Bridging the Autism Service Chasm:

Implementation of a Coordinated Care Continuum for Patients with the Most Significant Behavioral Health Challenges

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HANDS in Autism® Interdisciplinary Training and Resource Center
IU School of Medicine

Stay Engaged Today

Polling: Use of PollEverywhere to incorporate your perspectives

- Respond at **PollEv.com/handsinautis698**
- Text **HANDSINAUTIS698** to **37607** to join the session, then text responses as we go!

Social media: Post takeaways, pictures & “aha” moments. Tag us so we can support your dissemination.

@HANDSinAutism @TiffanyNeal_PhD

@NaomiSwiezy

Stay connected: Sign up for pointers or newsletters (all or areas of interest) **HANDSinAutism.iupui.edu/eupdates.html**

WHO IS HERE?

Pick a method and keep it handy to share during the session!

Describe your role in 5 nouns.

Follow the link to fill out on your device:
PollEv.com/handsinautis698

Or **text** your response:
Text **HANDSINAUTIS698** to **37607** to join the session, then text responses as we go!

Describe your role in 5 nouns.

OBJECTIVES

Participants within the session will actively:

- Learn about complications and/or regression that leads to sustained support needs across the lifespan for individuals with autism spectrum disorder (ASD)
- Reflect upon their organizational capacity to facilitate and implement evidence-based practices (EBPs) across settings
- Engage with case reviews and the impact of communication, capacity and accessibility upon both provider staff and patient experiences
- Consider the impacts of organizational climates and factors upon competencies and service outcomes
- Explore and inform agile strategies to enhance workforce capacity and retention

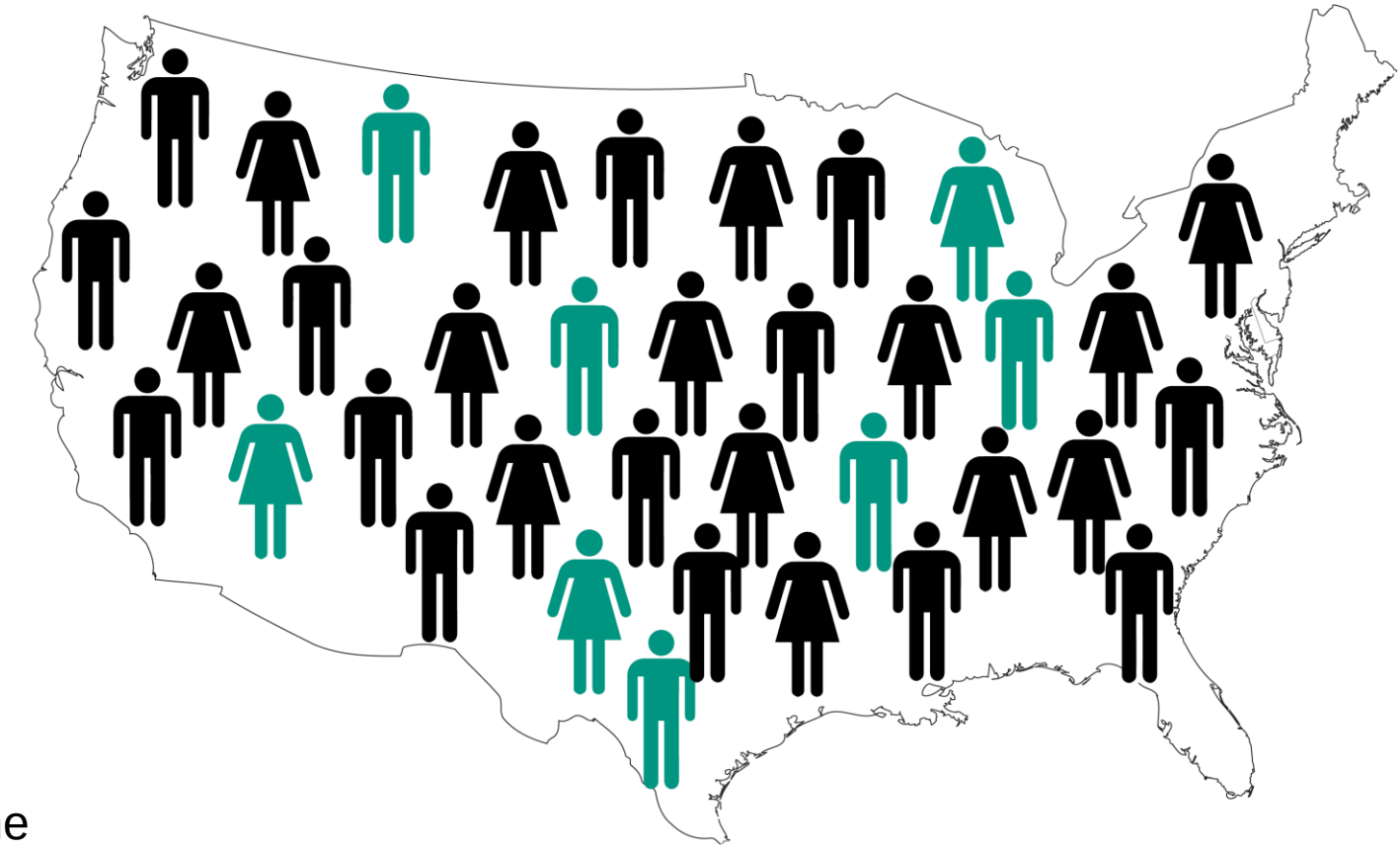
Agenda

1. Autism Services as a Critical Care Need
2. Community-Engaged Frameworks: Capacity, Diversity, and Equity from the Inside Out
3. HANDS in Autism® Coordinated Care Continuum
4. Solution-Focused Impacts and Strategies

Autism Services as a Critical Care Need

Autism Spectrum Disorder (ASD) & Disabilities

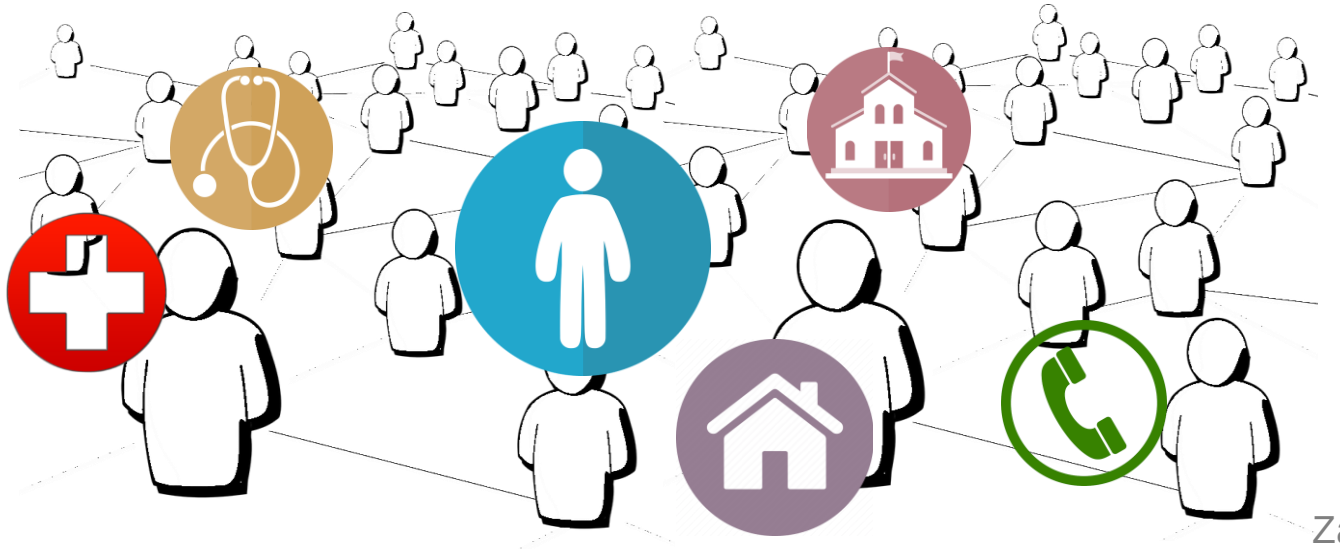
- Disability affects **>15%**
- Nation's largest minority group
- Spans races, ethnicities, socioeconomic status, and more
- ASD affects **>2%** or 1:44 of population
  - Comorbidity with many psychiatric or neurodevelopmental disorders
  - Frequent co-occurring medical problems
  - Support requirements increase across the lifespan
  - Essential interventions relevant to all

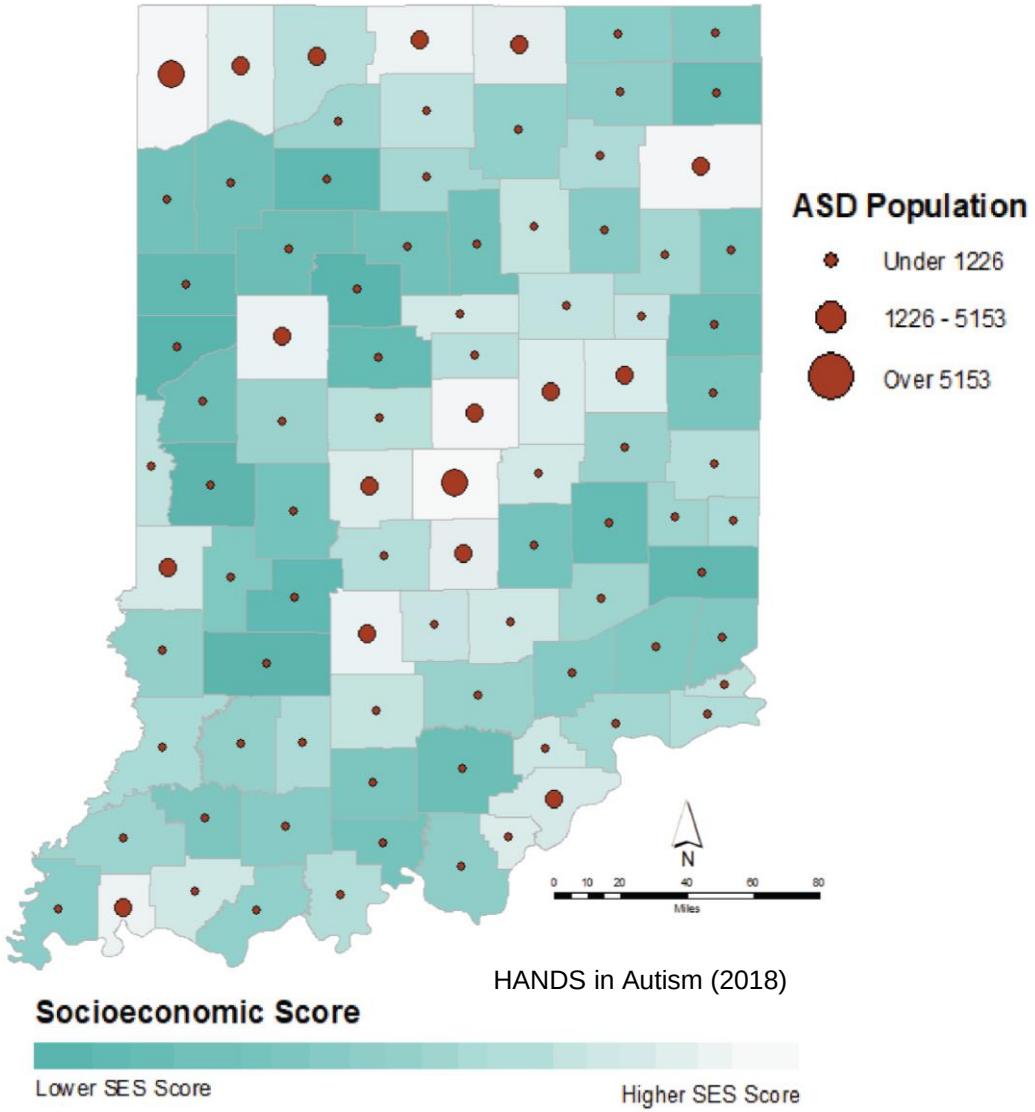


CDC (2021); J Intellect Disabil Res. (2017); WHO (2018)

