The START Model Overview

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Presentation Overview

Describe the START Model

START in Action: Clinical Vignettes

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IDD and Mental Health Conditions

The DSM-5 defines IDD as a neurodevelopmental disorder characterized by significant limitations both in intellectual and adaptive functioning in three domains. These domains determine how well an individual copes with everyday tasks.

17%

Approximately 17% of children (3-17) have one or more developmental disabilities

(Centers for Disease Control and Prevention, 2022)

2%

Approximately 2% of the US population has an Intellectual Disability

(McBride et al., 2021)

33 – 59%

Studies have shown 33 – 59% of individuals with IDD have at least one mental health condition

(Lineberry et al. 2023)

21%

In comparison, 21% of adults in the US have a diagnosable mental health condition

(Lineberry et al. 2023)

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IDD and Mental Health Conditions

- These mental health conditions often contribute to challenging behavior.

- Aggression and self-injurious behavior are two of the most common reasons for referrals for mental health services for individuals with IDD.

- These difficulties are often **misdiagnosed**, **underdiagnosed**, or **undiagnosed.**

- Few evidence-based treatments exist even when detected.

(Pena-Salazar et. al. 2018, Krahan et al. 2006)

- This gap has translated into the use of costly and ineffective care for individuals with IDD, resulting in:
  - Frequent emergency department and psychiatric hospital visits
  - Poorer quality of life
  - Earlier age of mortality

(Kalb et al 2012, 2016, Lauer et al. 2015, Nota et al. 2007)

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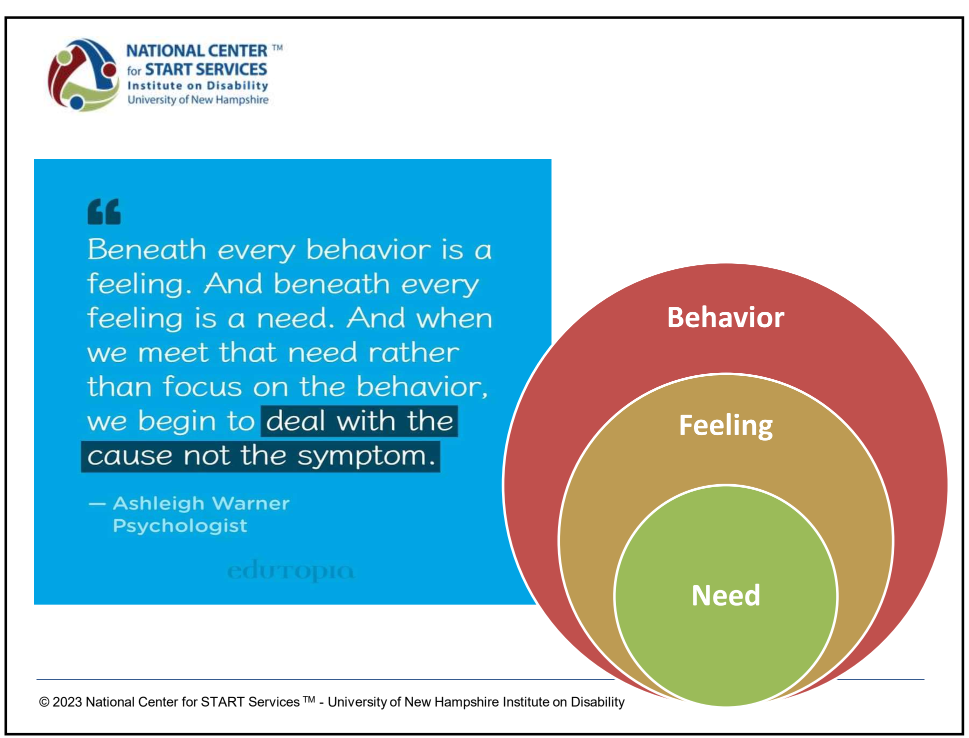

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Barriers in the IDD System

- "Troublesome" behaviors are considered unacceptable in many support and service venues
- The last and least served
- Concept of "primary" vs "secondary" disorders
  - Not trained in mental health or health practices that could contribute to the challenging behavior

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Barriers in the Mental Health System

- Stigma
- Lack of training and expertise
- Medication issues
- Believe that challenging behavior is a result of developmental issues alone *(diagnostic overshadowing)*
- Belief that individuals with IDD don't or can't experience mental health conditions

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Defining Effective Services
"The 3 A's"

Access

(timely, available)

Appropriateness

(matches real needs, provides tools)

Accountability

(responsiveness, engaging, flexible, cost-effective)

