



*University of New Hampshire
Institute on Disability/UCED*

START

Systemic, Therapeutic, Assessment, Resources and Treatment

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www.centerforstartservices.com

"Time after time, I have found that when people are taken seriously, when they are respected, when their behavior is interpreted, understood and responded to accurately, when they are engaged in mutual dialogue rather than subjected to unilateral schemes of 'behavior management,' somehow as if miraculously, they become more ordinary. I know a number of people who have had severe reputations who have shed them when those supporting them listened more carefully."

Herb Lovett, Ph.D.

Crisis prevention and intervention through a system of care approach

AKA: "A Crisis is a problem without the
tools to address it"

Problems with Most ID/DD Systems:

- "Troublesome" behaviors considered unacceptable in many support and service venues
- The last and least served (i.e. latest trends in congregate or institutional living)

Problems with the MH System

- Stigma
- Much more likely to use emergency services
- Lack of training (diagnostic overshadowing)
- Lack of expertise
- Medication issues

Engaging the system through linkages

"The world as we created it is a process of our thinking. It cannot be changed without changing our thinking."

~ Einstein

The Need for Effective Services:

The Three As

- Access
- Appropriateness
- Accountability

Access

- Timeliness
- Array of services
- Availability
- Geographic proximity
- Resources alone should not define service use...

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"Unfortunately, you have what we call 'no insurance.'"

Appropriateness

- Roles are clear
- Providers have expertise
- Defining the problem
- Service matches needs...

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Assessment leads to appropriateness

"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."

~ Einstein

Accountability

- There is consensus with regard to roles and responsibilities on the part of providers
- Services are cost effective
- Recipient is satisfied with services
- Services meet objectively established goals
- Services change with the changing needs of the service user
- Listening and mutual respect in the system is required...

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*"I don't listen to the
evidence. I like to make up my own mind."*

Accountability and change..

"The measure of intelligence is the ability to change."