Autism Spectrum Disorder (ASD) & Disabilities: Spotlight on Indiana

- **17%** with developmental disabilities (DD) with need for added intervention and support
- **>3 million** people directly and indirectly impacted by DD/ASD





HANDS in Autism (2018)

Zablotsky et al. (2019); US Census Bureau (2021)

Autism Spectrum Disorder (ASD) & Mental Health

- **Up to 70%** of youth with ASD have co-occurring mental health conditions compared to 25% of youth without ASD
- Many meet criteria for **>1 co-occurring mental health condition**
  - Attention-deficit/hyperactivity disorder (ADHD)
  - Disruptive behavior disorders
  - Anxiety

} Most frequent co-occurring mental health conditions

- Assessment, stabilization and treatment of all applicable diagnoses and related symptoms are critical to best serve the needs of individuals and improve outcomes

Costello et al (2003); Gurney et al (2006); Lai et al (2019); Simonoff et al (2008)

Service Status

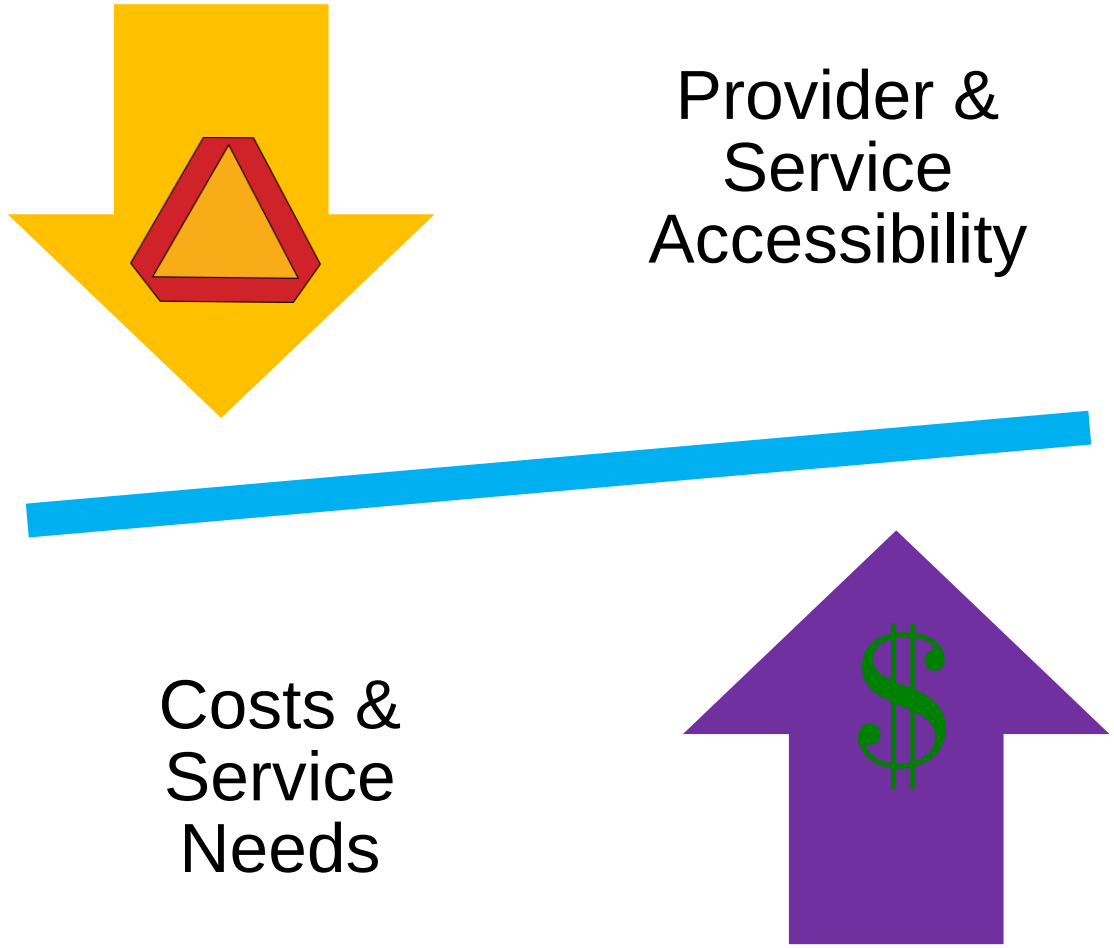
- **<20%** report having any disabilities training
- **>50%** feel “inadequately prepared” to provide ASD/DD treatment
- Lack of available crisis beds to match stabilization needs
- Providers unwilling or unable to accept acute/aggressive youth with ASD/DD
- Lack of front-end diagnostic/assessment services to inform placement
- Inability to meet needs of youth with ASD/DD within the community

Provider & Service Accessibility

Damar and Dept of Psychiatry, IUSM (2019); Ryan & Scior (2010)

Service & Support Costs

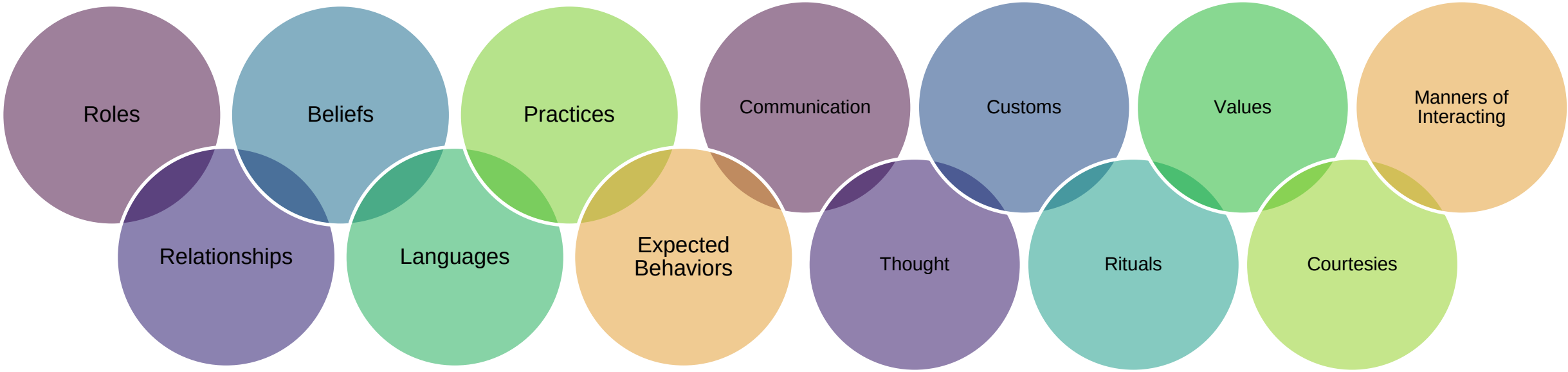
- **$126 billion/year** spent nationally for DD/ASD care
- **$2.3 million/individual** projected costs across the lifespan
- Greatest costs tied to ***long-term residential care*** and ***repeated emergency and/or hospital admissions*** that do not impact or improve long-term functioning of individuals



Ciday, Marcus, & Mandell (2012)

Culture

- The learned and shared knowledge that specific groups use to generate their behavior and interpret their experience of the world

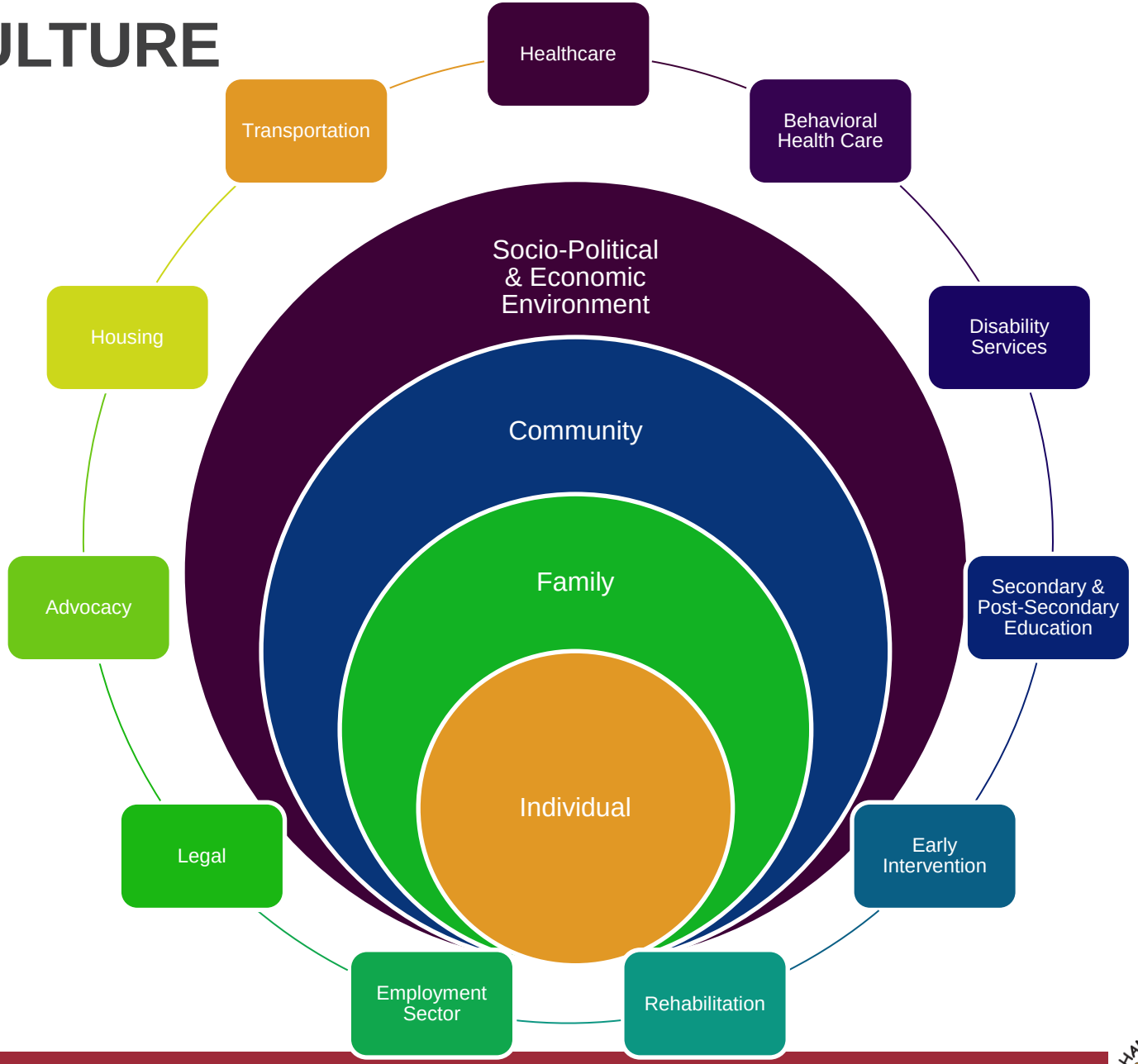


- Applies to racial, ethnic, religious, political, professional and other social groups (e.g., regional areas, SES catchments)
- Transmitted thru social and institutional traditions and norms between generations
- While many aspects remain the same, it is dynamic and constantly changing

Georgetown University National Center for Cultural Competence (2018), Gilbert, Good, & Dunne (2007)