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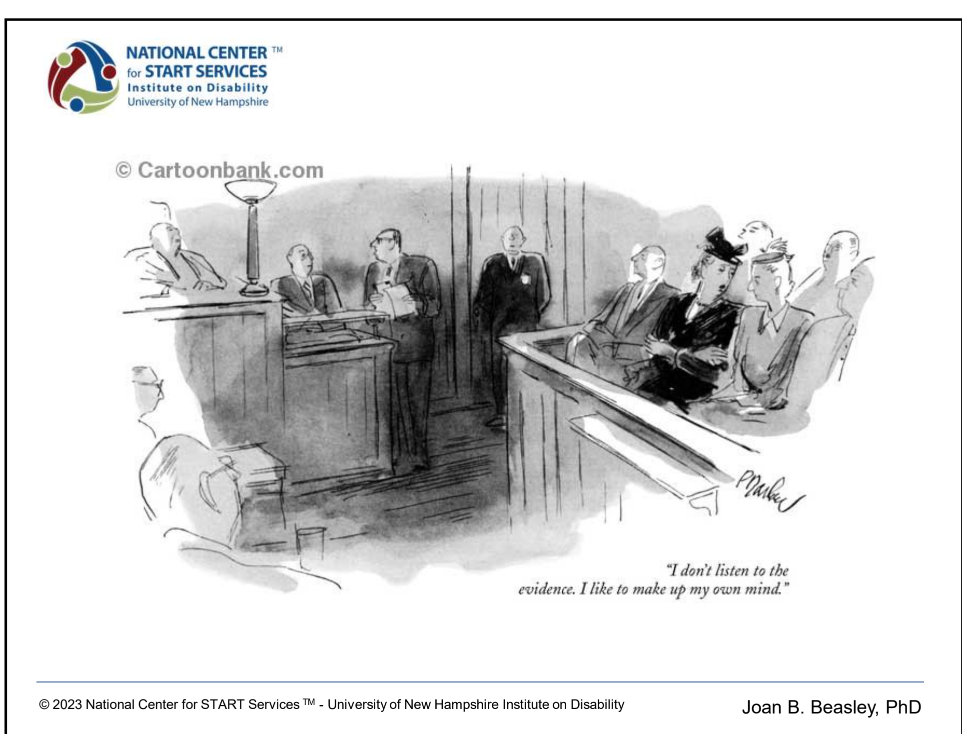

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The START Model

- **START** is an evidence-based model of integrated community crisis **prevention** and **intervention** services for individuals ages 6 and older with **intellectual and developmental disabilities** and **mental health** needs.
- Focuses on community **linkages**, **filling in gaps**, and **capacity building** across the system of care rather than segregated or duplicative service development.
- First developed in 1988 by Dr. Joan B. Beasley, and we're **still learning**!
- Cited as a **best practice** in the 2002 US Surgeon General's report and by the National Academy of Science in 2016

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(Beasley, Kroll, & Sovner, 1992)

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START

S – *Systemic*

T – *Therapeutic*

A – *Assessment*

R – *Resources*

T – *Treatment*

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Crisis Prevention and Intervention through a System of Care Approach

"A crisis is a problem without the tools to address it"

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Reflective Inquiry and Assessment

"If I had an hour to solve a problem I would spend 55 minutes thinking about the problem and 5 minutes thinking about the solution."

-Albert Einstein

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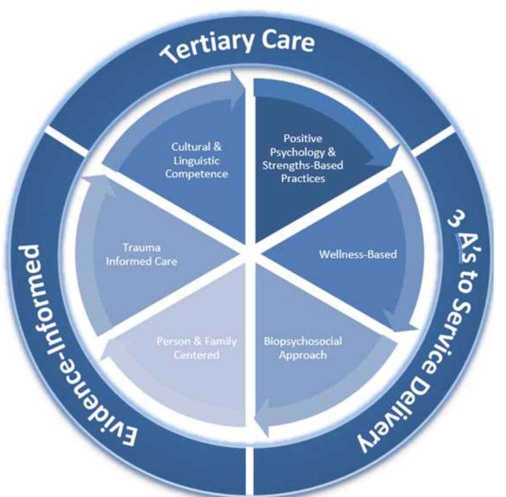
START Principles and Approaches to Best Practice

- Each approach used and endorsed by the START model is an effective best practice.
- Because they are interrelated, outcomes are strongest when they are combined and used across all aspects of START service delivery.



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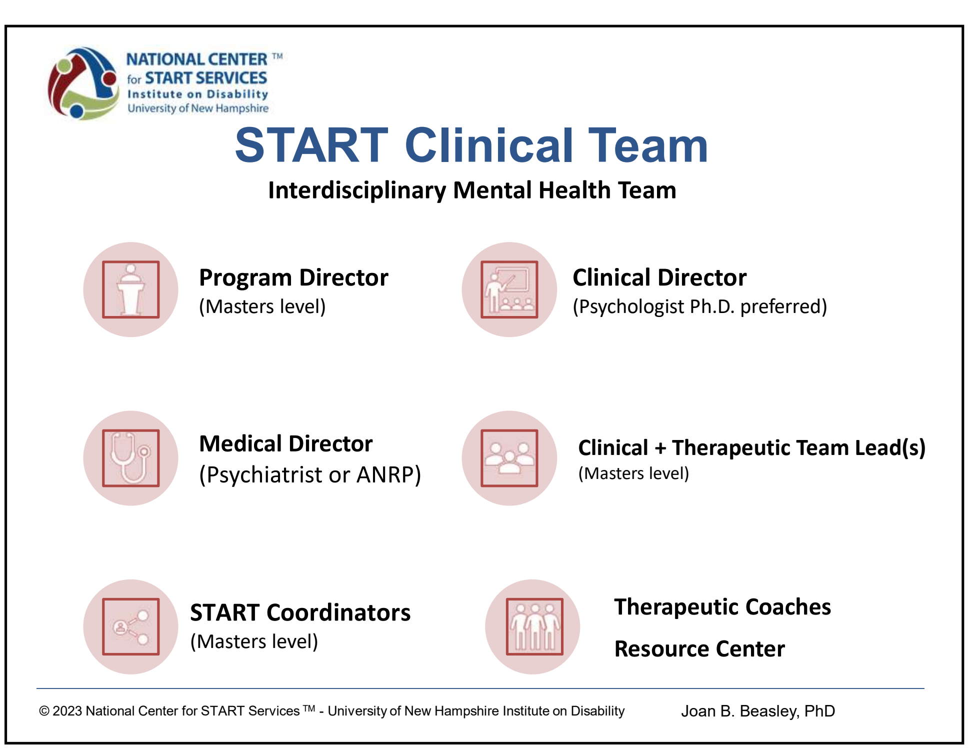

