START Model Implementation and Outcomes

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Presentation Overview

Describe the START Model

As time allows, review outcomes associated with implementation in various locales

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IDD and Mental Health Conditions

The DSM5 defines IDD as a disability that involves impairments of general mental abilities that impact 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, and 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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Beneath every behavior is a feeling. And beneath every feeling is a need. And when we meet that need rather than focus on the behavior, we begin to **deal with the cause not the symptom.**

— Ashleigh Warner
Psychologist

edutopia

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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 *(Beasley, 1997)*

Access

(timely, available)

Appropriateness

(matches real needs, provides tools)

Accountability

(responsiveness, engaging, flexible, cost-effective)

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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 IDD 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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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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The 10 Elements of the START Model

1. **Interdisciplinary Mental Health Team**
2. **Skills Workforce, Program Standards, Integrated Assessment**
3. **Person and Family Focused / Outreach**
4. **Crisis Interventions / Safety Net**
5. **Synergy – the whole is greater than the sum of its parts**
    - Collaboration
    - Linkages
    - Systemic

1. **Strength Activation**
    - Positive Psychology
    - PERMA
    - Humanism
2. **Whole Person Approach**
3. **Cross-Systems Crisis Prevention and Intervention Planning**
4. **Evidence-Informed**
    - Data Collection
    - Analysis and Research
5. **Capacity Building**
    - Training
    - Coaching

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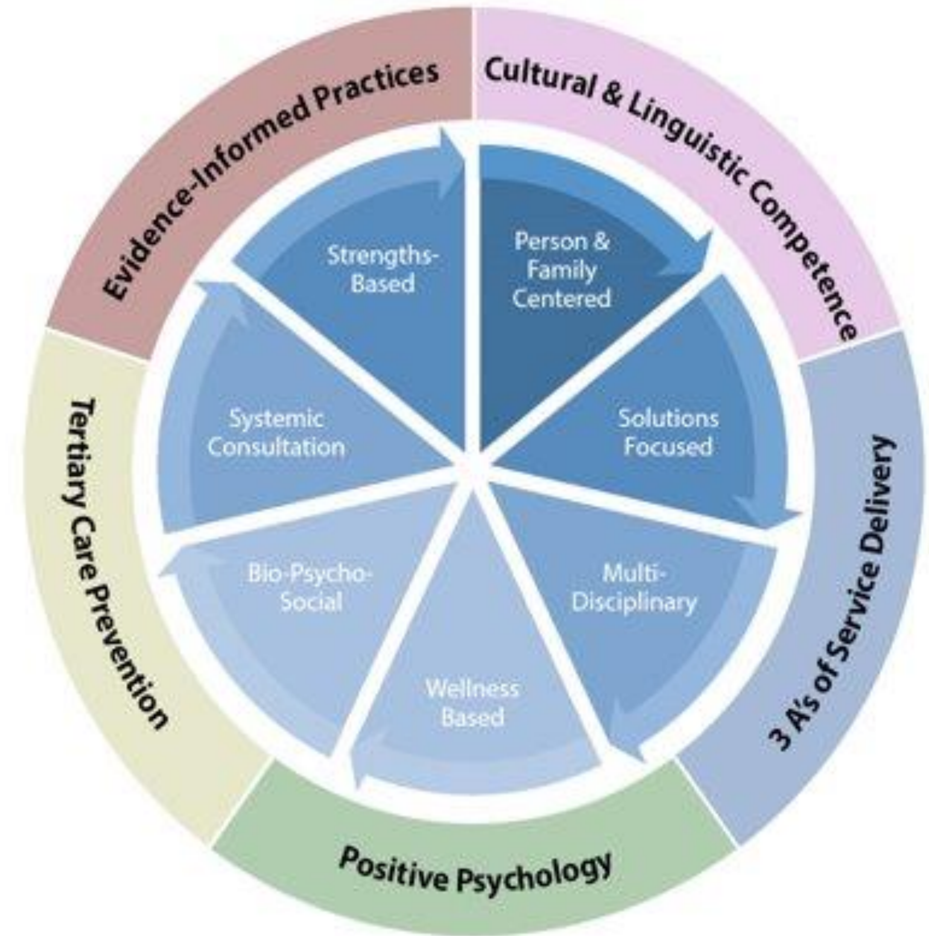
START Principles and Approaches to Best Practice