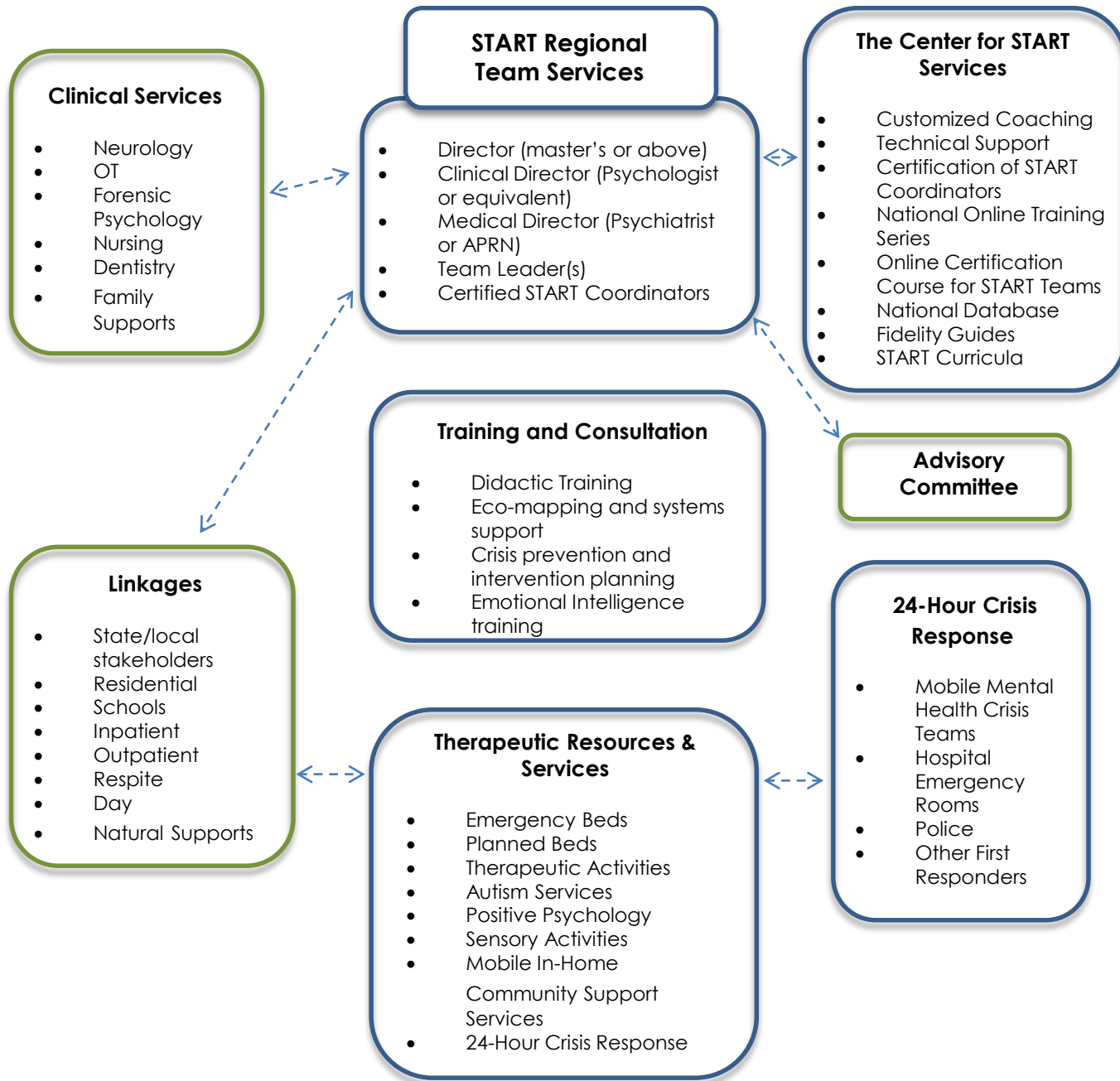
~ Einstein

The "START" model: Systems Linkage Approach

- KEY: Enrich the system (avoid strain)
- Resources allocated to promote linkages (i.e. the use of a linkage "team")
- Resources allocated to fill in service gaps
- Services provided across systems
- Expertise improves capacity
- Outreach is key
- Develop a common language

Core START Elements

- Trained Linkage Coordinators
- Linkages (local, statewide, national)
- Consultation, service evaluations
- Training, forums for collaboration
- Crisis support 24 hours/7 days a week
- Planned therapeutic resources (respite; in-home and program-based)
- Emergency therapeutic resources (respite, mostly program based)
- Expertise as members of core team
- National Center for Excellence
- Data-driven, evidence-informed practices (SIRS)



Core Concepts

- Tertiary Care
- BioPsychoSocial Approach
- Positive Psychology
- Evidence Informed

Tertiary Care Approach

World Health Organization

- Primary: Capacity building; communication and collaboration, improved quality services and quality of life; accountability
- Secondary: Expertise, access to appropriate care, cross systems communication; crisis prevention; accountability
- Tertiary: Expertise, appropriate response, stabilization, intervention; accountability

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

Primary Intervention/ Capacity

- Professional Learning Community/Training
- Access to experts in the field
- Linkages
- Coaching/apprenticeship
- Opportunities for learning
- Shared values and norms
- Development of common practices
- Improved knowledge, access to care and services

START Secondary Intervention the tools of START

- Certified Coordinators
- Access to experts
- Multimodal consult teams
- CETs, START Plans, CSCPs, CSEs, SIRS, Systemic analysis
- Study Groups across the country
- PLCs
- In home supports
- Therapeutic Centers

Tertiary Intervention:24 hour Community-Based Crisis Response

- Integrated into the overall system, use a multidisciplinary team approach, and be able to communicate effectively; Working with inpatient units, mobile crisis teams, emergency rooms
- Crisis Evaluation, Prevention, Intervention, and Stabilization: START Center
- 24 hour access to care providers for assistance
- Discharge planning meetings within 24 hours with START Coordinators linked with home services inpatient and START Centers

Biopsychosocial Model Engel, 1977

- The **biopsychosocial model** (abbreviated "BPS") is a general model or approach stating that biological (physical make up or condition) , psychological(thoughts, emotions, level of development, communication) and social (socio-economic, environmental, cultural experiential influences) significant role in human functioning in the context of disease or illness.
- Health is best understood in terms of the context of these combined factors rather than purely biological terms.
- Used in mental health and humanistic psychology, family systems and other practices
- Applied assessment of people with IDD and challenging behavior (Gardner)
- Contradicted the premise of the Mental Health Act of separation of systems of care

BioPsychoSocial Approach

- Takes into account biological, psychological and social factors that may contribute to an individual experiencing a crisis
- Provides a person-centered understanding of the individual's history and life experiences
- Provides context to explain why a trigger is a trigger for that individual

Medical Factors

- People with IDD have higher rates of medical problems
- Medical problems are often the source of the chief complaint for individuals with ID
- Generally the association of medical conditions with mental disorder is not understood by the individual, caregivers or the clinician assessing
- Pain or physical discomfort may act as a “setting event” lowering the threshold for challenging behavior
- People with IDD have few ways to express distress and are poor at reporting their internal states

Medical Factors

- Medical problems may cause significant changes in mood, behavior and mental states that mimic acute psychiatric illness
- Common Medical issues include:
 - **Genetic disorders and syndromes**
 - **Diabetes**
 - **Sleep Irregularities**
 - **Constipation**
 - **Gastrointestinal problems**
 - **Infections**
 - **Seizure disorders**
 - **Physical pain**
 - **Vision/hearing changes**
 - **Medication side effects and drug toxicities**

Medical Factors- Study

Non-psychiatric health problems among psychiatric inpatients with Intellectual Disabilities.