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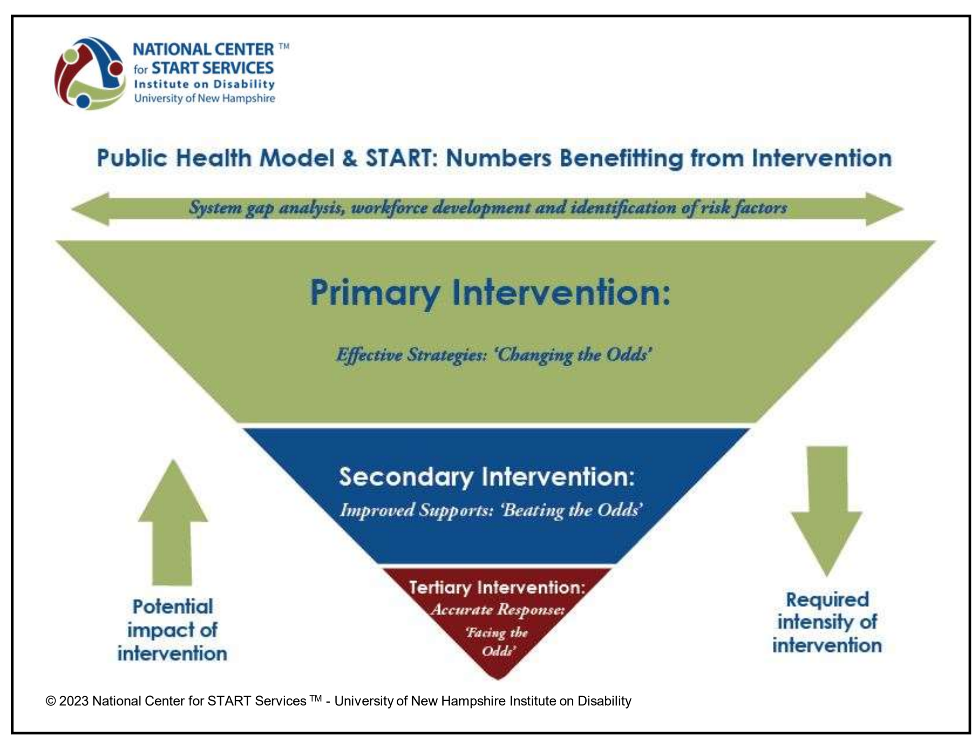

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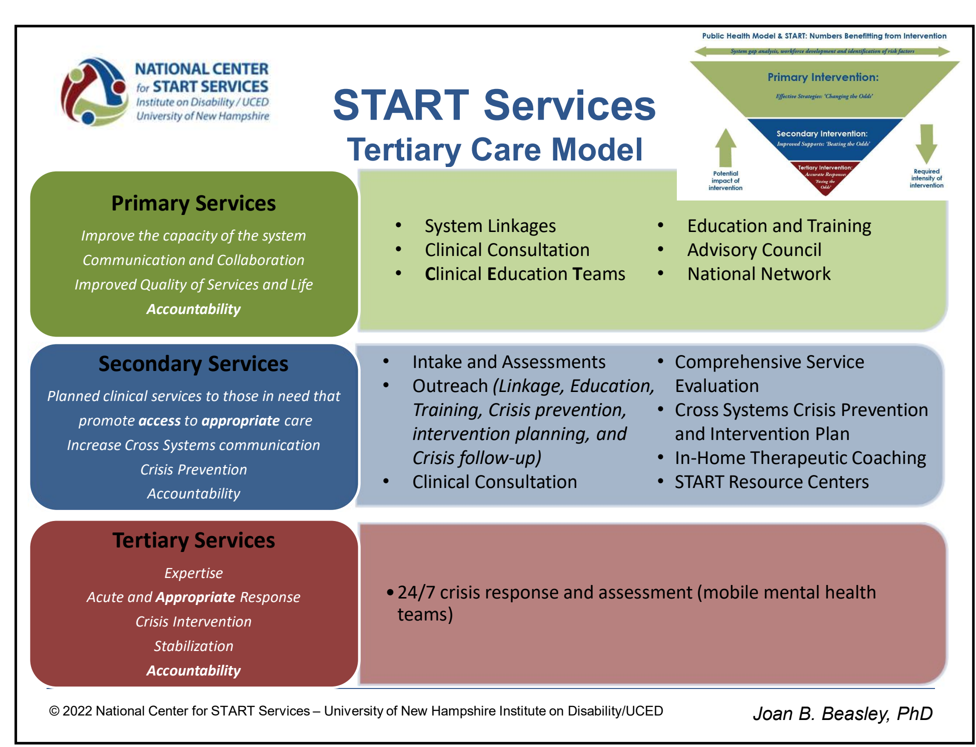

