



Patient & Caregiver Perspective: What You Want Your Provider to Know

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Learning Objectives

1. Understand the short and long term, data-driven management of complex patients with TSC and Epilepsy with anxiety and aggressive behavioral issues
2. Understand the collaboration of the care givers, doctors (Psychiatrist, Neurologists, Behavioral Specialists), and services that are needed to understand and create and iterative plan



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2

Relation: Nathan: Son 26 Years of Age



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3

The Road to Data Driven Collaboration

- The Time Line:
 - Seizure control
 - Adaptive education / IEPs
 - Tracking medication effectiveness and time laps side affects
 - Monotherapy, cocktails and behaviors
 - Applied Behavior Analysis (ABA) and Cognitive Behavioral Therapy (CBT) effectiveness
 - Combination of ABA + CBT + Psychiatrist + Psychologists + Neurologists + Caregivers = Roadmap to training and control



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4

Complexities Along the Way

- Interoception/executive functions and abstract thinking
- Medications: Ramp/anxiety and emotional aggression
- Independent living/Quality of life balance
- Family and schools influence
- Physical weight gain & medical conditions (MRIs, anesthesia)
- Food and sleep
- Collaboration with Psychiatrist, Neurologists, Behavioral Specialists

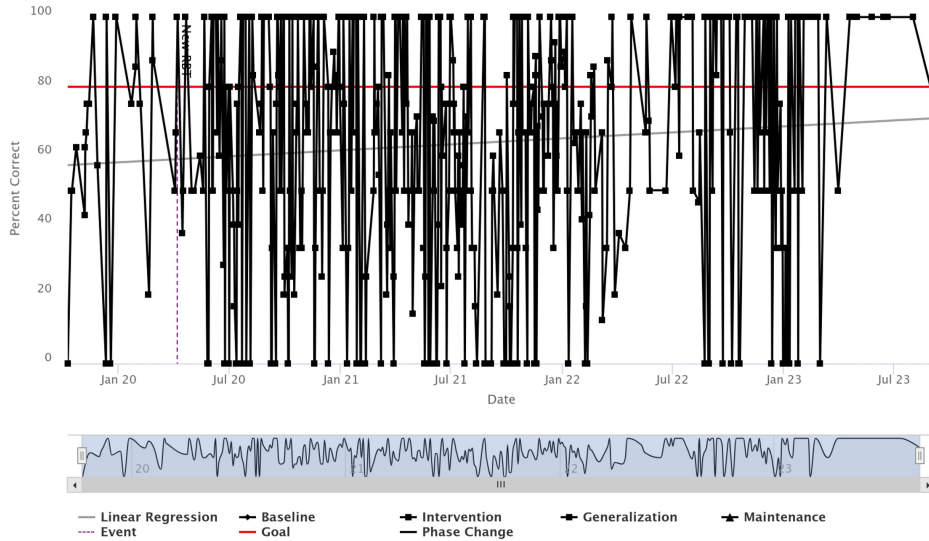


Collaboration Examples

- Data gathering around aggression, medication administration, food, sleep and incidents (positive and negative) gave insight to cyclic outbursts, lows and highs
 - Holidays
 - Reaffirmations of social engagement
 - Surprise avoidance
 - Medication mono-therapy and ramp
 - Download/regular counseling (with ABA and CBT application)