Charlot, L., Abend, S., Ravin, P., Mastis, K., Hunt, A., & Deutsch, C. *Journal of Intellectual Disability Research* doi:10.1111/j.1365-2788.2010.01294.x

MEDICAL PROBLEMS

Medical Diagnoses	N = 50 Consult	N = 198 Inpts
Constipation	64%	60%
GERD*	26%	38%
Seizure D/O	36%	25%
Hypothyroidism	20%	19%
Hypertension	12%	19%
Anemia	16%	18%

Mental Disorder due to a Medical Disorder

- For **41%** the medical issue seemed to be the cause of the problem behaviors leading to the admission
- Why do these get missed?
 - Patients with ID are poor reporters of their own health problems
 - Physical problems are often expressed behaviorally
 - Developmental features alter the manifestation of psychological and psychiatric symptoms

Psychiatric/Mental Health Factors

- Behaviors that may indicate comorbid conditions:
 - Self-injurious behaviors, tics, stereotypies, obsessive thoughts and compulsive behaviors, levels of attention, hyperactivity, impulsivity, fears and phobias
- Have to assess whether there have been any changes (increase/decrease in intensity or frequency)
- These same behaviors may be due to side-effects of medications being used/changed to address “problem behaviors”, medical and/or environmental factors

Social/Environmental Factors

- Are often over-looked, not considered
- These are often the things that act as “triggers”
- Common social/environmental factors include:
 - **Noise**
 - **Temperature**
 - **Lighting**
 - **Space – too large, too small**
 - **Changes in daily routine**
 - **Changes or loss of important people**
 - **Loneliness, social isolation**
 - **Boredom**
 - **Lack of Control/Choice**

Why a Positive Psychology approach?

- “We believe that persons who carry even the weightiest psychological burdens care about much more in their lives than just the relief of their suffering. Troubled persons want more satisfaction, contentment, and joy, not just less sadness and worry.”

Duckworth, Steen, & Seligman, 2005

Positive psychology

- Shift in perception reframe and refocus
- Focus on strengths in individuals, families, and systems
- There is more than one way to view a situation
- Optimism can be taught
- If you practice these skills you will be more effective in all elements in your life
- If you use these practices with teams, it will have an impact on everyone connected to you



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Evidence Informed

SIRS Database

START Information Reporting System

SIRS is a web-based data collection system
for managing START services

Purpose

Collect and report on various data to provide evidence-informed information to stakeholders, community members

SIRS Database

START Information Reporting System

- Provides service outcome feedback to project managers and administrators to assess the effectiveness and efficiency of START services
- Captures de-identified information about START clients and has the ability to provide reporting by case load, by region and by state
- Supports a continuous quality improvement approach



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Psychiatric Hospitalization Among Individuals in the START Program

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www.centerforstartservices.com

Results

- 28% of referrals reported past year hospitalization. Similar prevalence across states (24%-37%)
- Multivariate Analyses
 - Increased Odds of Hospitalization
 - Predisposing Variables
 - Lower level of ID, Younger Age, and Black/AA race ($p < .05$)
 - ASD diagnosis and Year (ns)
 - Enabling Variables
 - “Other” Setting and No receipt of SSD ($p < .05$)
 - Need Variables
 - Psychotic/Schizophrenia Diagnosis and Increased ABC scores ($p < .05$)
 - Number of Medical Diagnoses and Psychiatric Diagnosis (ns)



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Improvement in Mental Health Outcomes and Caregiver Service Experiences Associated with START Clinical Team Services

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Study Goals

1 Year Pre-Post



Aberrant Behavior Checklist

Caregiver Report
Symptom Checklist

Caregiver's Service Experiences

Family Experiences Interview
Survey

Emergency Psychiatric Services

ED visits and
Psychiatric
Hospitalizations

Results

- Improvements in caregivers' perceived inclusion in their dependents care and how responsive the mental health system was when they expressed their concerns.
- Improvements in the perceived quality of services provided directly to the caregivers' dependent
- Improvements in the hyperactivity, lethargy, and irritability on the ABC were observed
- ~40% reduction in ED visits and Hospitalizations