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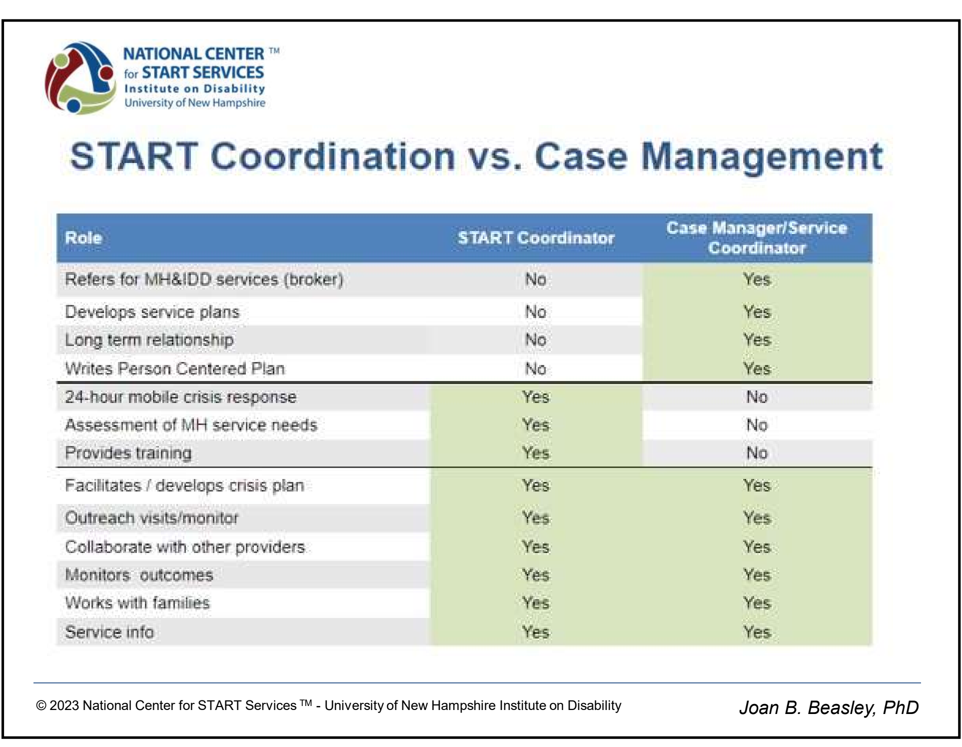

START Coordination vs. Case Management

Role	START Coordinator	Case Manager/Service Coordinator
Refers for MH&IDD services (broker)	No	Yes
Develops service plans	No	Yes
Long term relationship	No	Yes
Writes Person Centered Plan	No	Yes
24-hour mobile crisis response	Yes	No
Assessment of MH service needs	Yes	No
Provides training	Yes	No
Facilitates / develops crisis plan	Yes	Yes
Outreach visits/monitor	Yes	Yes
Collaborate with other providers	Yes	Yes
Monitors outcomes	Yes	Yes
Works with families	Yes	Yes
Service info	Yes	Yes

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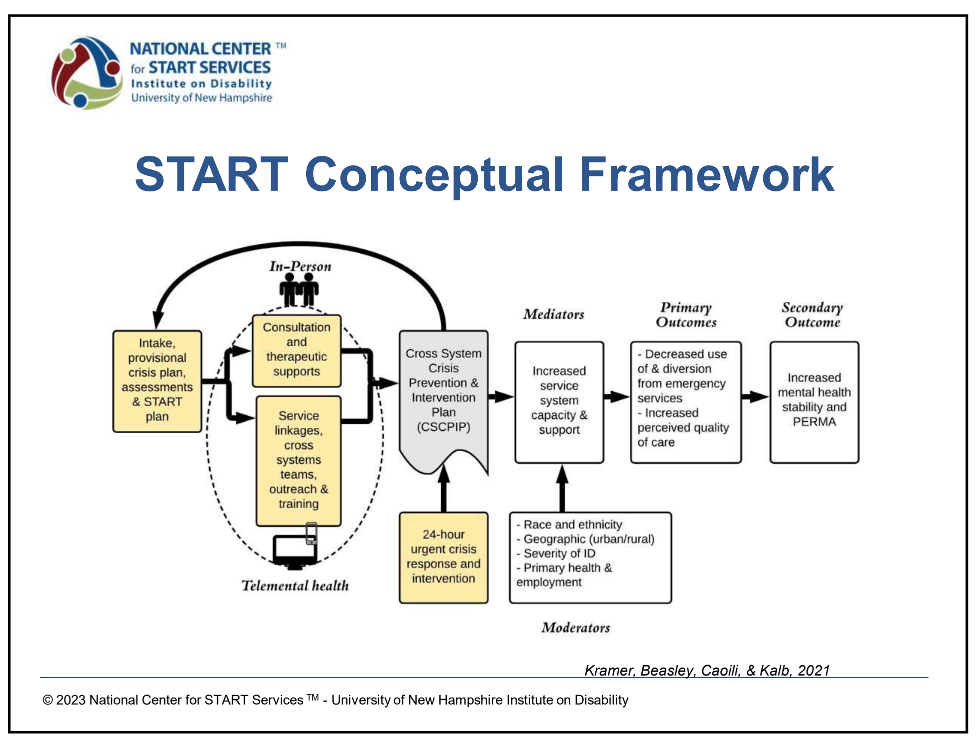