- 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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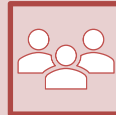
START Lifespan Services Clinical Team

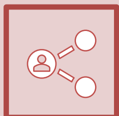
Program Director
(Masters level)

Clinical Director
(Psychologist Ph.D preferred)

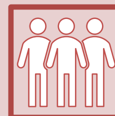
Medical Director
(Psychiatrist or ANRP)



Clinical + Therapeutic Team Lead(s)
(Masters level)



START Coordinators
(Masters level)



Therapeutic Coaches

Resource Center

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Public Health Model & START: Numbers Benefitting from Intervention

System gap analysis, workforce development and identification of risk factors

Primary Intervention:

Effective Strategies: 'Changing the Odds'

Secondary Intervention:

Improved Supports: 'Beating the Odds'

Tertiary Intervention:

Accurate Response: 'Facing the Odds'

Potential impact of intervention

Required intensity of intervention

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START Services

Primary Services

Improve the capacity of the system
Communication and Collaboration
Improved Quality of Services and Life
Accountability

- System Linkages
- Clinical Consultation
- Clinical Education Teams
- Education and Training
- Advisory Council
- National Network

Secondary Services

Planned clinical services to those in need that promote access to appropriate care
Increase Cross Systems communication
Crisis Prevention
Accountability

- Intake and Assessments
- Outreach Linkage
- Clinical Consultation
- Cross System Crisis Prevention and Intervention Planning
- Crisis Follow-Up
- Training
- Comprehensive Service Evaluation
- In-Home Therapeutic Coaching

Tertiary Services

Expertise
Acute and Appropriate Response
Crisis Intervention
Stabilization
Accountability

- 24/7 crisis response and assessment (mobile mental health teams)

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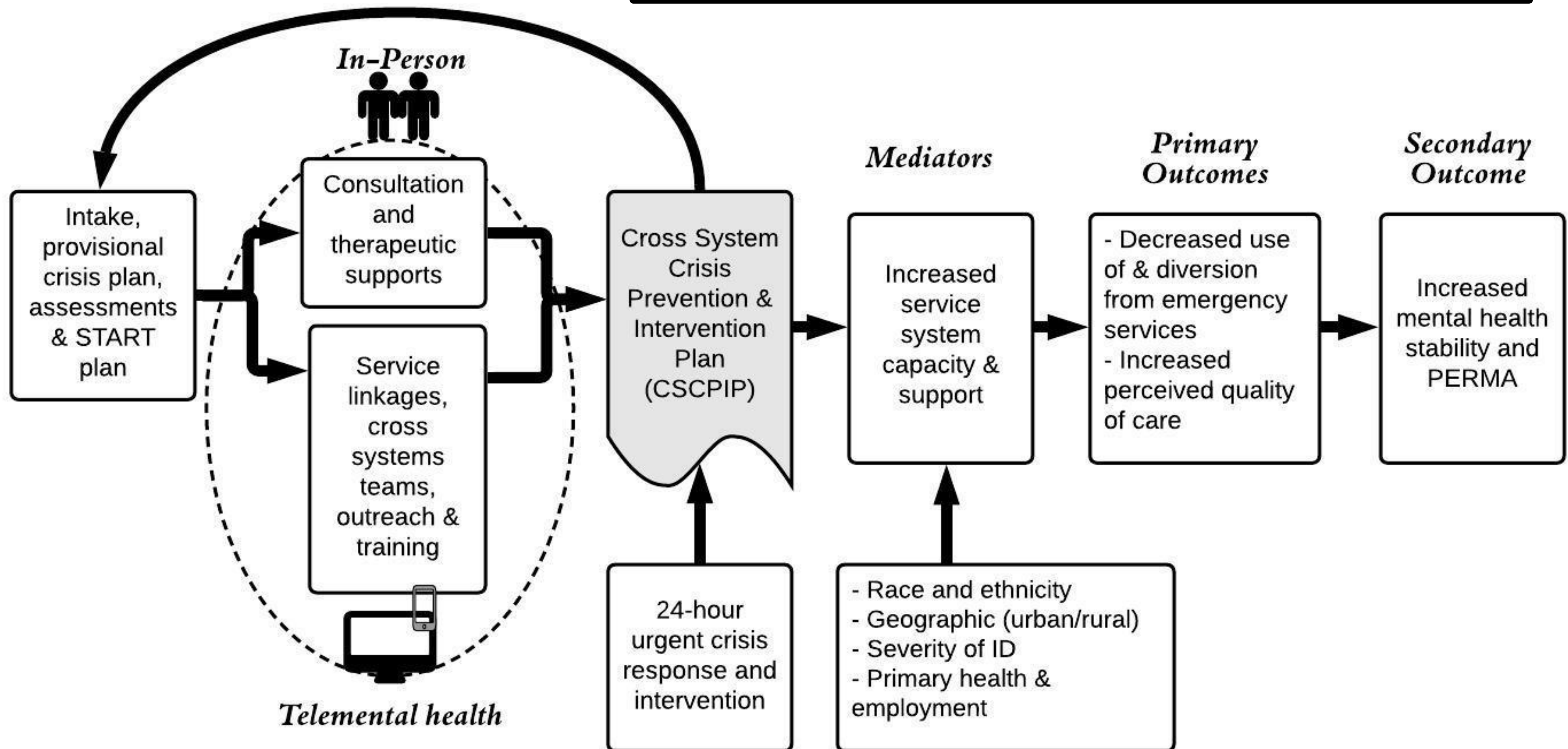
Influence on START Practices



