gov/trauma-violence/types

The Impact of Trauma

Trauma overwhelms an individual's capacity to integrate the experience (e.g., Putnam, 1985)

Traumatic response remains subconscious and has the power to shape an individual's daily functioning and behavior. (e.g., Allen, 1993)

From: Oberlander, et al, (2012) - National Forum on Youth Violence Prevention

How Do Children or those with a Developmental Disability Experience Trauma?

- Increased vulnerability to develop negative outcomes, as compared to adults
- Poorly studied; clinicians and researchers agree that it is under-reported

Goldson, 2002 reports maltreatment among children with disabilities:

Incidents per 1,000

	Children without Disabilities	Children with Disabilities
Physical Abuse	4.5	9.4
Sexual Abuse	2.0	3.5
Emotional Abuse	2.9	3.5

Trauma and Fragile X Syndrome

- There are **no studies** to report the prevalence of trauma within FXS.
- An informal survey of representative Fragile X clinics suggests that trauma occurs in the adult population with a concerning degree of frequency.
- Despite this, a direct query to the leading FX interventionists in the US, found no one with experience, expertise, or an informed approach to this problem.

The Startling Truths about Trauma and Disability

- Individuals with disabilities are 2-to-10 times more likely to be sexually abused than those without disabilities (Westat Inc., 1993).
- In non-disabled populations, 1 in 5 cases are reported; in disabled populations, the rate drops to 1 in 30 (James, 1988).
- Even when the abuse is reported, the charges are rarely investigated when the victim is disabled (Senn, 1988).

Startling Truths, cont.

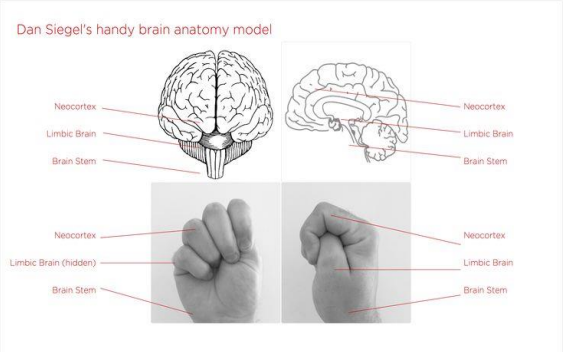
- In the care of the "disabilities service system", risk of abuse increases by 78 % (Sobsey & Doe, 1991).
- In institutional settings, sexual abuse occurs nearly 4 X more often (Blatt & Brown, 1986).
- 99% of those who commit abuse are well known to, and trusted by, both the child or the child's care providers (Baladerian, 1991).

Traumatic experiences and the response to them result in changes to brain and development

- Abuse and neglect have profound influences on brain development.
- The more prolonged the abuse or neglect, the more likely it is that permanent brain damage will occur.
- Exposure to trauma can modify the person's ability to access different levels of brain functioning, resulting in changes in:
  - perception of time,
  - cognitive style,
  - affective tone,
  - ability to develop solutions to problems,
  - and ability to respond to and understand rules, regulations, and laws

(Perry, 2001); Bremner (2006) http://www.ncbi.nlm.nih.gov/pmc/articles/PMC3181836/

Brain Science and Trauma Intervention



Traumatic stress symptoms

Re-experiencing

Thoughts & feelings pop into one's mind.

Re-living what happened - feels like it's happening again.

Get upset at reminders.

Avoidance

Try to block it out & not think about it.

Try to stay away from reminders.

Feel numb or no emotions.

Increased arousal

Always afraid something bad will happen.

More easily startled / jumpy.

Trouble with sleep or concentration.

Dissociation

Things feel unreal -- like a dream.

Trouble remembering parts of what happened.

http://www.nctsn.org/resources/topics/creating-trauma-informed-systems

FXS and Trauma – Dual Vulnerability

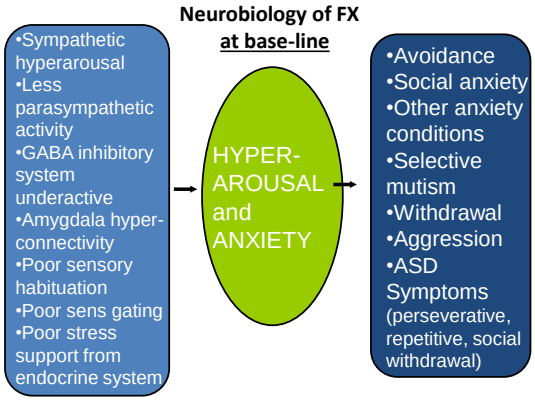
"Trauma…has biological consequences on the regulation of brain functions…"
~from Brevard Family Partnership

Underlying Biology of Hyperarousal:

Because the neural circuitry involved in the traumatic response is already disrupted at baseline, the devastating effects of trauma are further compounded.