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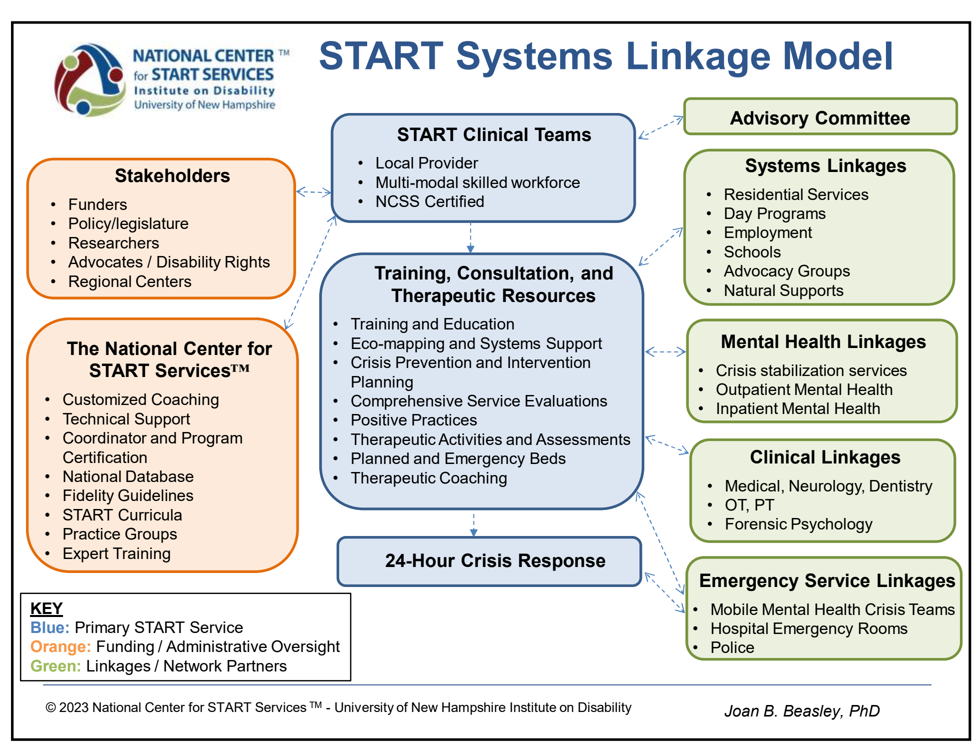

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START in Action

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Referral to START

Reason for Referral

- Mental health symptoms - psychosis
- Suicidal ideation
- Suicidal action
- At risk for loss of placement
- The family and residential program needed assistance
- Frequent emergency service utilization. In the 2 months prior to the referral alone, Nick had
  - 12 emergency department visits
  - 4 psychiatric hospitalizations

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Nick's Demographics

- Caucasian Male
- Mid 20's
- Lived in a group home with 3 other males
- Did not attend a day program or have a job
- Own legal guardian
- Saw a therapist sporadically
- Mild intellectual disability (full-scale IQ of 69)

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Diagnosis at Referral

Psychiatric Diagnosis	• Major Depressive Disorder with Psychotic Features • Post Traumatic Stress Disorder • Psychogenic Nonepileptic Seizures "Pseudo seizures"
Neurodevelopmental Disorders	• Mild Intellectual Disability
Medical/Health Conditions	• Visually Impaired: Loss of one eye – prosthetic, history and cataracts and glaucoma • Gastroesophageal Reflux Disease • Obesity
Social Stressors	• Primary support group • Interpersonal relationships • Occupational • Environmental stressors

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Medications at Referral

Medication	Dosage	Purpose
Haldol	30mg 1x day	Psychosis
Lamictal	150mg 2x day	Anticonvulsant used to tx mood instability
Prozac	20mg 1x day	Antidepressant
Ativan	1mg 3x day 1mg PRN	Anxiety
Effexor	150mg 1 day	Antidepressant
Cogentin	.5mg 1x day 1mg 1 x day	Tremors- side effects of antipsychotic
Benadryl	50mg PRN	Help sleep following pseudo seizure
Protonix	40mg 1x day	GERD
Mineral Oil	1 drop daily	Dry eye socket
Erythromycin	1cm 1x day	Eye ointment

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Intake and Assessment

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Nick's History

Born at 44 weeks gestation and experienced Meconium Aspiration Syndrome during birth.
Parents divorced when he was 4 years old. Inconsistent relationship with father.
Delayed in most childhood milestones.
Bullied by peers throughout school.
Best friend passed away in a tragic accident when he was 16 years old
At age 19, he was placed at a residential care facility for 3 years at. He attempted suicide 3 times during this time.
Moved to a community group home

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Strengths, Skills, and Interest

Strengths
- Kindness
- Forgiveness
- Gratitude

Skills
- Cooking
- Technologically savvy
- Empathy
- Playing basketball
- Pedestrian skills

Interests
- Spending time with family
- Animals
- Sports: Basketball
- Video Games
- Going to the community recreation center

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At His Best!

- Enjoys playing, watching, and talking about sports
- Active in his community
- Spends time with family and others who are important to him
- Looks forward to the future

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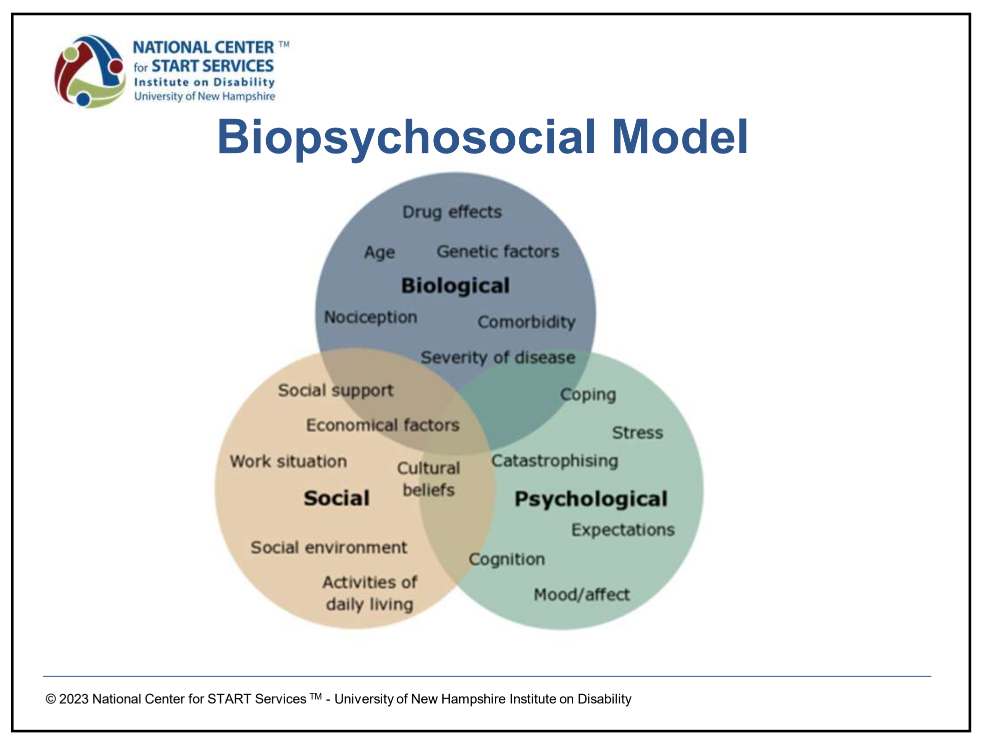
Biopsychosocial Model