Convergence of Culture & Disability

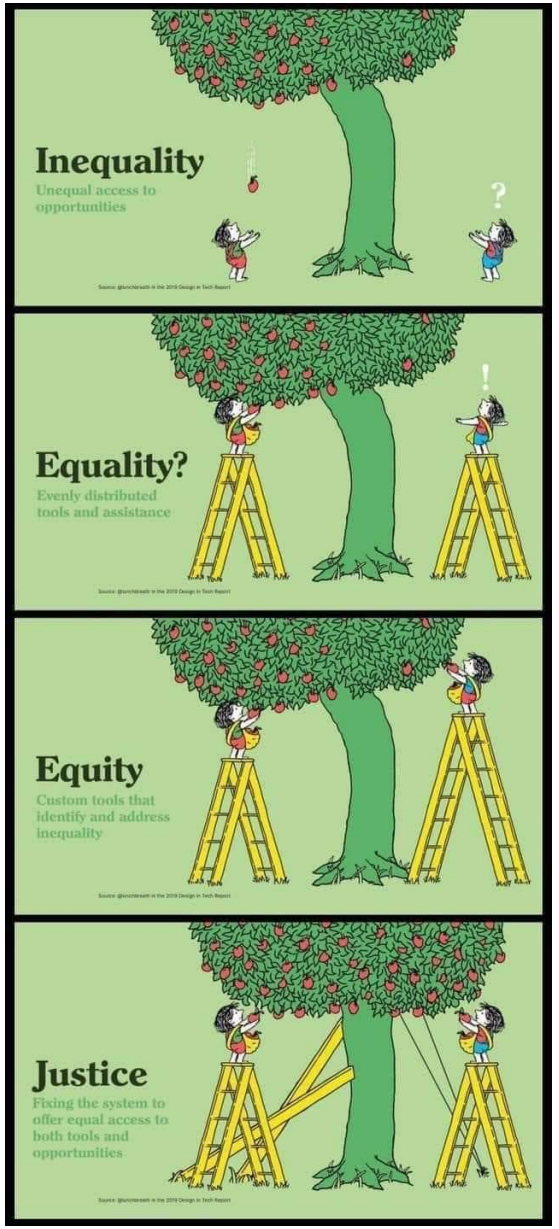
- Impacts of multiple system cultures (outer context)
- Intersection of the core culture surrounding the individual and family (inner context)



Georgetown University National Center for Cultural Competence (2018); Nilsen & Bernhardsson (2019)

Service Needs

- **Assessment:** Safe and effective initial and ongoing assessment to inform services and care
- **Stabilization:** Medical and behavioral stabilization
- **Coordinated and integrated care:** Community-based support towards team facilitation and consistency in implementation with community-informed, culturally responsive plans that respect, respond and adapt to all individuals, family/caregivers, providers and teams towards stabilization and success in the community



Activity: Where does your perspective fall?

Pebbles
&
Feathers

Where does your perspective fall?

POSITIVE: Many positive experiences

GOOD: More positive than negative

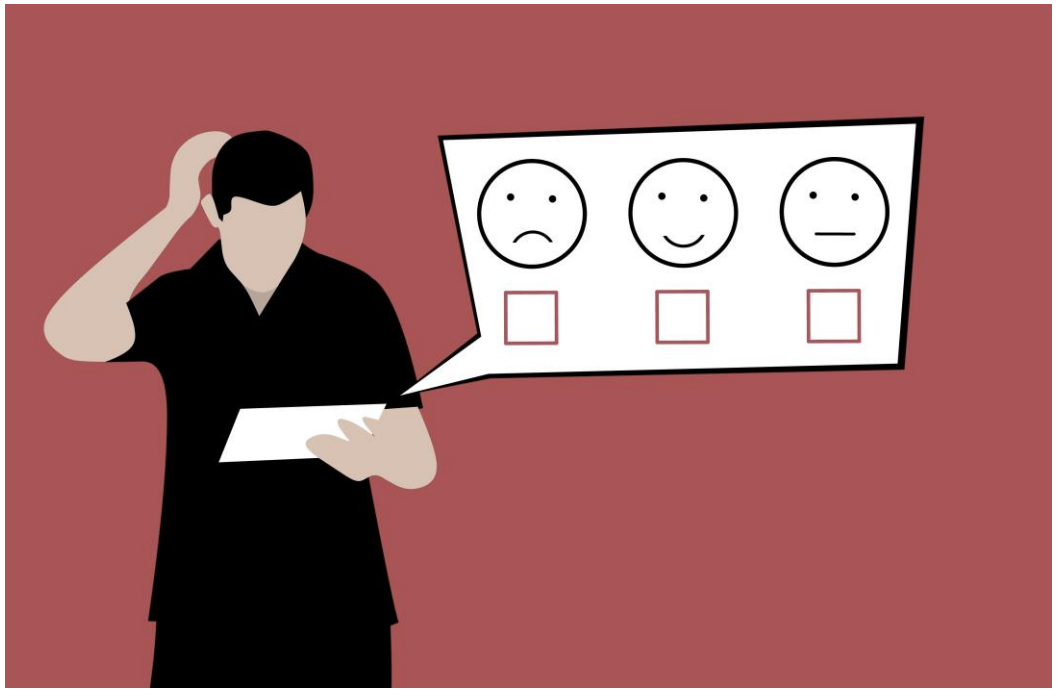
OKAY or NEUTRAL: Both positive and negative feelings and experiences

UNSURE: More negative than positive

NEGATIVE: Only negative experiences

Activity: Personal Perspectives

- When considering your perspectives, how has it been influenced?
  - Subjective experiences (positive or negative) thru training, impressions or other,
  - Individual interactions with autistic individuals,
  - Organizational culture and capacities in service delivery, training, or other.



When considering your perspectives, how has it been influenced?

A. Subjective experiences (positive or negative) thru training, impressions or other

B. Individual interactions with autistic individuals

C. Organizational culture and capacities in service delivery, training, or other

D. Both A & B (subjective & individual interaction)

E. Both B & C (individual interaction & organization)

F. Both A & C (subjective & organization)

G. All of the above - A, B & C

Community-Engaged Frameworks:

Capacity, Diversity, and Equity from the Inside Out

Organizational Context: It takes a community!

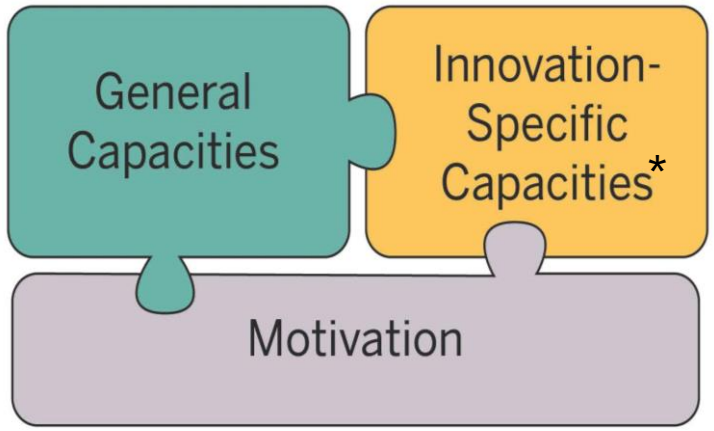
- Community-informed processes and coordinated care involve:
  - Use of evidence-based practices
  - Service and decision-making coalitions and networks

- Accessibility to these is limited among those with more diverse, non-white backgrounds to fully consider needs of community

- Effectiveness of these is hindered without true representation to inform intervention and strategy::
  - Acceptability
  - Usability
  - Utility
  - Feasibility
  - Fidelity

Lord et al (2021); Hays (2008)

Implementation Climate: Takes a Proactive Eye towards Readiness for Change



*Innovation-Specific = EBP

General Capacities - aspects of an organization's healthy functioning that reflect its potential to initiate and sustain change

- Flexible thinking about team members and roles
- Willingness to engage in training and coaching

Innovation-Specific Capacities - specific conditions and supports needed to implement a particular program or practice effectively

- Reconsider and learn new approaches – attitudes towards approaches
- Preparation for behavior, extinction bursts and potential for crisis
- Emphases and fidelity with proactive orientation

Motivation - willingness or desire of individuals in an organization to change and adopt an intervention, as reflected in their beliefs and attitudes

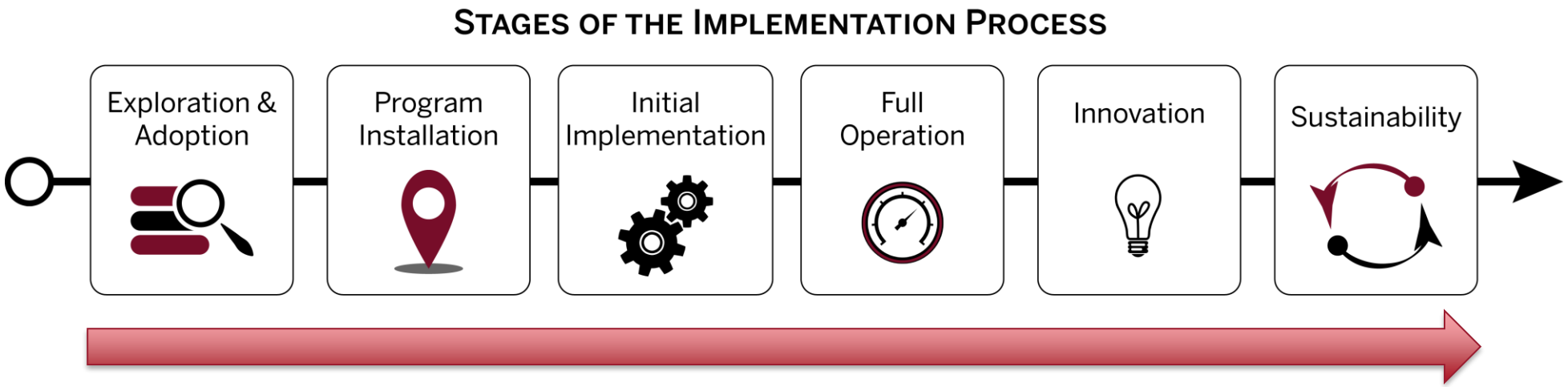
- Interest in working thru and holding one another accountable
- Accessibility and work to build and engage as a team

Facilitators & Barriers to the Process…

Moderators: While it is well-established that evidence-based practice can improve outcomes for individuals with disabilities, consideration of the ***strategies required for, and the barriers and facilitators to, successful implementation*** are essential. Examples may include:

- Service access and diversity (i.e., providers, hours)
- Knowledge and resources (i.e., training and tools)
- Sense of personal safety and support
- Rights and regulations vs local policies
- Behavioral and skills teaching knowledge: Understanding of behavior (e.g., burst not mean back to BL)
- Openness to collaborative consultation: Expectations to working together, assessing before changing direction
- Timing: Systems change takes 3+ years, families are not without other demands

Implementation Outcomes: Require Leadership

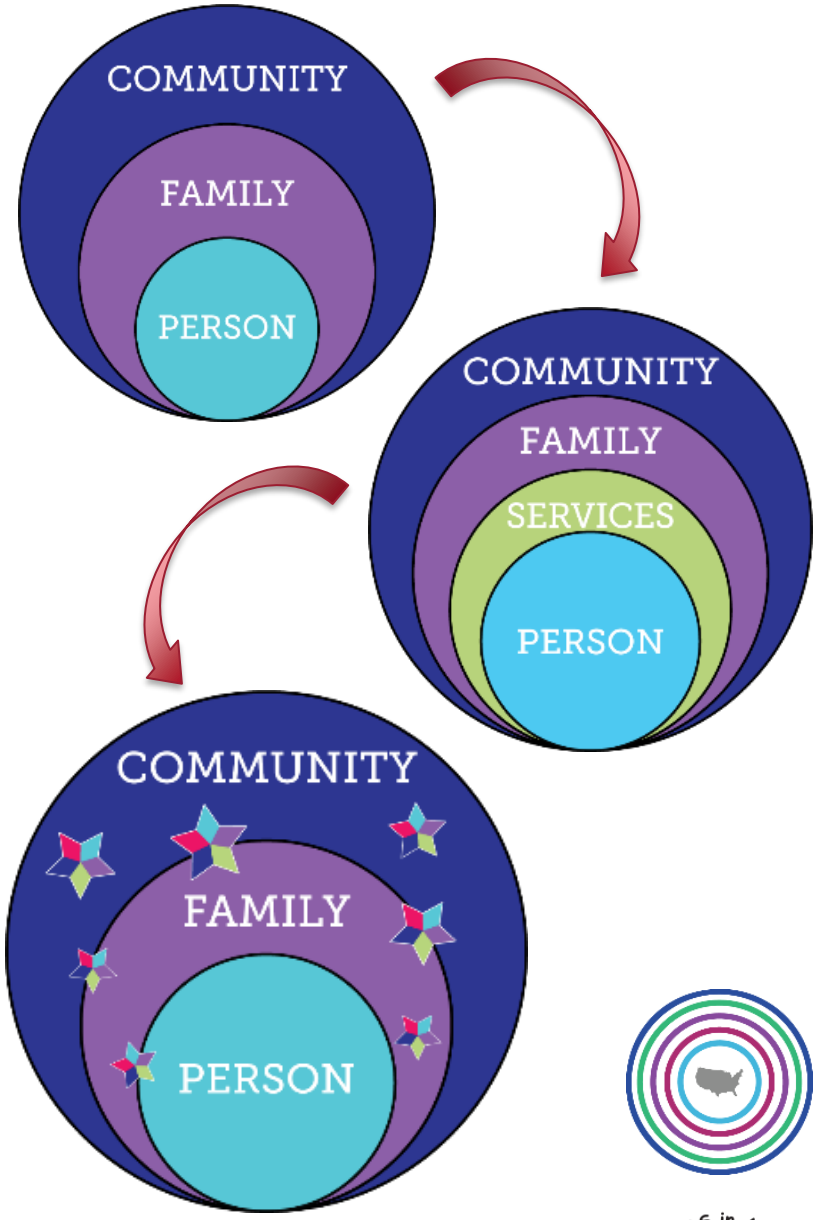


Necessary components of an ***influential champion or organizational partner*** to move from exploration to sustainable systems change across inner and outer contexts

