START
Systemic, Therapeutic, Assessment, Resources and Treatment

Jill Hinton, Ph.D.
Clinical Director

AADMD Conference
June 2018
IDD and Mental Illness

• 30-40% of all persons with IDD have a psychiatric disorder compared to 27% of the general population
• 10-20% have challenging behavior (self-injury, aggression, destructive behavior) severe enough to impair daily life
• Yet, they are under-diagnosed, not treated, or inappropriately diagnosed
• Symptoms of mental illness often present differently in individuals with intellectual disabilities
• Determining accurate psychiatric diagnosis becomes especially difficult as the level of intellectual functioning declines
Factors that make Psychiatric Diagnosis More Difficult

• Cognitive abilities limit understanding of questions and answers
• Difficulty with receptive and expressive language
• Deficit in ability to articulate abstract concepts as depressed moods
• People with IDD have tendency to “please” others some may not answer questions accurately
• Atypical presentations suggest incorrect diagnoses
"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"
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...
“Unfortunately, you have what we call ‘no insurance.’”
Appropriateness

- Roles are clear
- Providers have expertise
- Defining the problem
- Service matches needs...
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...
"I don't listen to the evidence. I like to make up my own mind."
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
- Data-driven, evidence-informed practices (SIRS)
Clinical Services
- Neurology
- OT
- Forensic Psychology
- Nursing
- Dentistry
- Family Supports

Therapeutic Resources & Services
- Emergency Beds
- Planned Beds
- Therapeutic Activities
- Autism Services
- Positive Psychology
- Sensory Activities
- Mobile In-Home Community Support Services
- 24-Hour Crisis Response

Linkages
- State/local stakeholders
- Residential
- Schools
- Inpatient
- Outpatient
- Respite
- Day
- Natural Supports

START Regional Team Services
- Director (master’s or above)
- Clinical Director (Psychologist or equivalent)
- Medical Director (Psychiatrist or APRN)
- Team Leader(s)
- Certified START Coordinators

Training and Consultation
- Didactic Training
- Eco-mapping and systems support
- Crisis prevention and intervention planning
- Emotional Intelligence training

Advisory Committee
- Director (master’s or above)
- Clinical Director (Psychologist or equivalent)
- Medical Director (Psychiatrist or APRN)
- Team Leader(s)
- Certified START Coordinators

The Center for START Services
- Customized Coaching
- Technical Support
- Certification of START Coordinators
- National Online Training Series
- Online Certification Course for START Teams
- National Database
- Fidelity Guides
- START Curricula

24-Hour Crisis Response
- Mobile Mental Health Crisis Teams
- Hospital Emergency Rooms
- Police
- Other First Responders

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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
BIO PSYCHOSOCIAL
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:
  o Genetic disorders and syndromes
  o Diabetes
  o Sleep Irregularities
  o Constipation
  o Gastrointestinal problems
  o Infections
  o Seizure disorders
  o Physical pain
  o Vision/hearing changes
  o Medication side effects and drug toxicities
Medical Factors- Study

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

Charlot, 2014
# MEDICAL PROBLEMS

<table>
<thead>
<tr>
<th>Medical Diagnoses</th>
<th>N = 50 Consult</th>
<th>N = 198 Inpts</th>
</tr>
</thead>
<tbody>
<tr>
<td>Constipation</td>
<td>64%</td>
<td>60%</td>
</tr>
<tr>
<td>GERD*</td>
<td>26%</td>
<td>38%</td>
</tr>
<tr>
<td>Seizure D/O</td>
<td>36%</td>
<td>25%</td>
</tr>
<tr>
<td>Hypothyroidism</td>
<td>20%</td>
<td>19%</td>
</tr>
<tr>
<td>Hypertension</td>
<td>12%</td>
<td>19%</td>
</tr>
<tr>
<td>Anemia</td>
<td>16%</td>
<td>18%</td>
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BIOPSYCHOSOCIAL
IDD

• Consider impact of Intellectual Disability, Autism Spectrum Disorder, other developmental disabilities on presentation of psychiatric symptoms
• Understand executive functioning deficits.
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?
  o Patients with ID are poor reporters of their own health problems
  o Physical problems are often expressed behaviorally
  o Developmental features alter the manifestation of psychological and psychiatric symptoms

Charlot, 2014
Psychiatric/Mental Health Factors

• Behaviors that may indicate comorbid conditions:
  o 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
• **More Common:**
  o Anxiety Disorders
  o Depressive Disorders
  o Trauma and Stressor Related Disorders

• **Less Common:**
  o Bipolar and Related Disorders
  o Obsessive Compulsive Disorder
  o Schizophrenia and Other Psychotic Disorders
### Social/Environmental Factors

Often overlooked, not considered

<table>
<thead>
<tr>
<th>Environmental</th>
<th>Social</th>
</tr>
</thead>
<tbody>
<tr>
<td>o Noise</td>
<td>o Changes or loss of important people</td>
</tr>
<tr>
<td>o Temperature</td>
<td>o Loneliness, social isolation</td>
</tr>
<tr>
<td>o Lighting</td>
<td>o Boredom</td>
</tr>
<tr>
<td>o Space – too large, too small</td>
<td>o Lack of Control/Choice</td>
</tr>
<tr>
<td>o Changes in daily routine</td>
<td></td>
</tr>
</tbody>
</table>
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
PERMA
Seligman

positive emotion
engagement
relationships
meaning
accomplishments
Evidence Informed
SIRS Database

**SIRS**

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
Psychiatric Hospitalization Among Individuals in the START Program

Luther Kalb, MHS
PhD Student, Department of Mental Health
Johns Hopkins Bloomberg School of Public Health

Co-Authors
Joan Beasley, PhD; Ann Klein, MA; Jill Hinton, PhD; Lauren Charlot, PhD
Results

• 28% of referrals reported past year hospitalization. Similar prevalence across states (24%-37%)

• Multivariate Analyses
  o Increased Odds of Hospitalization
  o Predisposing Variables
    • Milder level of ID, Younger Age, and Black/AA race (p<.05)
    • ASD diagnosis (ns)
  o Enabling Variables
    • “Other” Setting and No receipt of SSD (p<.05)
  o Need Variables
    • Psychotic/Schizophrenia Diagnosis and Increased ABC scores (p<.05)
    • Number of Medical Diagnoses and Psychiatric Diagnosis (ns)
Improvement in Mental Health Outcomes and Caregiver Service Experiences Associated with START Clinical Team Services
University of New Hampshire
Institute on Disability/UCED

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.
The best treatment plans are derived from a comprehensive multidisciplinary diagnosis, assessment, and case conceptualization which includes:

- Understanding IDD
- Consideration of Bio-Psycho-Social factors
- Consideration of diagnostic overshadowing, intellectual distortion, psychosocial masking, cognitive disintegration, baseline exaggeration
- Recognizing the impact of trauma
- Considering the impact of health issues and medication side effects
- Applying strategies at all levels of tertiary care model
- Utilizing data to inform treatment and strategies