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BioPsychoSocial Conceptualization Identified Vulnerabilities

Bio

- **Mild IDD**
- **Visual Impairment**
- Untreated constipation (exploring)
- **Regular changes in medications and polypharmacy**

Psycho

- **PTSD**
- **Psychogenic Nonepileptic Seizures (PNES) "Pseudo Seizures"**
- Depression and Grief (exploring)

Social

- **Minimal interaction with peers at home**
- No friends outside the home
- No job, day program, or community engagement
- Limited contact with father

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Biological

Mild Intellectual Disability

- Difficulty with problem solving
- Emotional regulation - challenges with coping with difficult emotions
- Concrete thinking
- Difficulty with managing impulse
- Impaired social judgment
- Difficulty with planning and prioritizing
- Higher expressive than receptive communication skills
  - Appeared to understand things he may not have
  - Difficulty articulating abstract thoughts and feelings

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Biological

Visual impairment

- Glaucoma and cataracts as a child
- Continued pain in his right eye and had surgery to remove it
- Replaced with a prosthetic eye, however, it was misplaced and not replaced (he never asked).

Medications

- Changed frequently, especially during hospitalization
- Experienced polypharmacology and was on extremely high dosages
- Symptoms primarily presented during times of stress
- Missed psychiatric appointments due to hospitalizations
- Experiencing side effects
  - Constipation
  - Shuffling gate
  - restlessness

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Psychological

Post Traumatic Stress Disorder

- Bullied "I deserved it" "I was better off alone anyway"
- Learning of the death of his friend "I was supposed to be there." "It should have been me"

Symptoms

- Flashbacks and intrusive thoughts
- Emotional distress and physical reactivity to traumatic reminders
- Avoidance and fear of rejection
  - Avoided engaging with peers or social gatherings
  - Limited interest in activities he enjoyed
- Irritability and hypersensitivity to stress (fight or flight)
  - Difficulty managing his reaction to stress
  - Difficulty regulating emotions
- Guilt, shame, and persistent sadness
- Low self-esteem - Negative beliefs about himself and the way others viewed him
- Impulsivity and risk-taking – suicidal ideation, threats, and attempts
- Difficulty sleeping

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Psychological

Psychogenic Nonepileptic Seizures ‘PNES’

- Psychiatric Disorder: Seizures caused by a psychological condition – emotional or stress-related. *(not caused by abnormal electrical activity in the brain)*“Physical manifestation of psychologic distress” *(Alsaddi et al.)*
- PTSD increases the risk for PNES
- Experienced PNES daily - Many times followed by suicidal threats or attempts
- System referred to them as “pseudo seizures” (an outdated term), and had the misunderstanding that pseudo seizures met, he was “faking it”
- System was not able to identify pre-cursors and felt they came out of no where

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Social

Minimal interaction with peers at his group home

- Difficulty building or maintaining relationships
- Often avoided conversation
- Spent most of his time alone in his room

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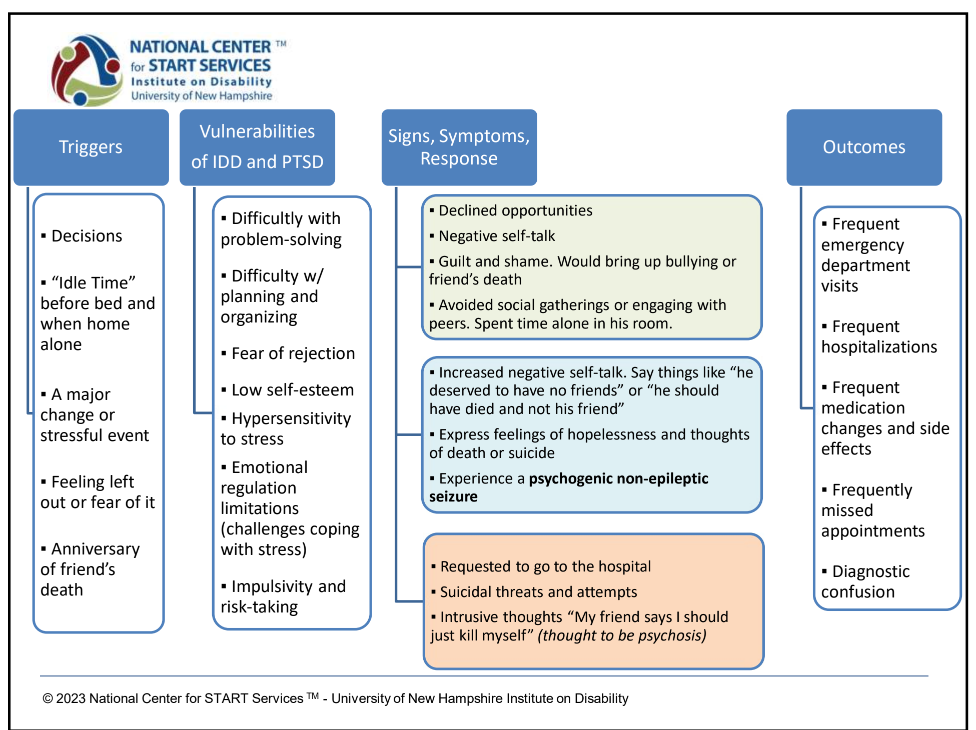