- Community-Informed Processes
- Ongoing Data-Driven Processes
- Customizable Services, Materials, & Resources
- Team Facilitation
- Evidence-Based Principles
- Proactive and Skills Focused
- Systems & Implementation Science Approach

Inner Context: Needs Integrated Care & Navigation Support

- ***Integration and continuity within the natural setting*** to prevent hospitalization, EMG interventions, and overall recidivism
- ***Relevant*** across the lifespan, disabilities and communities
- Importance of more ***robust and ongoing support*** to increase local capacity and sustainability:
  - family and provider training and access to materials and resources
  - real-time monitoring of outcomes to inform programming
  - team facilitation for consistent perspective/approaches across systems
  - technology innovations for greater continuity
- Key to ***minimizing gaps*** of providers through support, networking, training in fidelity of implementation

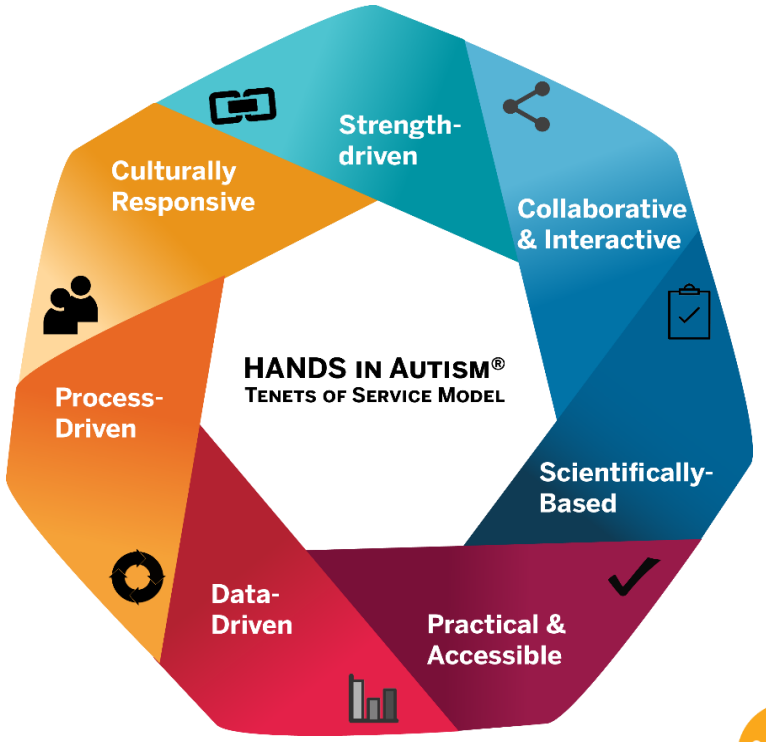


Responding to Needs:
HANDS in Autism® Coordinated Care Continuum

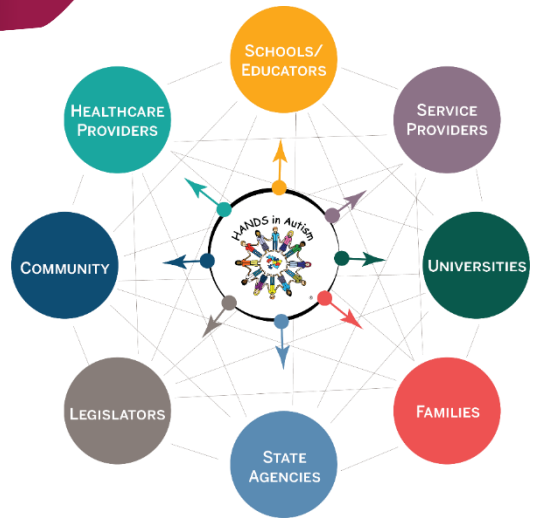
*NDI is overseen and sponsored by DMHA, FSSA

HANDS Missions

1 Provide **unique, interactive learning opportunities** towards improved understanding and implementation of EBPs.

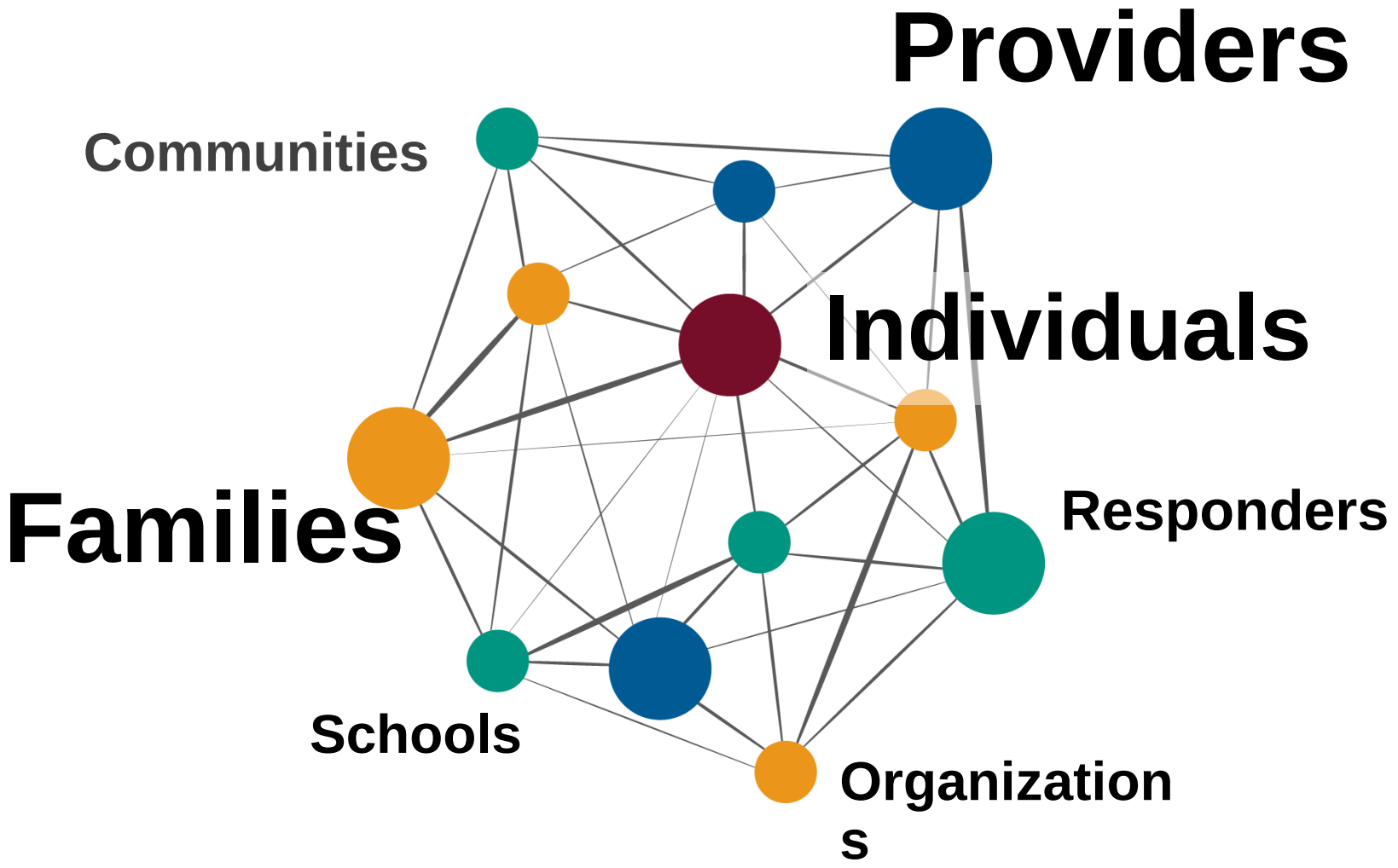


2 **Build bridges** of information, resources and collaboration across family, educational, medical and community systems.



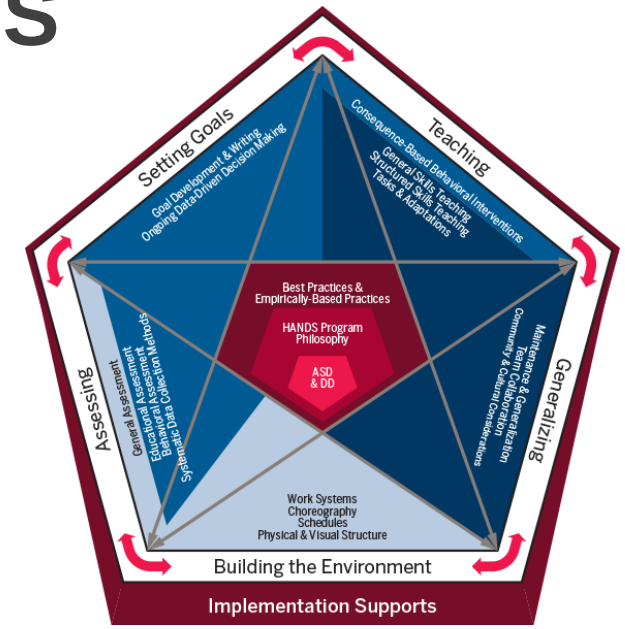
HANDS Vision

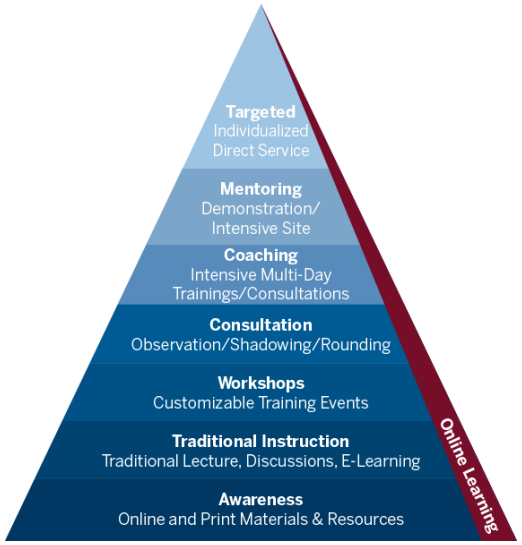
Building **local capacity** in effective implementation of **EBPs** and local community networks with **shared responsibility** for positive individual and family outcomes.