Kramer, Beasley, Caoili, & Kalb, 2021

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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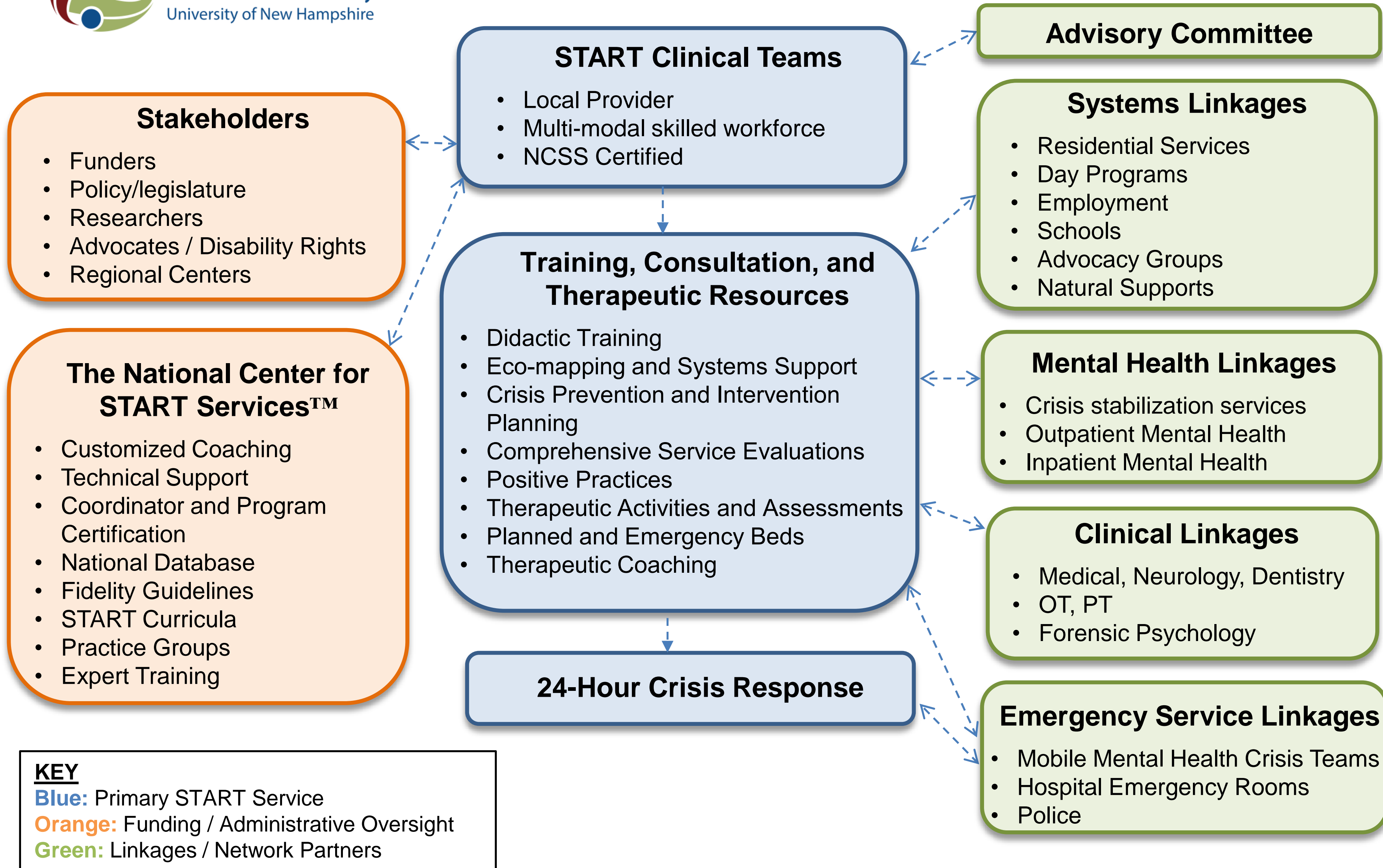
START Systems Linkage Model