Social Naivete :

Because individuals with FX are friendly and disinhibited, they are not equipped to self-protect or self-advocate; further, they are often in environments where trauma is likely to occur



Case Review

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John, an adult with FXS who experienced a series of traumatic events that changed his life and the life of his family

Trauma Informed Care

- **Trauma-informed care is an overarching term**
- Trauma Informed Care is an structure and treatment framework that involves understanding, recognizing, and responding to the effects of all types of trauma.
- Trauma Informed Care also emphasizes physical, psychological and emotional safety for both consumers and providers, and helps survivors rebuild a sense of control and empowerment.

Eight Phases of EMDR Trauma Treatment

Phase 1: History and Treatment Planning
Phase 2: Preparation/Safety
Phase 3: Assessment
Phase 4: Desensitization
Phase 5: Installation
Phase 6: Body scan
Phase 7: Closure
Phase 8: Reevaluation

EMDR Trauma Treatment: Fragile X Protocol

- Non-verbal
- Concrete
- Creative
- Narrative/Storytelling
- Movement/yoga
- Visuals
- Family involvement
- Weekly in-home sessions
- Sensory
- Emphasis on Body Sensations and behavior changes verses SUDs and VOCs

EMDR Trauma Treatment: Fragile X Protocol

- **Phase 1: *History and Treatment Planning* (about 1 month)**
- Meet with referring consultants
- Meet with parents and PCA
- Meet client in-home
- Email/phone with referring consultants
- Gather and study hospital records
- Consult with regional trauma expert
- Medication management
- Trauma psycho-ed
- EMDR psycho-ed

EMDR Trauma Treatment: Fragile X Protocol

- **Phase 2: *Preparation/Safety* (about 5 months, symptoms began to decrease within 5 sessions)**
- Weekly in-home sessions
- Build relationship: calm voice, let client come to clinician, go slow, careful with body positions
- Teach deep breathing: emWave and breathing ball
- Introduce and apply Bilateral Stimulation via tappers (under shoulders) and headphones (beeps and songs), 10-30 minutes per session
- Head scratcher
- Restorative Yoga (5-30 minutes) with tappers in pockets
- Safe Place Collage
- Hold safe feeling, shift into something hard, shift back
- Walk with tappers
- Emotional ID and Expression

EMDR Trauma Treatment: Fragile X Protocol

- **Phase 3: *Assessment* (about 2 weeks/sessions)**
- Identified triggers (with parents): the "bad guy," haircuts, dentists, day treatment center, doctors, cops, "Police shot me!" and "Help me dad!"; tasered in the back of his leg. Body sensations and scary thoughts. Negative beliefs; scares himself with aggressive behaviors

EMDR Trauma Treatment: Fragile X Protocol

- **Phase 4: *Desensitization* (about 3.5 months)**
- EMDR initially focused on body sensations and SUDS faces
- EMDR progressed to focusing on scary thoughts
- EMDR progressed to focusing on trauma triggers
- The Magic Remote: make the cop smaller, now he's dancing, and driving away in the car
- Safe Place Collage with BLS and yoga with tappers at the end of each session for grounding
- EMDR progressed to Trauma Narrative, done in two parts, two sessions for each part. Read aloud by clinician, BLS intervals, checking SUDs and body sensations throughout
- EMDR progressed to picture desensitization: cop and doctor

EMDR Trauma Treatment: Fragile X Protocol (*Desensitization* continued)

"The Trauma Narrative"

EMDR Trauma Treatment: Fragile X Protocol

- **Phase 5: *Installation* (about 1 month)**
- Essential oils used to give memory a new smell
- Imagine a happy ending to the story (given a choice). Parents and PCA were also asked to create happy endings
- Addressed core beliefs: "I am not safe"/"I am safe" --- "I am bad"/ "I am well" – "I am happy"
- Addressed how fears lead to violence, compassion for self: "I am safe to be around" --- "I am peaceful"
- VOC: 6/7