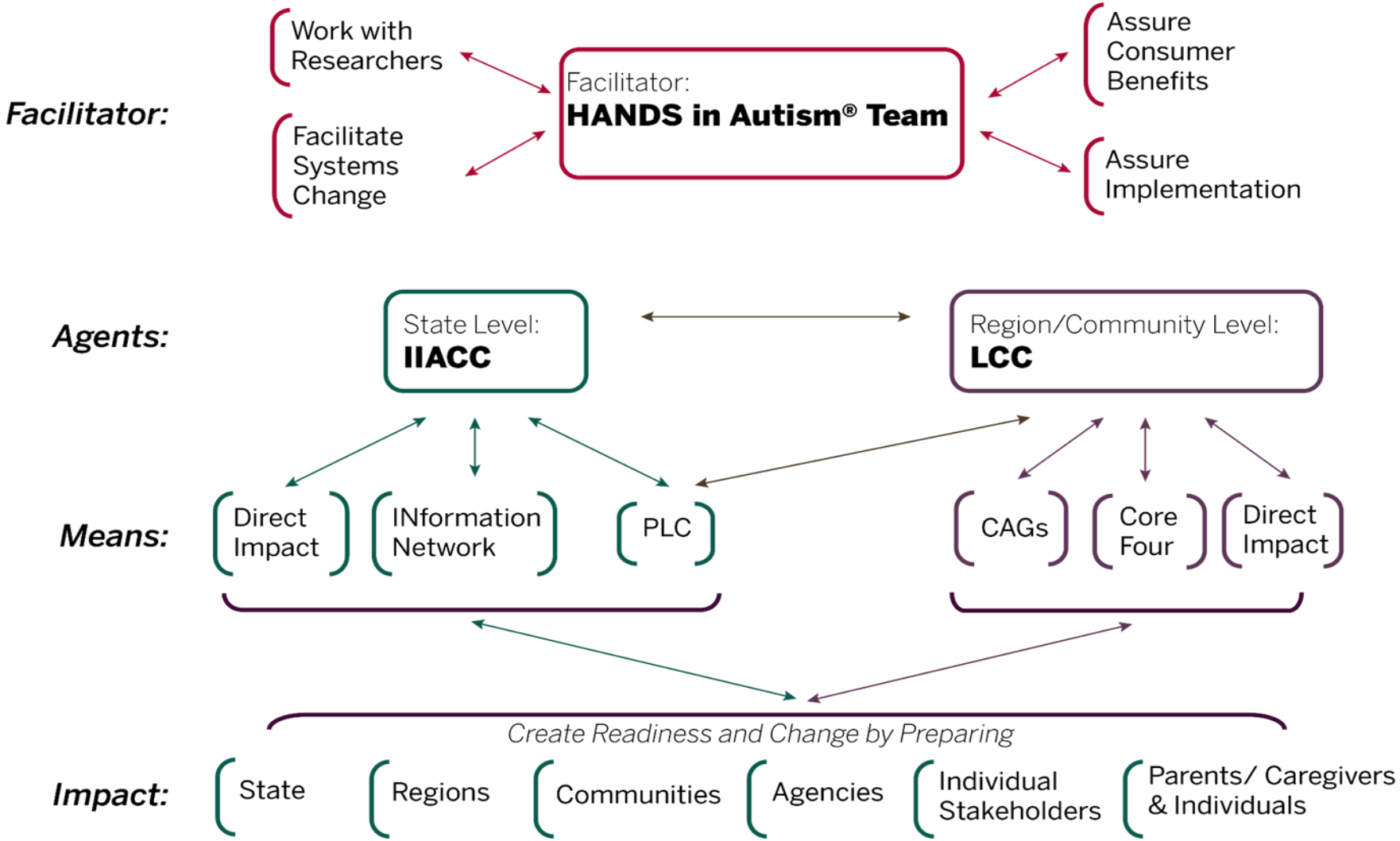
Essential to the Process

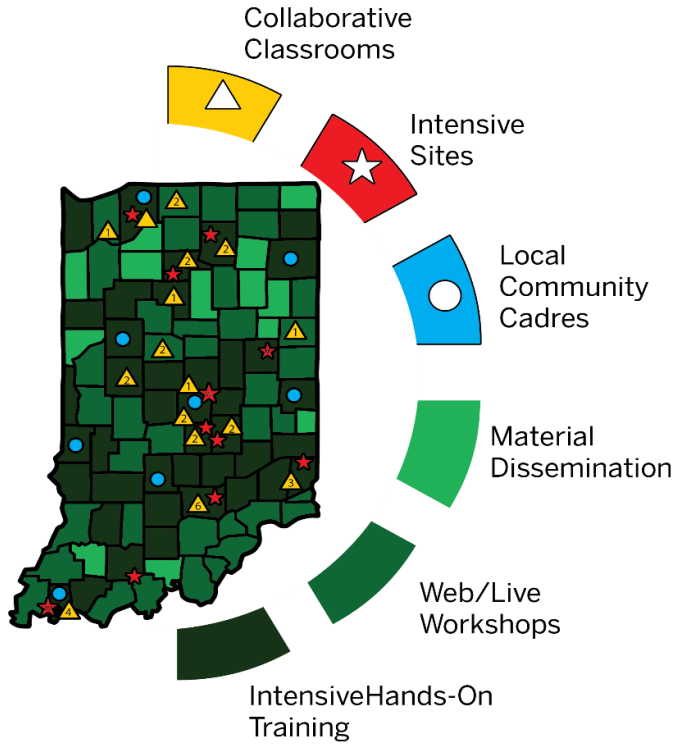
- Systematic Process for Training and Intervention
- Customizable Service Levels
- Customizable Resource Options





Large Engagement Network





Lewis et al (2018)

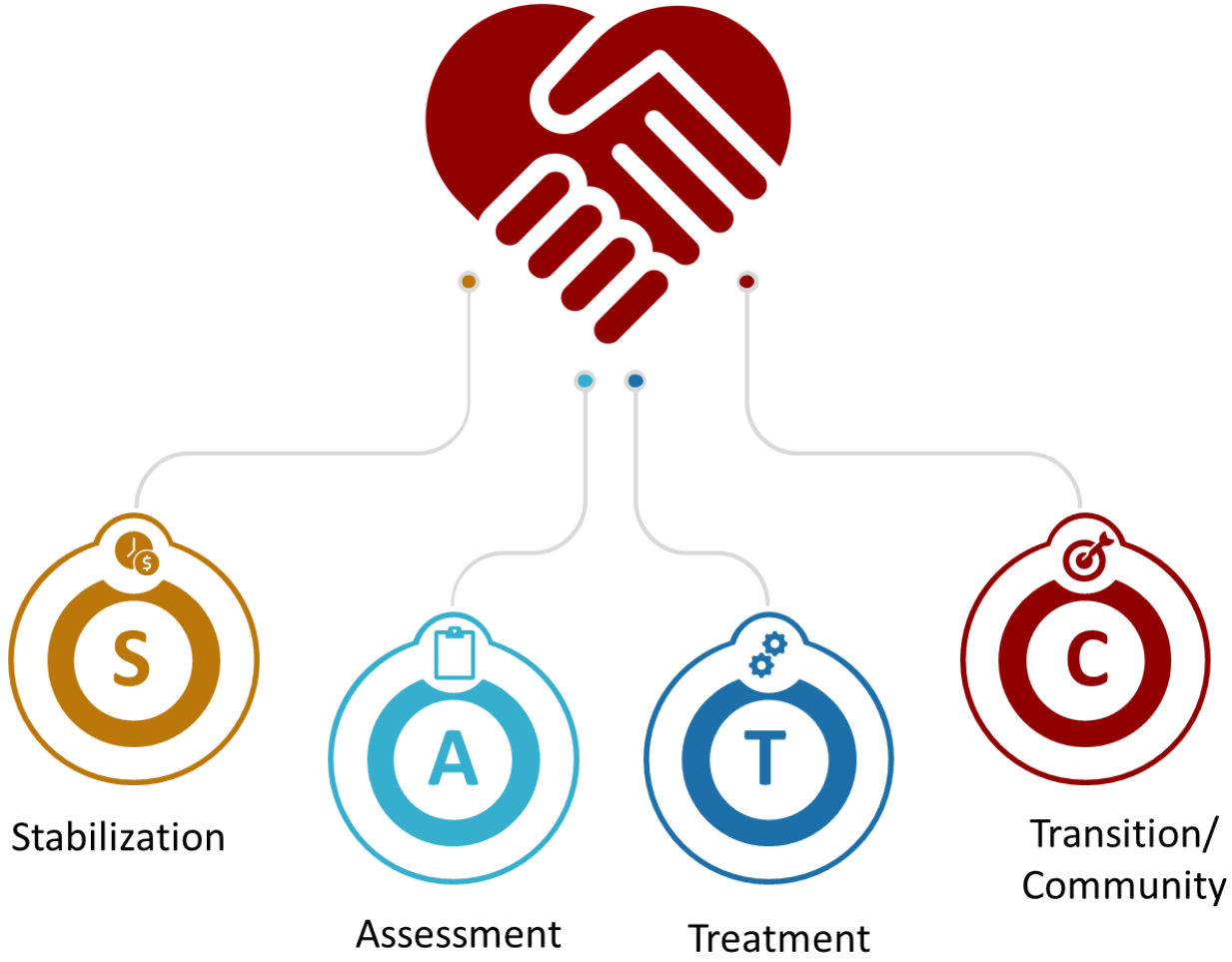
Indiana NeuroDiagnostic Institute (NDI) Advanced Treatment Center, Adolescent Autism Unit

- Filling a need in patient care and coordination
- Building on unique strengths thru partnership

DAMAR
Remarkable people. Remarkable results.