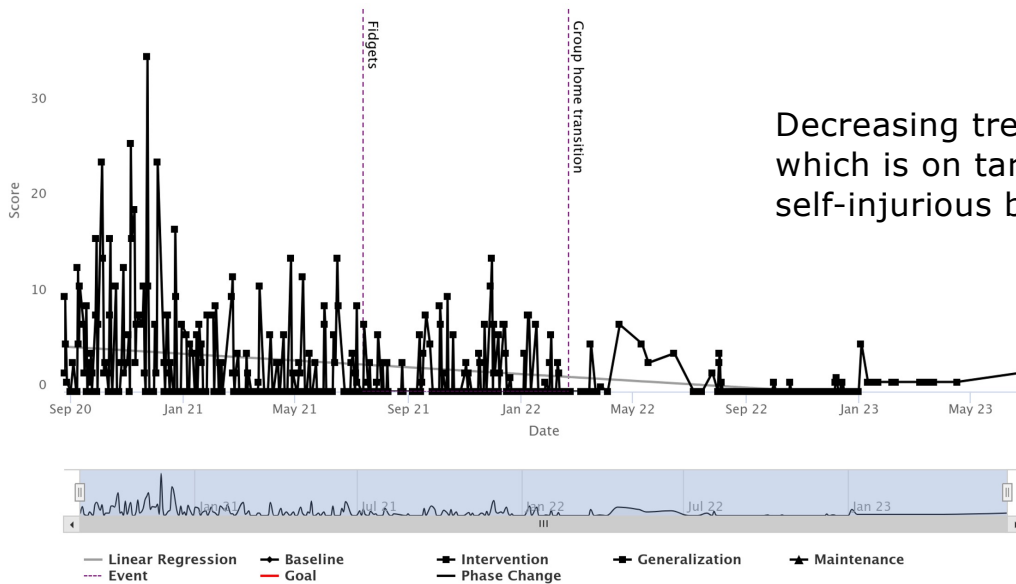
Polite Responses



Polite responses has a slight increasing trendline

7

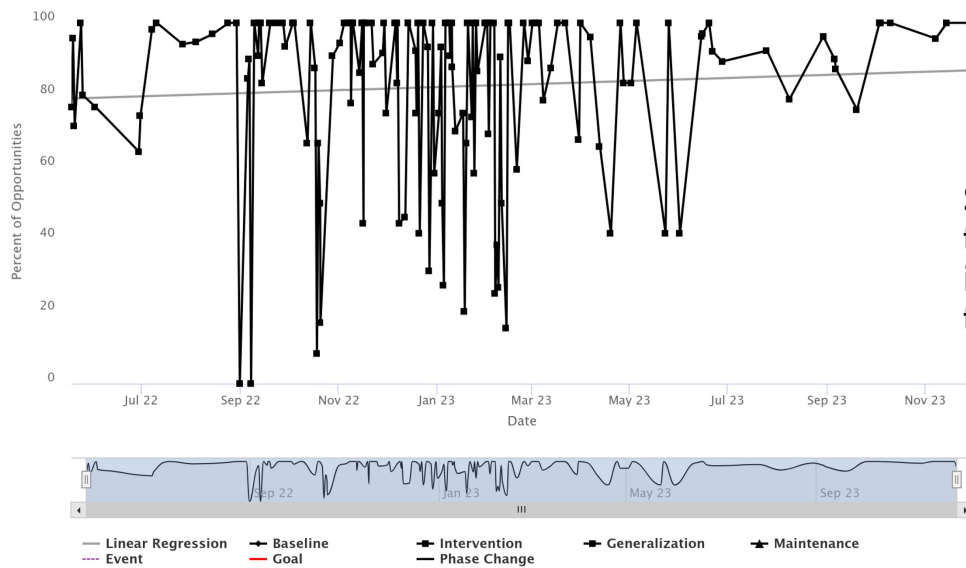
Self-Injurious Behavior (SIB)



Decreasing trendline which is on target for self-injurious behavior

8

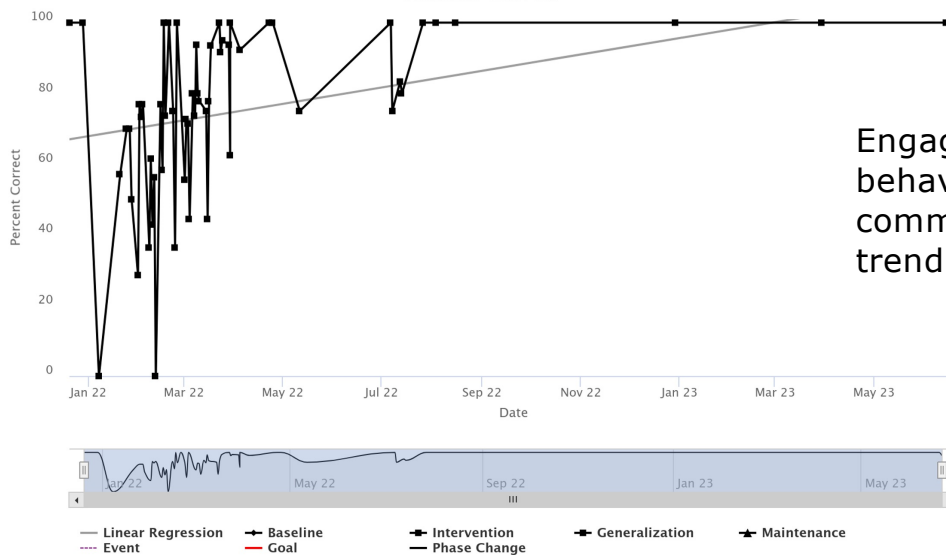
On-Task (Home Environment)



Staying on task has an increasing trend line

9

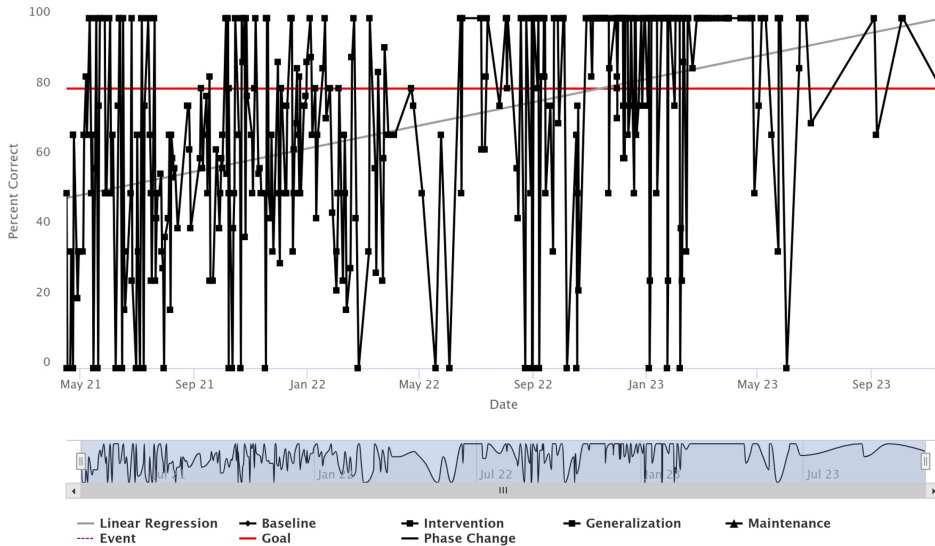
Pro-social Interaction (Community)