EMDR Trauma Treatment: Fragile X Protocol

- **Phase 6: *Body scan* (about 1 month)**
- Used body chart, client points to distressing areas: stomach, heart, groin, head
- Use Safe Place Collage and essential oil
- SUD: 0

EMDR Trauma Treatment: Fragile X Protocol

- **Phase 7: *Closure* (about 1 month)**
- EMDR Body Scan/CBT worksheet for "times I need to hit someone"
- Taught and practiced The Butterfly
- Flying Wish Paper: say goodbye to/let go of bad person, fear of hospital/doctors, headaches
- Cake at end

EMDR Trauma Treatment: Fragile X Protocol

- **Phase 8: *Reevaluation* (ongoing)**
- Recent distress at birthday party
- Trauma psycho-education for family
- Parent coaching
- EMDR treatment for parents
- Fragile X coaching for post-high school

What worked for J.

- The case necessitated collaboration between Fragile X experts and trauma experts, along with the family and the individual, to create a novel intervention approach to meet this unique challenge.
- An EMDR (Eye Movement Desensitization and Reprocessing therapy) approach was utilized and adapted to meet the Fragile X needs of the client, in addition to other therapies that combined to help the client and the family move forward on the new path that trauma necessitates.

From J's Family – June 2016

I remember when you came to visit us in February 2014. We were in a pretty desperate situation and you gave us ideas, friendship, and some hope. We always looked forward to your subsequent visits and got tangible boosts from each of them. Basically, you were our only hope. There was no one else to help us. You were awesome. We trust you guys as much as anyone we know.

We have learned a lot over the past couple of years. We have read books and done so much research. We have attended trauma seminars and conducted yoga sessions. There are Fragile X trained people. And there are trauma educated people (and there are EMDR people). But there are no EMDR trained people for those with developmental disabilities.

We are happy to report that J. is showing steady and clear progress. We have learned to give him total control over his day. And he is slowly bringing himself back. There are now times during the day at home when he is his old self. He laughs, kids us, sings songs, comes up with ideas of people he wants to call and write letters to, and shows life in his face and his being. His mom has become his security blanket. We have learned to solicit J's input and to follow him. And he has learned to advocate for himself.

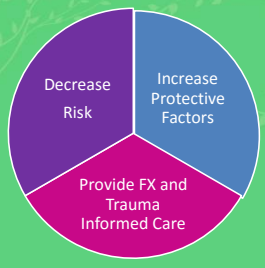
We had to learn the hard way. We ended up causing him anxiety and overloading him. We won't do this again. We no longer have any preconceived notions of what we want him to be able to do. He'll do what he ends up wanting to do. Now that we unconditionally accept him and his situation - he is coming back. Kudos to Bessel Van der Kolk for teaching me this. He still has a long ways to go. But he is happier and more "alive" and we are following his lead.

Trauma happens to an individual and then to the whole family constellation

- Parent stress and treatment/support
- Sibling stress and treatment/support
- Change is profound, grief is profound, the future does not come from the past

Trauma is shrouded in secrecy and denial and is often ignored.
~The National Council for Behavioral Health

What We Ask of You
What Can the FX Community Do?



Print/download from: www.nctsn.org/medtoolkit

fppt.com

Promoting Child and Family Resilience

Protective Factors		
Individual Characteristics	**Family Characteristics**	**Community Characteristics**
• Cognitive Ability (thought process)	• Family Connection	• Positive school experiences
• Self-efficacy (belief in one's ability to succeed in a particular situation)	• Supportive parent-child interaction	• Community resources
• Internal locus of control (i.e., a sense of having control over one's life and destiny)	• Social support (e.g., extended family support)	• Supportive peers and/or mentors
• Temperament		
• Social Skills	Traditional trauma vs fx trauma – add column and compare for indiv charac's	

http://www.ncdsv.org/ncd_911.html

Thank you!!

And, a special thank you to J's family for their generous sharing of the difficult journey they are on and allowing you all to benefit from it.

fppt.com

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Van Der Kolk (2014) *The Body Keeps the Score: Brain, Mind and Body in the Healing of Trauma.*

Harris, M. & Fallot, R.D. (2001) Envisioning a trauma-informed service system: A vital paradigm shift. *New Directions for Mental Health Services, 89*, 3–22.

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Resources

Free Internet Resources:

- http://pathwaysrtc.pdx.edu/pdf/fpW0702.pdf
- http://www.traumainformedcareproject.org/resources.php
- http://www.traumacenter.org/products/publications.php