HANDS in Autism

INDIANA UNIVERSITY
SCHOOL OF MEDICINE



HANDS in Autism 15 YEARS

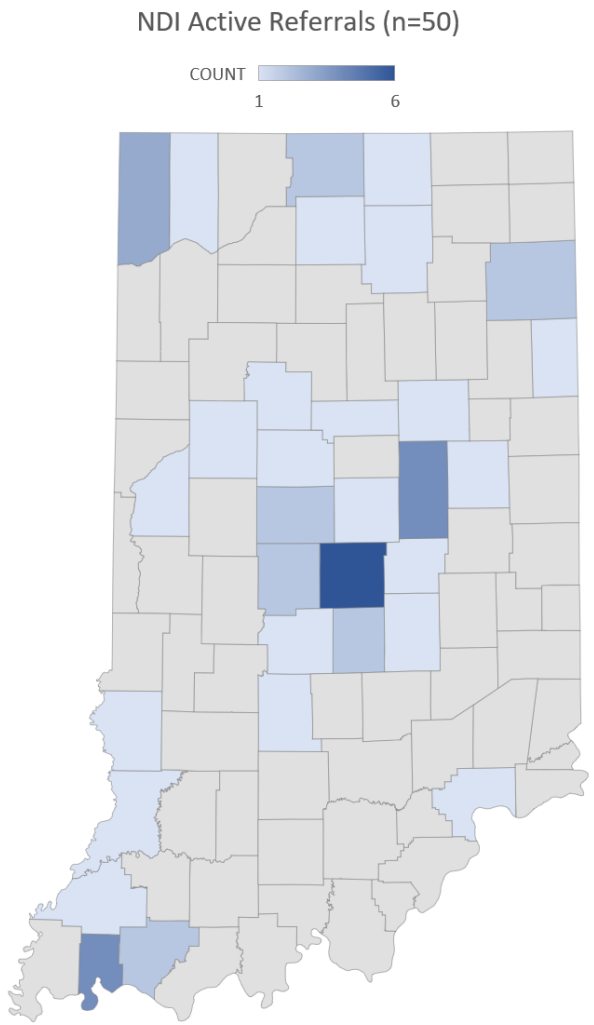
Setting up for Sustained Implementation

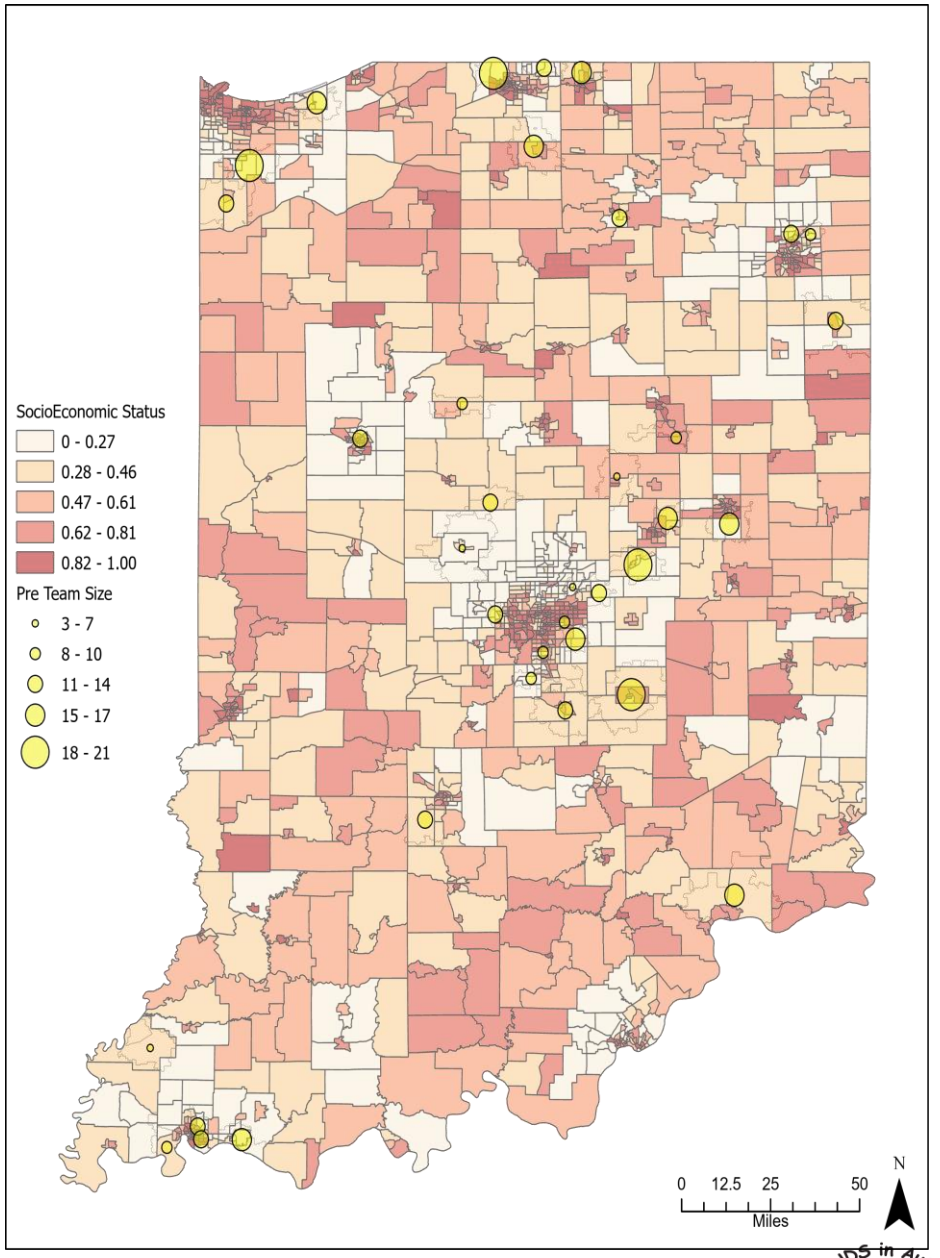
Well-established that evidence-based practice can improve outcomes for individuals with disabilities

Also essential is consideration of the ***strategies*** required for and the ***barriers and facilitators*** to successful implementation

Fixsen & Blasé (2008)

Patient Demographics

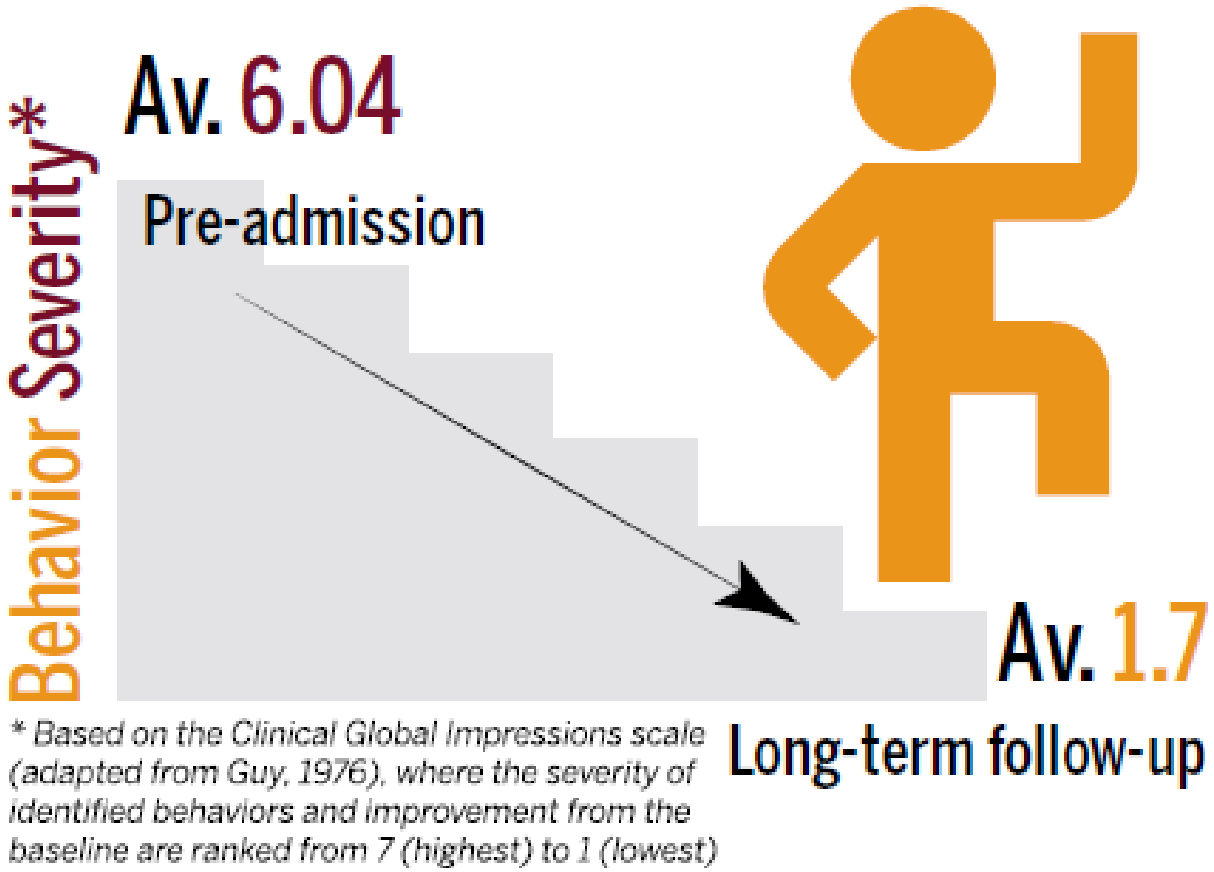




HANDS in Autism (2022)

Patient Demographics

- **71 referrals** since 02/2021
- **51 patients** accepted
  - 71% (n=36) male
  - Common target behaviors:
    - Physical aggression
    - Property destruction
    - Self-injurious behavior
    - Verbal aggression
    - Elopement



Solution-Focused Impacts & Strategies

Case Example 1

The 15-year-old patient treated for intermittent explosive disorder (IED), autism spectrum disorder (ASD), attention deficit hyperactivity disorder (ADHD), and asthma, had a ***history of meltdowns beginning in 4th grade*** that resulted in ***multiple school placements and provider changes***. With the greatest behavioral impacts occurring within the home setting and the family having a limited network of resources, behaviors had escalated to the level of ***injury of caregivers and need for first response involvement across more than 170 times in the 2 years prior to admission***.

Case Example 1: Moderators and Care Considerations

Inner context

- Mother and father: health and other challenges (e.g., past traumas with first responders and PG)
- Limited social supports (i.e., maternal uncle)

Outer context

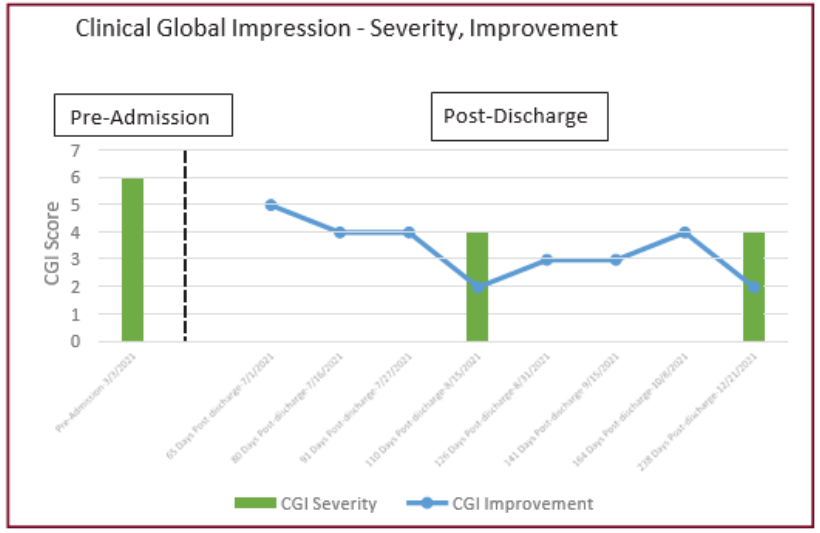
- Limited success in accessing regular and trained support (provider “hangs” with PG) especially at start during “honeymoon” when needed for consistency and support
- School: limited engagement at start
- First responders: emotions and frustration running high—seen as imposing, threatening and safety concerns to community

Case Example 1: Readiness

Through facilitation and training, it took a philosophical shift to prepare and understand change:

- **General capacity**
  - Large team (others added ongoing) with shared responsibility and many perspectives and approaches
  - All valid but all impact one another and may compete (e.g., family bx to police to ED med change without good disposition plans to back to family/school and cycle)
  - Shuffled across MH, medical and justice systems—need training
  - Siloed work ineffective—need coordination and integration towards consistency in implementation
- **Innovation-specific capacity**
  - Emergency and crisis does not address root issues
  - No placement will result in quick or LT resolve to the issues
  - Proactive vs. crisis orientation (e.g., tiers of intervention and support/family safety plan; build relationships and new skills to facilitate teaming between all—family, child, first resp, school, probation; build on strengths and resources of all)
- **Motivation**
  - Family as asset, backbone, decision maker, advocate
  - Alter LT behavior patterns, ask questions, follow recommendations, learn to advocate despite own disabilities, use resources provided

Case Example 1: Data



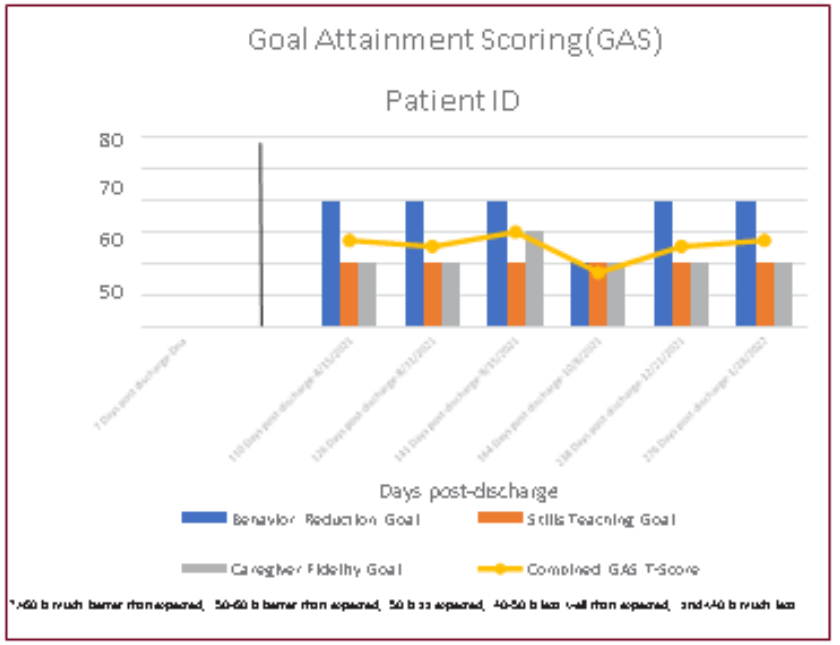
CGI: Behavioral reduction

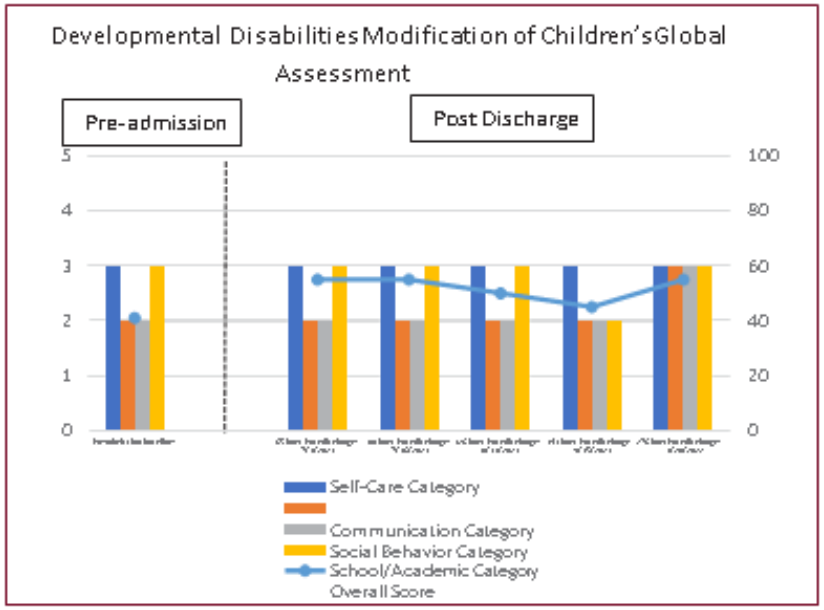
GAS:

Behavior reduction,

Skills acquisition, &

Parent/Caregiver Fidelity





DDCGAS: Overall functioning

Activity: Trajectories, Readiness and Moderators

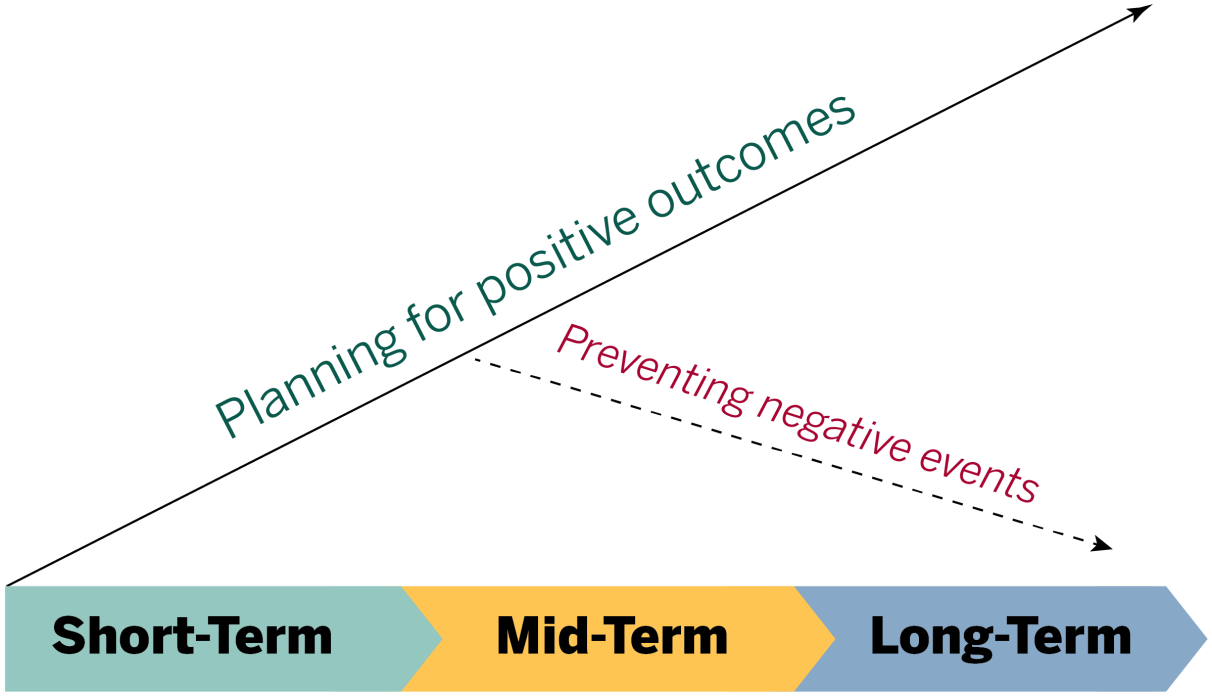
Keep this up for the next few slides & activities.

1. Connect to our shared JamBoard
   - https://tinyurl.com/HANDSreflect

2. Listen to each case and individual trajectory specific to movement towards positive outcomes and/or negative events

3. As each step or activity is shared along the trajectory or course, consider what alternatives could have been considered within areas of:
   - Readiness (proactive preparedness steps in general capacity, intervention capacity, motivation),
   - Inner (individual) contexts, or
   - Outer (organizational and system) contexts

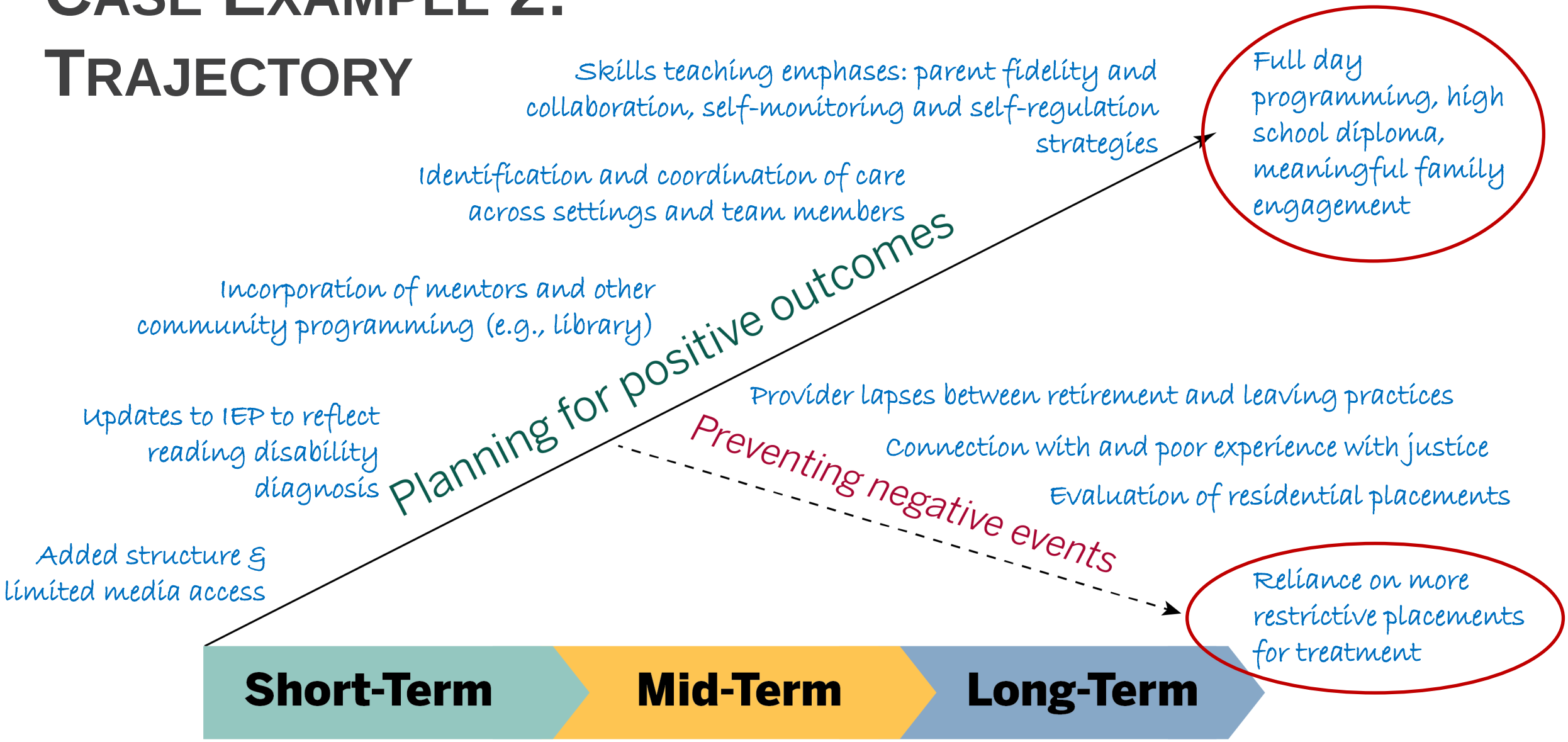
4. Record your thoughts for each step on the JamBoard (see the key on the slides and examples for a start to each…)



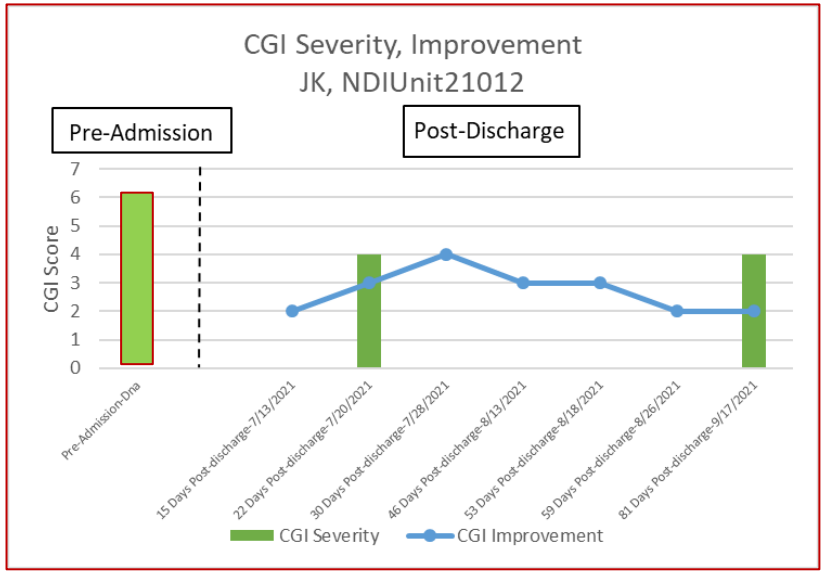
Case Example 2

The 15-year-old patient treated for disruptive mood dysregulation disorder (DMDD), attention deficit hyperactivity disorder (ADHD), anxiety and a reading disorder had struggled significantly within the school setting having not completed any formal or standardized testing since early elementary and had gradually decreased to one hour of homebound with a phased plan to incrementally increase only coming in for reinforcing activities. Family was regularly picking the patient up and looking for residential options given the high rates property destruction, noncompliance, physical aggression and elopement across settings. While considerable structure was in place in the school setting, a lack of providers, the patient's increasing size and differences in behavioral programming implementation across settings led to behaviors that were increasingly resistant to behavioral change. The patient greatly enjoyed talking with others but would often exaggerate stories.