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Joan B. Beasley, PhD

*The Role of Research and Evaluation in the Examination of START Crisis Prevention and Intervention Services**

*Slides were originally developed by Caoili (2023) and Klein, Beasley, and Kalb (2022). Citation available at conclusion of the presentation

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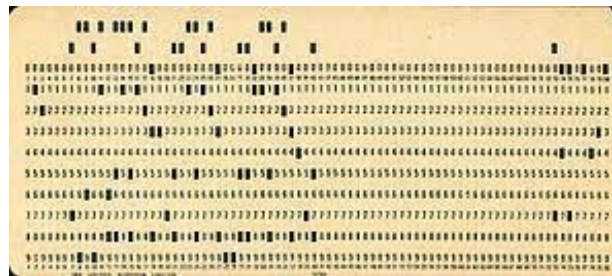
Data Collection in START

START has been a data-informed model since the beginning (1989)



Klein, Beasley, Kalb, 2022

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Why It Matters

- We need to re-think human services delivery using data driven insights: *transformational* instead of traditional *transactional* service delivery
- We need to be accountable to funders and the general public
- It is our responsibility to share what works and provide evidence to support the formation of public policy
- Contribute to the broader knowledge base about effective supports for individuals with IDD-MH

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NCSS Research and Evaluation

The SIRS Database

- START Information Reporting System (SIRS) has been in place since 2013 and is utilized by all START programs.
- SIRS collects demographic and clinical data, and service outcomes for every person that has been or is currently enrolled in a START program.
- Requires active participation of the entire START provider community.

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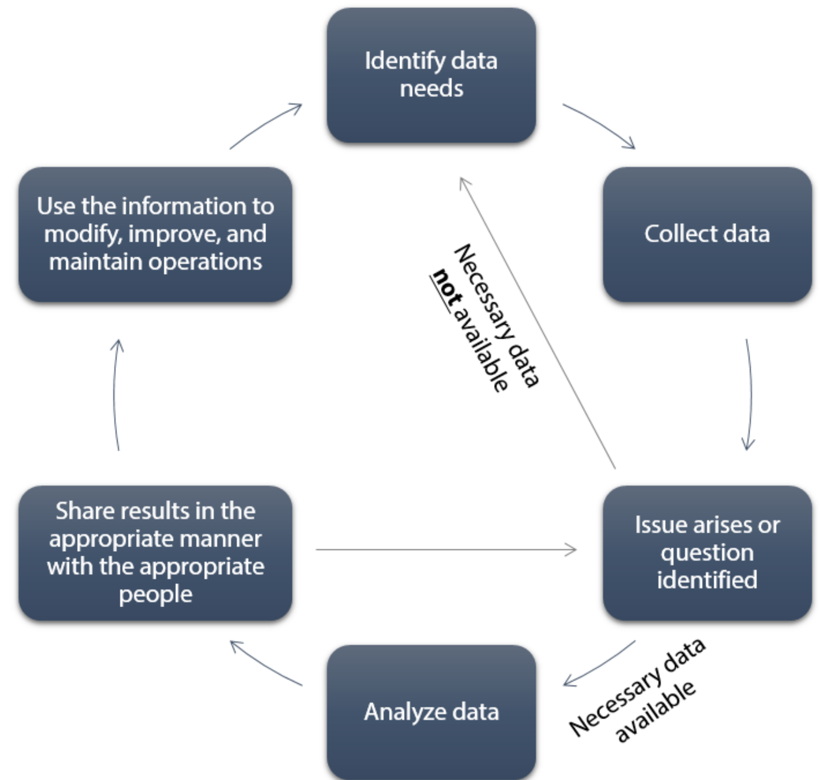
START is Evidence Informed