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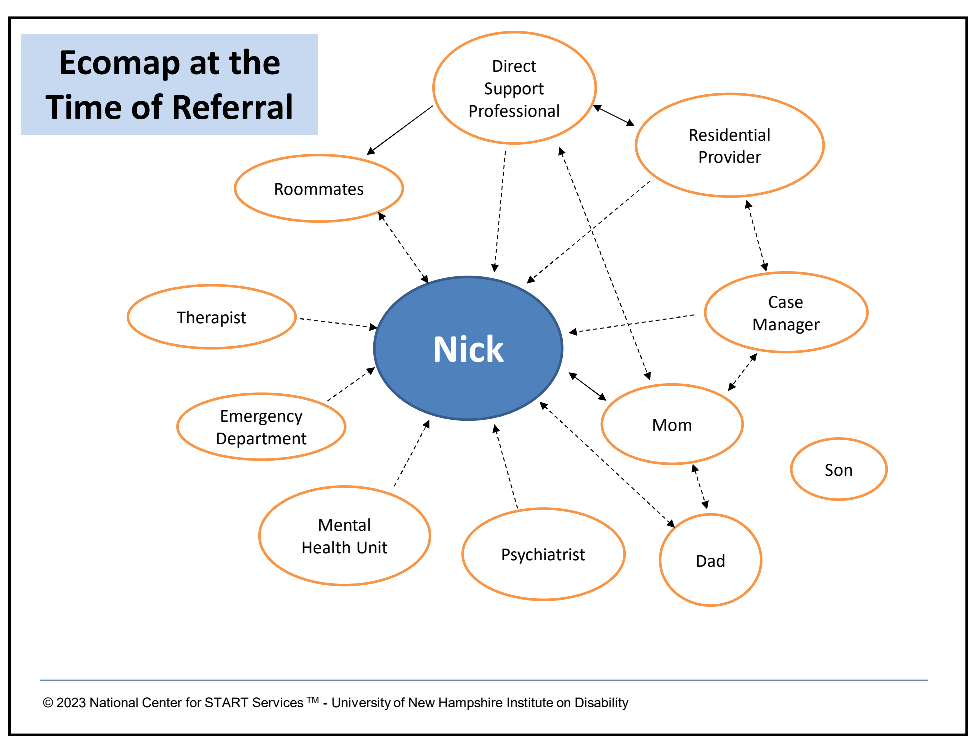

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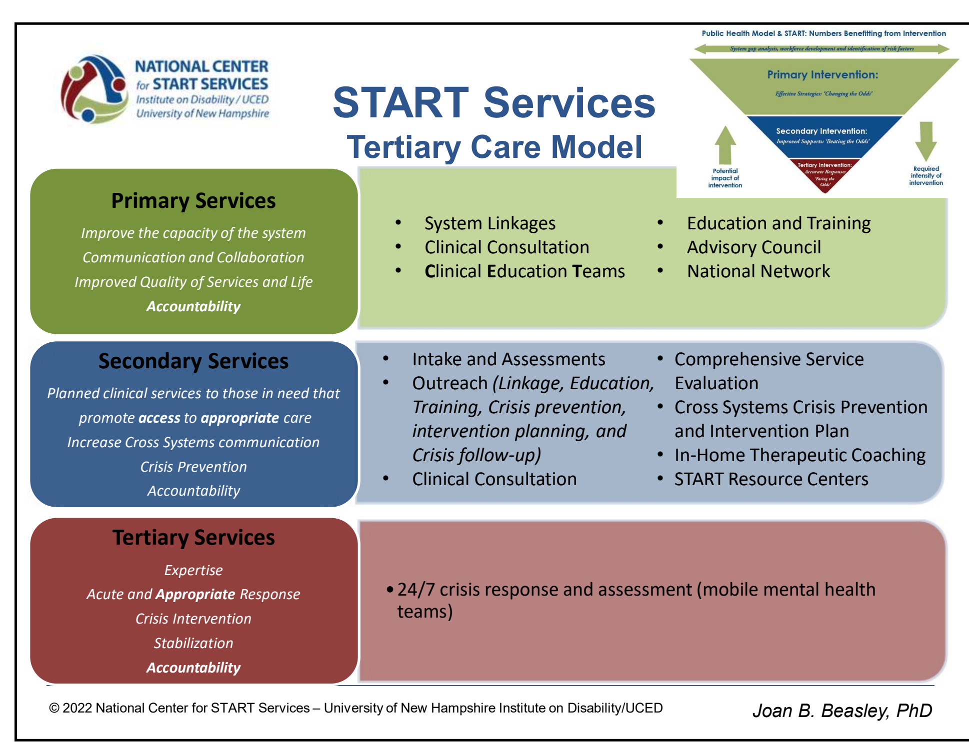