Case Example 2: Trajectory



Case Example 2: Data



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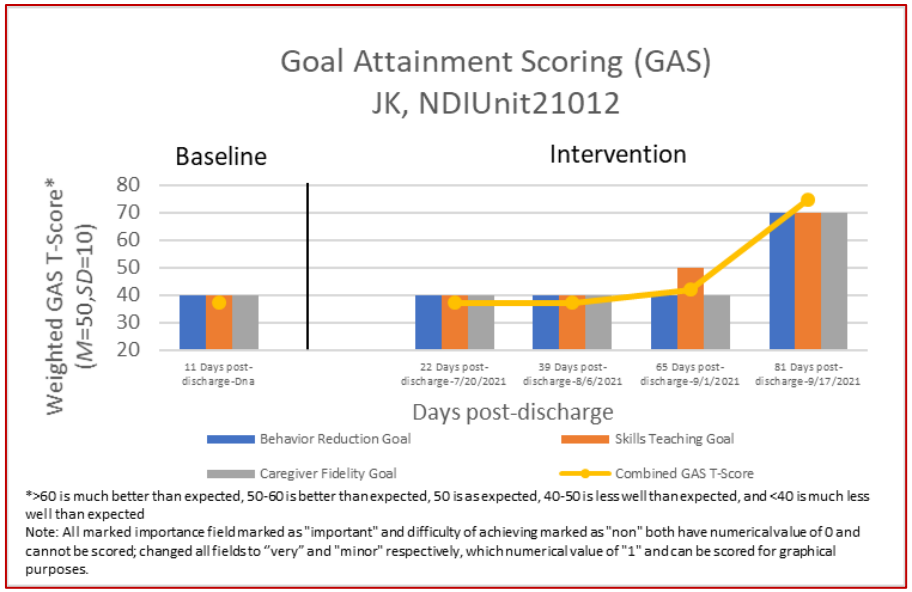
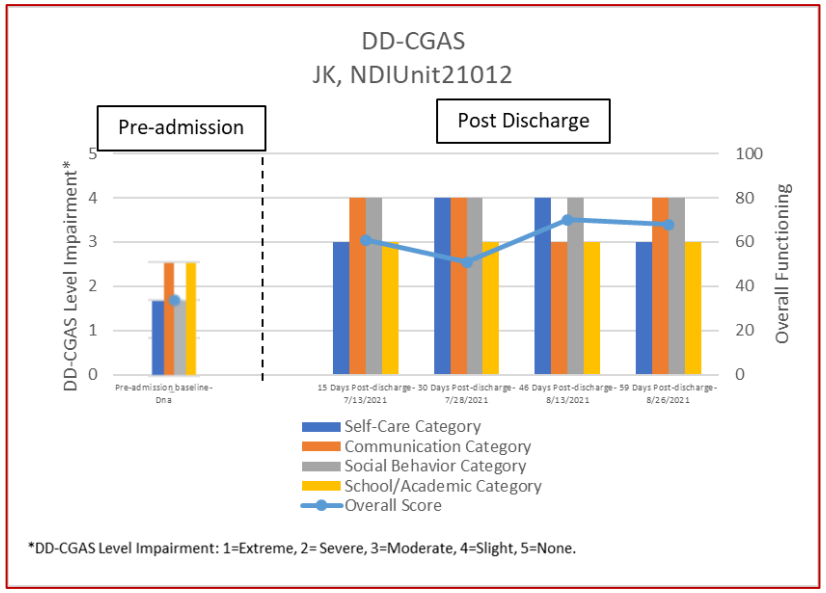


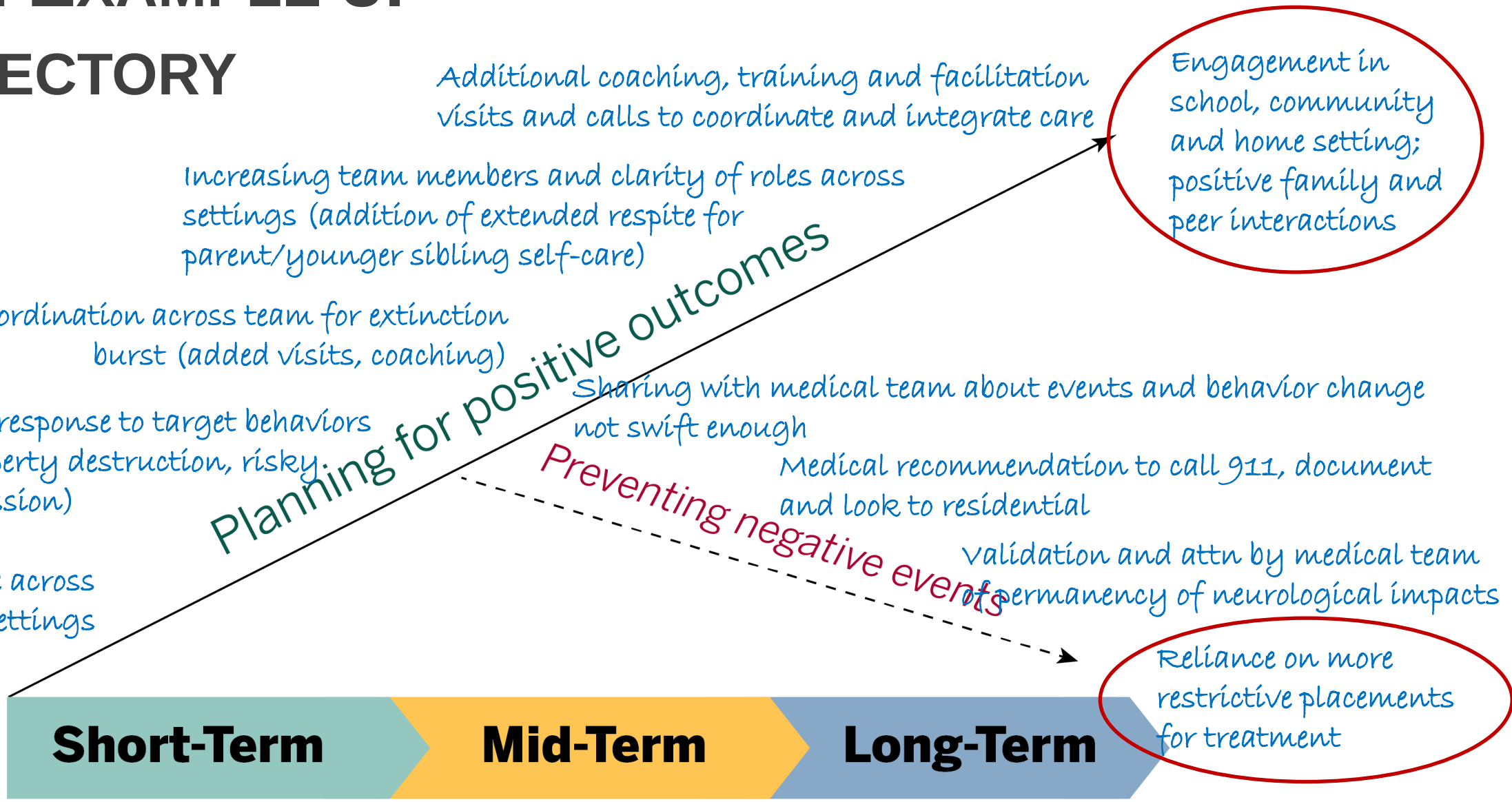


DDCGAS: Overall functioning

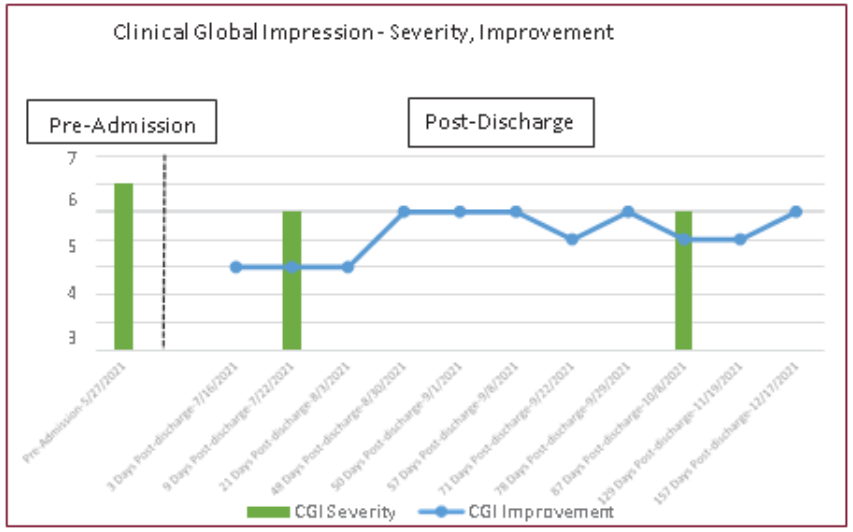
Case Example 3

The 13-year-old patient treated for disruptive mood dysregulation disorder (DMDD) and attention deficit hyperactivity disorder (ADHD), had a history of leukemia at 3 years of age followed by increased aggression attributed primarily to medical sequelae. Further increases in behavior were documented by year due to medication changes, expressed personal upheaval resulting in multiple family moves, and potential trauma. Differences in behavioral programming implementation across settings along with difficulties in team members being able to respond to the particular rectal behavioral topography and areas of restricted interest led to behaviors that were increasingly resistant to behavioral change.

Case Example 3: Trajectory



Case Example 3: Data



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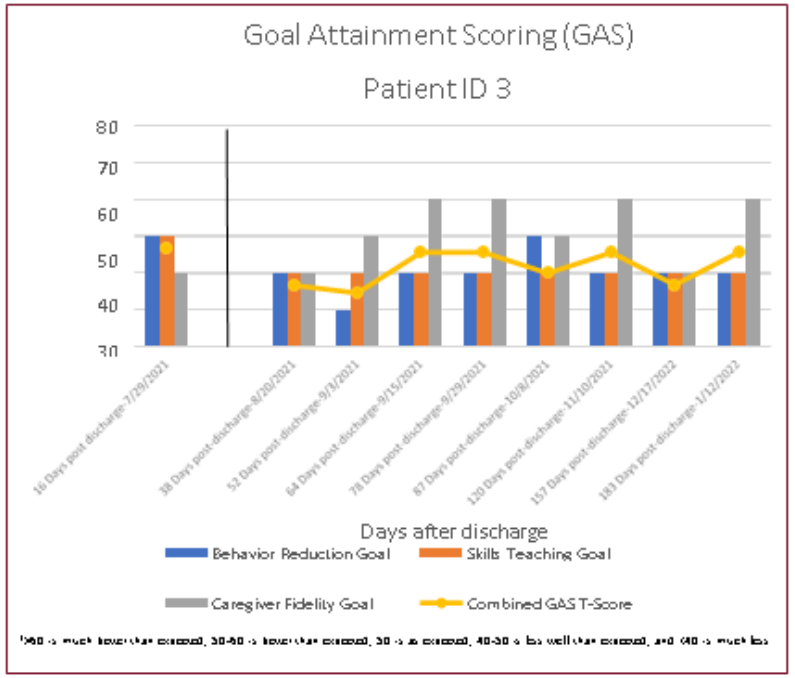
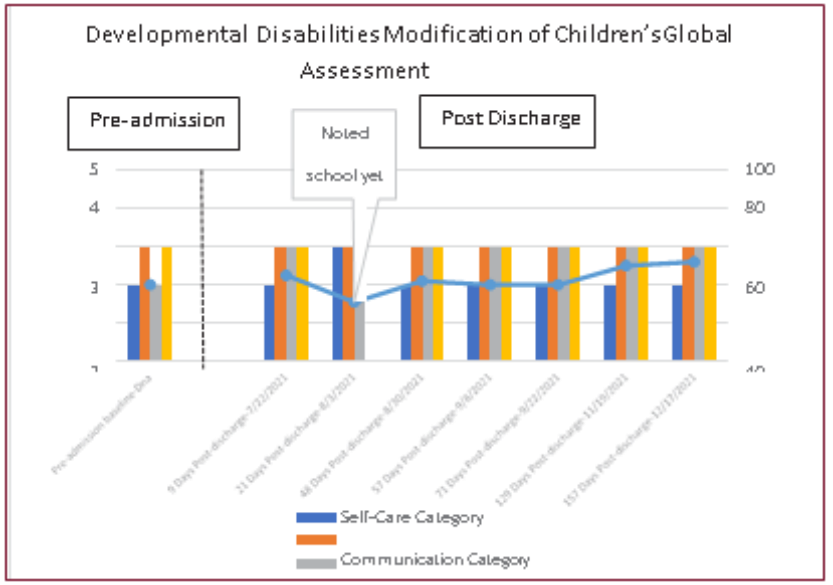
Skills acquisition, &

Parent/Caregiver Fidelity





DDCGAS: Overall functioning

Activity: Pause & Relect

Pause and stay on the same JamBoard but move to the next slide…

Reflect on the concepts discussed, make connections to your prior knowledge or experiences, and consider the most salient prompt(s) for you:

- I've changed my attitude about..
- I became aware of…
- I was surprised about…
- I related to…
- I questioned…
- I learned...

Let's continue the conversation and consider options towards more cost effective and sustainable outcomes…

Note your email to stay engaged!