Evidence-Informed practice incorporates ongoing research, evaluation, and assessment to inform and refine the evidence-based START model.

We use evidence to design, implement, and improve programs and interventions



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START as an Evidence-Based Practice

START is an **evidence-based** practice: Demonstrated effectiveness supported by the research

Health and service data on all individuals enrolled in START programs are entered into **SIRS** and analyzed to measure outcomes and trends.

Across the US, individuals in START have shown improvements in key outcome areas:

- Improved rates of stabilization following mental health crisis
- Reduced psychiatric hospitalization and ED usage
- Increased satisfaction with mental health and support services

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(Klein, Beasley, Kalb, 2022)

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History of Recent Crisis-Related Research in START

- Focus on four seminal studies
- All data collected and analyzed through SIRS

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Study 1

Psychiatric hospitalisation among individuals with intellectual disability referred to the START crisis intervention and prevention program

L. G. Kalb,[1] J. Beasley,[2] A. Klein,[2] J. Hinton[2] & L. Charlot[3]

1 *Department of Mental Health, Johns Hopkins Bloomberg School of Public Health, Baltimore, MD, USA*
2 *Institute on Disability, University of New Hampshire, Center for START Services, Concord, NH, USA*
3 *Department of Psychiatry, University of Massachusetts Medical School, Worcester, MA, USA*

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Study 1

Psychiatric hospitalization among individuals with ID referred to the START crisis intervention program

Methodology	Findings

• Data from **3,299** individuals referred to START
• Mean Age = 31 y/o (SD 14 y/o)
• Random effect logistics region model
• Examine the association between 11 factors and caregiver reports of psychiatric hospitalization in the past 12 months
	• 28% of persons referred were psychiatrically hospitalized in the past year
	  ○ Overreliance on restrictive services
	• Black/African Americans were 37% more likely to be hospitalized than Whites
	  ○ Important disparities exist
	• Lack of waiver supports was associated with a 41% increased likelihood of hospitalization
	  ○ Community supports matter

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Kalb et al., 2022

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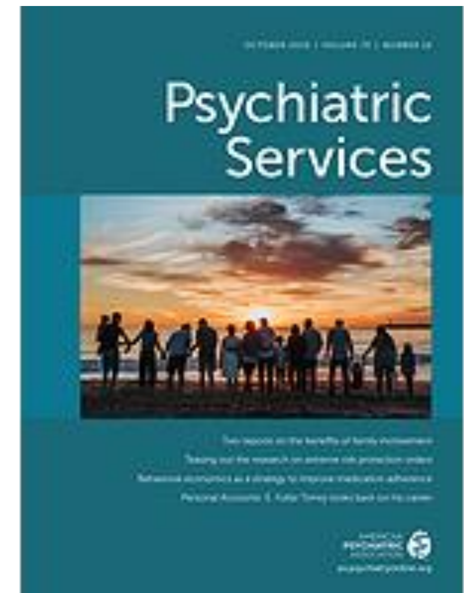
Study 2

Psychotropic Use Among Youths With Intellectual and Developmental Disabilities

Jennifer L. McLaren, M.D., Jonathan D. Lichtenstein, Psy.D., M.B.A., Justin D. Metcalfe, M.S., Ph.D., Lauren R. Charlot, L.I.C.S.W., Ph.D., Robert E. Drake, M.D, Ph.D., Joan B. Beasley, Ph.D.



