

START Model Implementation and Outcomes

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What we will cover

- Describe the START Model
- Review outcomes associated with implementation in various locales

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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 Systemic, Therapeutic, Assessment, Resources, and Treatment (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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Americans with Disabilities Act and Olmstead: Paving the Way

- Active treatment needed in facilities/hospitals
- Include people with IDD in remedies
- Community based services needed expansion
- IDD services and MH services segregated
- People with IDD not viewed as capable of benefiting from MH services, more work to be done

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Joan B. Beasley, PhD

“

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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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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Defining Effective Services The 3 A's (Beasley, 1997)

Access

(timely, available)

Appropriateness

(matches real needs, provides tools)

Accountability

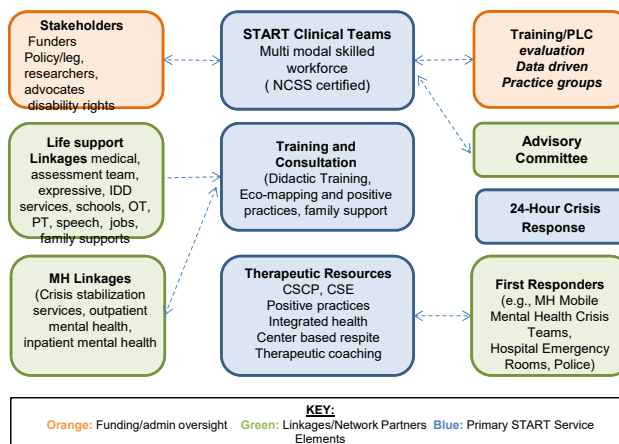
(responsiveness, engaging, flexible, cost effective)

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Joan B. Beasley, PhD



START Systems Linkage Model



START is a crisis prevention and intervention model that focuses on community linkages, filling in gaps, and capacity building across the system of care rather than segregated or duplicative service development (Beasley, Kroll, & Sovner, 1992)

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The 10 Elements of the START Model

- Interdisciplinary mental health team (MD, PhD, MSW, RN, direct support)
- Person and family focused/outreach
- Crisis intervention/safety net/mobile 24hrs
- Synergy the whole is greater than the sum of the parts: collaboration/linkages, no more silos
- Strength activation: positive psychology PERMA, humanism, systemic
- Cross systems crisis prevention and intervention planning
- Evidence informed/data collection and analysis/research
- Capacity building/coaching/training/CETs
- Whole person approach/CLC
- Skilled workforce, standards for programs and integrated assessment (NCSS)

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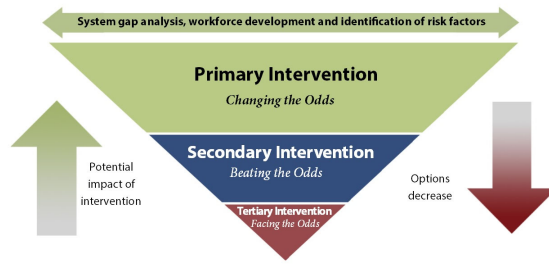


START Cross-Systems Crisis Planning: Practices used

- Tertiary Care
- BioPsychoSocial
- Positive Psychology
- Trauma Informed
- Cultural and Linguistic Competency
- Family and person-centered
- Wellness and solution-focused
- Systemic Engagement
- Other evidence-based strategies (e.g., motivational interviewing, CBT)

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WHO Public Health Model & START: Building Primary Capacity

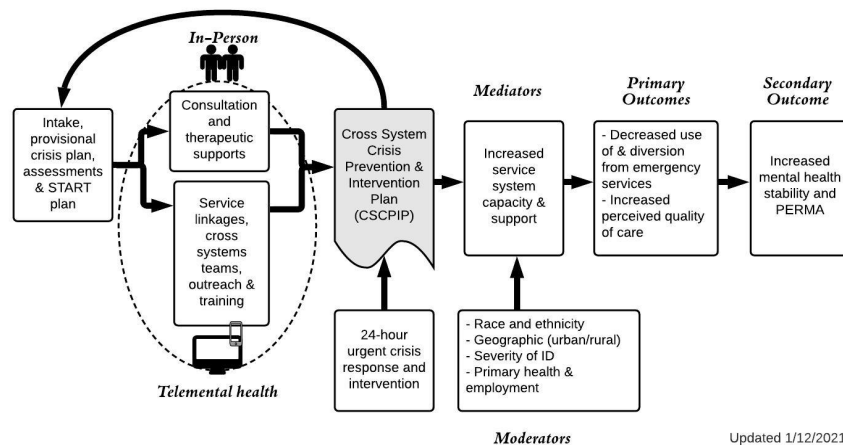


The START model is a tertiary care model that provides for all levels of crisis support

Primary interventions through capacity building to address needs in home settings are the hallmark strength activation with greater options and impact

Influence on START Practices

START Clinical Team Practices Framework





We Are Not There Yet... The MH-IDD System in the US (2023)

- People with IDD continue to experience numerous health disparities, including higher rates of mental health symptoms and behavioral challenges, compared to their typically developing peers.
- These difficulties are often misdiagnosed, under-diagnosed, or undiagnosed, and even when detected, few evidence-based treatments exist.
- This gap has translated into use of costly and ineffective care, resulting in frequent emergency department and psychiatric hospital visits, poorer quality of life, and earlier age of mortality for individuals with IDD.