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START Interventions

Cross Systems Crisis Prevention and Intervention Plan (CSCPIP)

- Collaborative development based on strengths and biopsychosocial conceptualization
- Support team in using as a preventative measure and in times of crisis

Clinical Consult

- Consultation with START MD helped facilitate a decrease in psychotropic medications
- Aided in getting medication to treat constipation
- Planned nightly anxiety medication

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START Interventions

Outreach

- Observation to enhance conceptualization and build rapport
- Education and Training on PNES and PTSD
- Crisis prevention planning
    - Identifying what supports or services are needed to address/support vulnerabilities
    - Identify stressors and ways to limit them as well as plan for them*
    - Increase PERMA and (Social) taking his strengths, needs, and interests in mind and being mindful of his vulnerabilities
- Linkage
    - Special Olympics – options of things he is interested in “help him say yes”
    - Optometry – eye ointment, prosthetic, glasses
    - ED and Psychiatrist – only PRN given in times of crisis, not medication change

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START Interventions

Emergency Assessment

- Increased communication
- Increased understanding of PTSD and PNES as the reasons for symptoms – reconsidered psychosis
- Facilitated hold in ED to address stressors and create a plan to safely return to his home

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Progress in Numbers

Month	Emergency Department Visits	Mental Health Admissions	In-Patient length of stay (in days)
September Y1	5	3	11
October Y1	5	2	10
November Y1 (START referral made mid month)	4	2	15
December Y1	3	3	16
January Y2	0	0	0
February Y2	0	0	0
March Y2	1	1	4
April Y2	4	1	6
May Y2	0	0	0
June Y2	0	0	0
July Y2	0	0	0
August Y2	2	1	5
September Y2	1	0	0

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Progress in Numbers

Aberrant Behavior Checklist (ABC): *Assessment of mental health symptoms*

- Initial Total Score: 35
- Total Score 1 year later: 19

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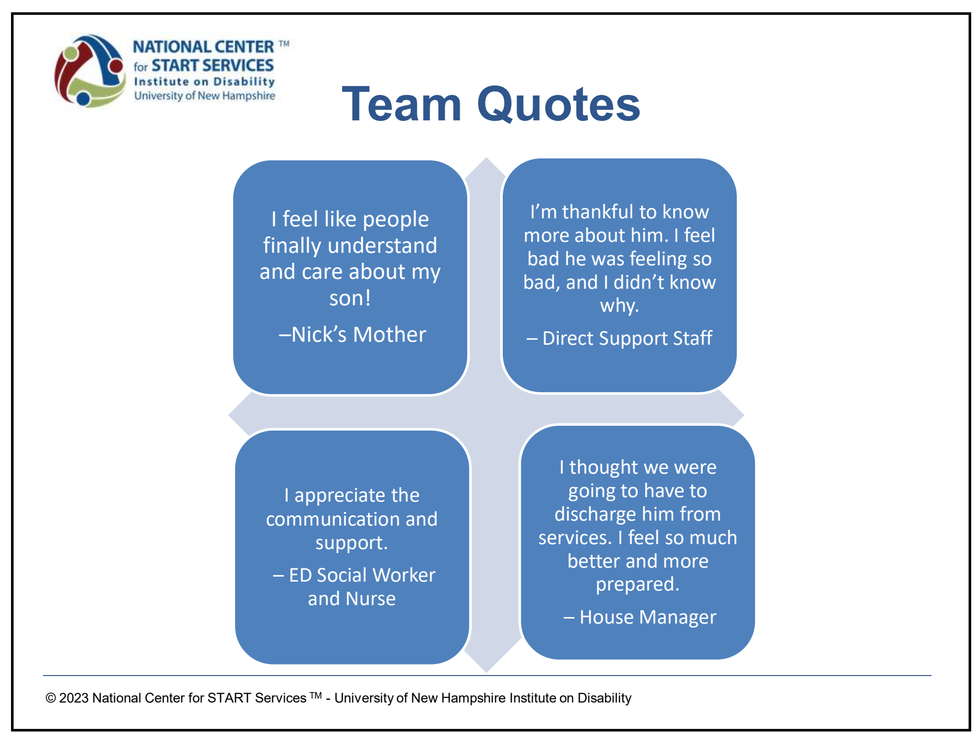

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Acknowledgement

The University of New Hampshire (UNH) recognizes the decades-long contributions of Dr. Joan Beasley, to the field of therapeutic interventions for individuals with intellectual and developmental disabilities and mental health needs. Beginning in 1992, Dr. Beasley and co-authors published a series of papers describing protocols that would ultimately become the **S**ystemic, **T**herapeutic, **A**ssessment, **R**esources, and **T**reatment (START)/Sovner Center Model.

The National Center for START Services™ (NCSS) was founded in 2011 at the University of New Hampshire's Institute on Disability. Through the efforts and dedication of Dr. Beasley and her colleagues, the National Center for START Services™, provides technical assistance, training, evaluation, and certification to START programs and resource centers in more than 15 states, serving the mental health needs of thousands of individuals with intellectual disabilities. Today, START is an evidence-informed and evidence-based model which strives to build capacity across systems to meet the needs of individuals with IDD-MH.

Dr. Beasley is a Research Professor at the University of New Hampshire where she conducts research on the mental health aspects of intellectual and developmental disabilities. She currently leads the National Research Consortium on Mental Health in Intellectual and Developmental Disabilities at UNH.

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Supporting literature for the START Model

The following publications provide additional information and context about the development and refinement of the START model by Joan Beasley, PhD, and colleagues.

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