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Study 2

Psychotropic Use Among Youths with IDD

Methodology	Findings
• Cross-sectional data on medications for **1,333** youth (ages 5-21 y/o) referred to START • Descriptive and regression analysis used to ○ Describe the study group ○ Identify correlates of psychotropic polypharmacy, antipsychotic use, and anticonvulsant use in the absence of a seizure disorder	• Overreliance on polypharmacy, especially in groups homes • 86% of youth were receiving a psychiatric medication • 65% were receiving an antipsychotic and 33% were receiving an anticonvulsant – **without a seizure disorder** • 55% were receiving 3+ psychiatric medications • Living in a group home increased the risk of medication by 26%

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McLaren et. al, 2021

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Study 3

Experiences With the Mental Health Service System of Family Caregivers of Individuals With an Intellectual/Developmental Disability Referred to START

Calliope Holingue, Luther G. Kalb, Ann Klein, and Joan B. Beasley

AJIDD
American Journal on
Intellectual and Developmental Disabilities

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Study 3

Experiences With the Mental Health Service System of Family Caregivers of Individuals with an IDD Referred to START

Methodology	Findings
• **488** caregivers of individuals referred to START • Caregivers completed the Family Experience Interview Survey (FEIS) • Examined caregiver's experience	• The largest gap in services was **crisis supports** o 55% didn't have assistance in times of crisis o 55% didn't have information on whom to contact in a time of crisis o 75% didn't have help on nights and weekends • Other gaps o Choice of services and providers o Communication and coordination between providers o Specialized training o Experiences were worse for fathers

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Holingue et. al, 2022

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Qualitative Findings

"I don't want to place my son outside of the house, but I don't know what else to do. I feel like that is my only option"

"I feel like the system has failed me"

"I don't want an overmedicated zombie of a child. I want him to reach his full potential but because of a lack of resources because we're poor, there isn't much available to him and I'm afraid he won't reach his potential"

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Holingue et. al, 2022

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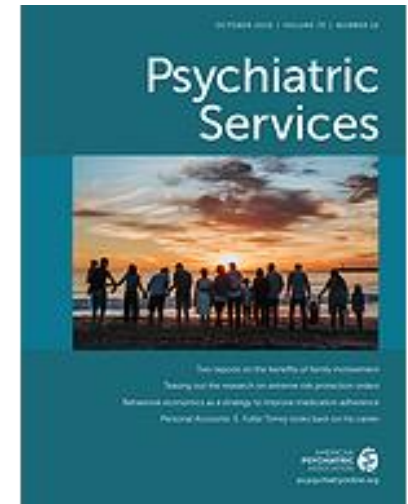
Study 4

Predictors of Mental Health Crises Among Individuals With Intellectual and Developmental Disabilities Enrolled in the START Program

Luther G. Kalb, Ph.D., Joan B. Beasley, Ph.D., Andrea Caoili, L.C.S.W., Jennifer L. McLaren, M.D., Jarrett Barnhill, M.D.



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Study 4

Predictors of Mental Health Crisis Among Individuals with IDD Enrolled in START

Methodology

- **1,188** individuals enrolled in START between 2018 and 2019
- Crisis contacts with the START program
- Baseline and clinical predictors were exampled with multivariate regression analyses

Findings

- Crisis stabilization takes time
  - Increase in crisis 90 days after enrollment. Steep drop-off thereafter.
  - Half of crisis happened after 6 months
  - 25% occurred after 9 months
  - Very few after 1 year
- Supports are needed during real life
  - 45% of crisis contacts took place after hours
  - 22% took place on the weekends
- When START emergency services are provided, we can prevent hospitalization
  - 3 of 4 contacts maintained their setting
- Need for Community Support
  - 2-fold (or 100%) increase in the likelihood of a crisis contact when a family member self-referred
- Need for meaningful employment
  - The likelihood of a crisis contact was reduced by 50% when the person referred was employed

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Kalb et. al, 2021

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Summary

Prior to START, reliance on hospitalization services and psychotropic medications is a significant concern. Family members want to avoid these outcomes

There are large gaps in crisis services in community settings, particularly on nights/weekends

When someone enrolls in START, significant stabilization takes place after 9 months for crisis services

Improving community support and employment services are important pathways forward for reducing crises.

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Questions?

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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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