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What Needs to Change 2023

- START is a reaction to the disparities that continue, not the solution, however we learn from START experiences
- The power of belief: facing our biases
- Research, research, research
- First person knowledge (nothing about us without us)
- Cultural and linguistic competency
- Synergy/linkages break down the silos
- Cross systems solutions require a common understanding

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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



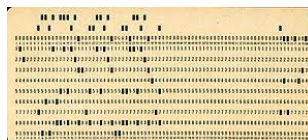
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Data Collection in START

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



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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

NCSS Research and Evaluation

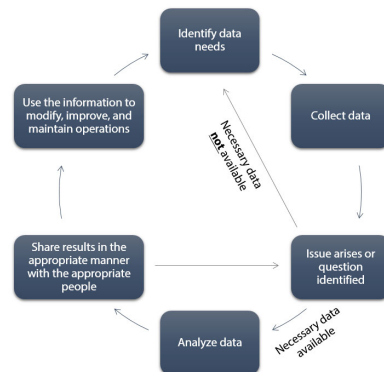
The SIRS Database

- START Information Reporting System (SIRS) has been in place since 2013 and is utilized by all START programs.
- SIRS collects demographic, clinical, 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

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

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. Hinton² & L. Charlot³

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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- More than 1 in 4 persons referred to START were psychiatrically hospitalized in the past year (28%)

Over reliance on restrictive services

- Black/African American's were 37% more likely to be psychiatrically hospitalized than Whites

Important disparities exist

- Lack of waiver supports was associated with 41% increased likelihood of hospitalization

Community supports matter

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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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- 86% of youth (5-21) 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%

**Over reliance on
polypharmacy,
especially in group
homes**

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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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- 55% did not have assistance in times of crisis
- 55% did not have information on who to contact in a time of crisis
- 75% did not have help on nights and weekends

Crisis supports were the largest gap in services

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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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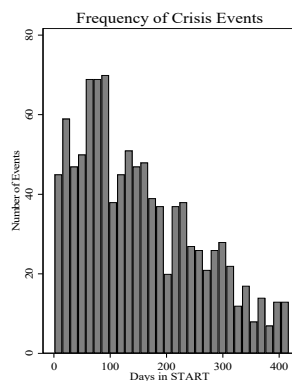
Study 4

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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Crisis Stabilization Takes Time

- Increase in crises 90 days after enrollment
- Steep drop off thereafter
- Half of crises happened after 6 months
- 25% occurred after 9 months
- Very few after 1 year

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- 45% of crisis contacts took place after hours
- 22% took place on weekends
- 3 out of 4 contacts were maintained in their setting
- When a family member self-referred, there was a 2-fold (or 100%) increase in the likelihood of a crisis contact
- When a START member was employed, the likelihood of a crisis contact was reduced by 50%

Supports are needed during real life

And when they are provided, we can prevent hospitalization

Need for community supports

Need for meaningful employment

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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 supports and employment services are important pathways forward for reducing crises.

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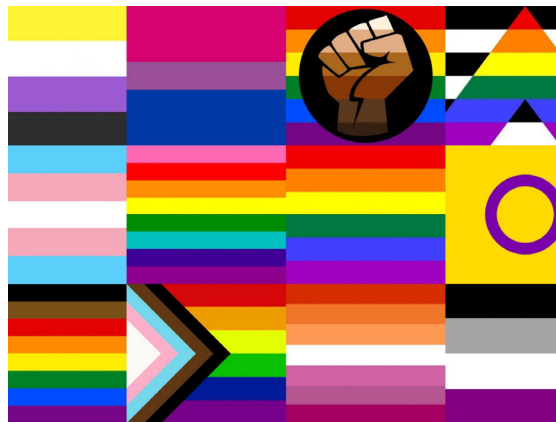
Other Recent and Current Studies

- **National Research Consortium on MHIDD** (Joan B. Beasley, Director)
- **Reconciling the Past and Changing the Future: Engaging Young Adults with IDD-MH and Researchers in Comparative Effectiveness Research**
 - Project leads: Beasley, Goode, Grosso, Guerro, Kramer, Peace Urquilla, & Watkins
 - [Reconciling the Past and Changing the Future](#)
- **Integrated Mental Health Treatment Guidelines for Prescribers in Intellectual and Developmental Disabilities**
 - Caoili, A., Hecker, M., Klick, S., McLaren, J., Beasley, J., & Barnhill, J. (2022). Integrated mental health treatment guidelines for prescribers in intellectual and developmental disabilities. *Journal of Policy and Practice in Intellectual Disabilities*, 1-13.
 - [IDD-MH Prescriber Guidelines](#)
- **Educating Medical Trainees on Mental Healthcare and Intellectual and Developmental Disabilities** (Caoili, Beasley, McLaren, & Peace Urquilla)
- **Evaluation of Telehealth Services on Mental Health Outcomes for People with Intellectual and Developmental Disabilities** (Beasley, Kramer, Kalb, Caoili, Goode, & Peace Urquilla)

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Questions?



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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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