Engaging in pro-social behavior in the community is upward trending

10

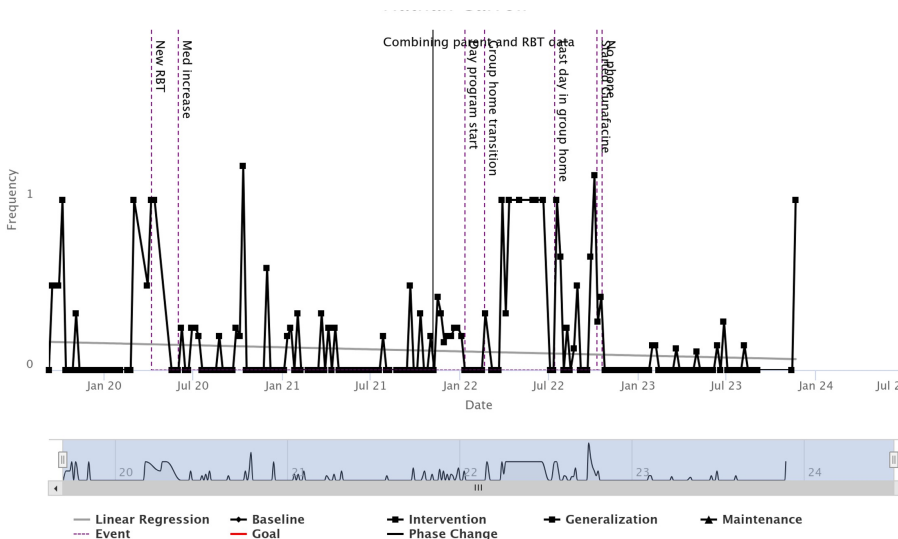
Self Advocacy / Expressing Emotions



Expressing emotions was our key adaptive replacement behavior for emotional outburst engagement. He made so much progress here.

11

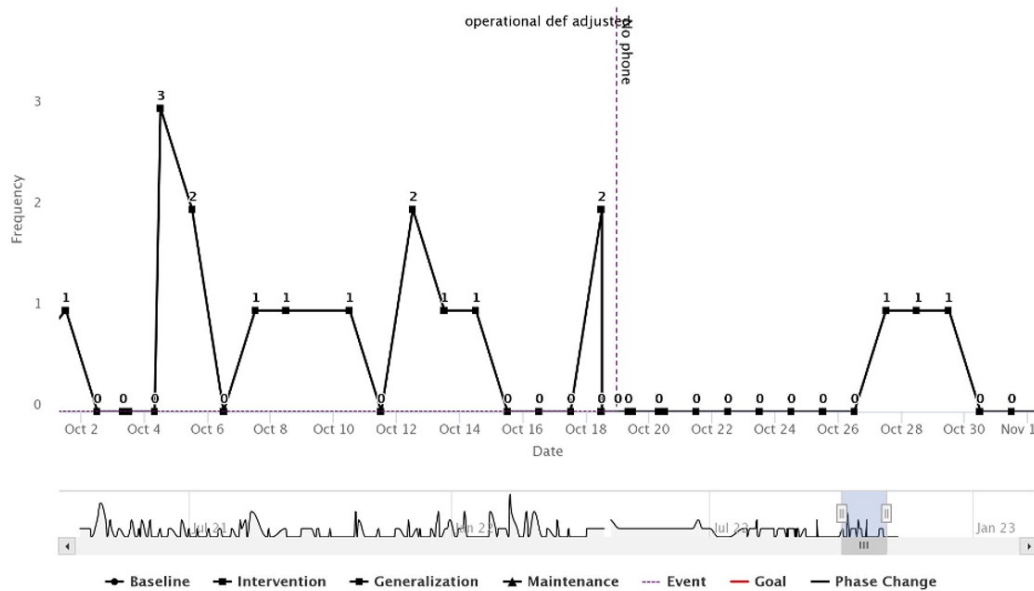
Level 2 Property Destruction



Property destruction has decreasing trend

12

Verbal Aggression (Smaller Scale)



13

Wrap Up – Last Slide Walk Aways

- Imperative to gather a baseline of data, and update with significant changes
- Important to identify cyclic behaviors that can be treated with ABA, CBT, and medications
- Important to collaborate with caregivers and doctors alike to understand medications, side effects (weight gain, anxiety, emotional and clouded thinking)
- This is both directions: physicians, parents and caregivers to start the collaboration discussion beyond simply control of seizures. Bringing data to start the conversation helps.



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