

## Interventions to support individuals with IDD and co-occurring MH conditions and their systems of support

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### Objectives

- Gain a clear understanding of the mental health aspects of IDD, including prevalence and common diagnostic evaluation challenges
- Understand how structural systemic interventions play a role in providing treatment and designing supports for individuals with IDD and MH conditions
- Identify practical interventions and strategies can be applied when working with this population of service users.
- Understand how to support individuals with IDD/MH and their teams during stressful situations

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### Intellectual Developmental Disorders (IDD)

- A neurodevelopmental disorder with onset during the developmental period of life that includes both intellectual and adaptive functioning deficits in conceptual, social and practical domains.
    - Intellectual impairments: reasoning, problem solving, abstract thinking, judgement, experiential learning
    - Adaptive impairments: activities of daily life, communication, social participation, independent living, generalizability of skills across environments
- DSM 5

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## Mental Health Conditions Defined

- Changes in thinking, feeling or mood that affects a person's ability to relate to others on a daily basis
- Can take many forms and even people with the same diagnosis can have very different experiences.

-NAMI

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## Co-Occurring Conditions

- There is an assumption that these are two completely separate issues that are combined into one human.
- Instead, co-occurring conditions are asset of biopsychosocial factors that impact a person's world view.
- HX:
  - Eugenics
  - Institutionalization
  - Community congregate care settings/behavior management/medication
  - Moving toward integrated community living

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## Prevalence of MH Conditions and IDD

- Myth: of Immunity: "People with IDD are worry-free"
- People with intellectual disability (ID) experience a higher rate of mental health conditions than the general population
  - 30% of individuals with IDD will experience MH symptoms in their lifetime.
- Yet, they are underdiagnosed, not treated, or misdiagnosed far more than the general population

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### Limits to the Research

- Samples are small
- Lack control groups
- Often completed in institutions and congregate care settings
- Studies often don't have controls
- Often exclude people with IDD with severe behavioral health issues.

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### Things to Consider:

- Wellness is key!!
- Focus on strengths, skills and meaning (PERMA)
- Apply the Biopsychosocial approach to assessment and treatment of MH conditions

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### Wellness and Strengths Based Work

- All human beings desire a meaningful life-we all have aspirations, dreams and want to feel a sense of belonging.
- Promotion of wellness (not just the absence of illness) and recognition of strengths help to:
  - Promote resiliency
  - Manage stress
  - Maintain positive relationships.

These factors impact the manifestation of MH symptoms.

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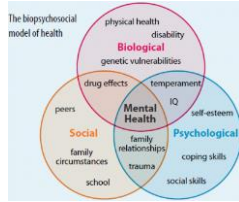
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## The Biopsychosocial Approach

- There are many factors which may contribute to the way a person feels or behaves and all of these aspects impact one another and inform us about who the person is.
- All factors of a person's life impact one another.



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## Vulnerabilities That May Be Present for Individuals with IDD

- Genetic & biological vulnerabilities
- Cognitive limitations and executive functioning
- Discrimination, social rejection, trauma & abuse

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## How Are Mental Health Conditions Diagnosed?

- Conversation--There are no lab tests for psychiatric disorders
- Typically, questions are asked of the person seeking help
- This can be challenging for individuals with IDD due to limited conversational ability

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## Initial MH Diagnostic Interview

General Population	ID Population
Establish relationship	Relationship with a Team
Conversation, detailed questions & answers	Verbal ability limited 3 <sup>rd</sup> party information
Evaluate overall presentation	Atypical presentation Behavioral phenotypes
Discuss diagnosis and treatment plan	"Team" treatment negotiation

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## Challenges in MH assessment

- Limited lectures, readings and clinical experience with ID during their training
- Very few MH professionals have opportunity to train in an ID-MH specialty setting

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## Individuals with IDD

- Have a desire to please others
- Have learned certain scripts that are typically in psychiatric interviews
- My say "odd" things

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## Diagnostic Overshadowing

Definition: professionals wrongly assume that symptoms are attributed to one diagnosis and do not take other factors into consideration

Is it "Behavior" or is it Mental Health?????

Primary vs. Secondary Diagnosis???

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## Key Challenges in MH Diagnosis & Treatment

- Intellectual distortion
- Baseline exaggeration
- Cognitive disintegration
- Psychosocial masking

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**Applying Structural-Systemic Theory of Intervention to Working with Individuals with IDD**



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### What is Systemic Analysis? Consultation?

- The act of building capacity within a system that promotes stability
- Understanding the perspective of all members of a system/unit, and helping them to develop a common goal that makes everyone feel confident and equipped to address stress
- Meeting people where they are
- Includes ongoing assessment and engagement of all subsystems

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### What It Isn't

- Linking to resources
- Making referrals
- Individual interventions
- Case management/service coordination
- Outpatient therapy
- Getting others to understand our perspective
- A one time thing...

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### The Structural-Systemic Model

- A lens in which we see people and systems interacting
- Structural change is main goal
- Maximizing resources that already exist within the system—all system members bring untapped resources to the table.
  - Everyone involved in the system is part of the solution.
- Focus is on identifying strengths and resources to identify solutions; not a focus on the reason the problem exists to begin with

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### Behavior is Communication

- All behavior is communication
  - What is the behavior of this system telling you?
  - What is the behavior of this individual telling you?
- Systems are in constant struggle to maintain homeostasis
  - Disruption in homeostasis can cause the system to be distressed
  - Members will engage in behavior and seek interactions in attempts to return to homeostasis
  - Any change imposed on the system can be seen as threatening and disrupts homeostasis. Change can cause rigidity and resistance

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### Boundaries

- All systems have boundaries which define the system's structural framework and how members relate to one another
- Boundaries can be closed, open or loose
  - Closed boundaries: fixed and rigid
  - Loose boundaries: scattered and irregular
  - Open boundaries: moveable, negotiable and flexible
- A system is most functional when:
  - Boundaries are clear and flexible
  - Communication is open

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### Seeing the big picture

- Seeing the forest from the trees
- Flexibility
- Thinking on your feet
- Finding a common goal
- CAUTION: Focus on training, training, training...and then missing the big picture



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## Strategies

- Joining—A working relationship; need to join in order to promote shifting.
- Active listening—non-verbal body language; summarizing, paraphrasing, clarification, reflection, etc.
- Reframing—based on the underlying attitude on the part of the clinician. Makes the situation more workable. Examples?
- Modeling
- Shifting
- FACILITATION

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## Role of the Clinician

- Join with the team. Help create a shift that enables the system to effectively handle problems
- Reframe identified problems as needs that can be met through the development of common language and goals
- Help the system redefine roles and relationships in order to effectively reach the goals agreed upon
  - The clinician does not necessarily need to "take control" of the system in order to support the change process
  - The clinician is a facilitator that supports the team in identifying a process to reach their goals

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## Putting Systemic Consultation Into Practice

- Respect and build upon natural supports as often as possible
- Remember that families who are the most stressed and go into crisis the most are the ones that are least likely to ask for help
- Work with the team to operationalize a process in which the team can begin to address the challenges identified
  - **Think critically about the information given**
- Notice where there are holes in the system of support and additional supports are necessary

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### Putting Systemic Consultation Into Practice

- REFRAME the problem or "behaviors" into a challenge the team will work together in addressing
- Help the team identify what "success" looks like for the client
- Help the team develop a common understanding of the goals for this individuals.

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### Putting Systemic Consultation Into Practice

- EMPATHIZE with the team as well as with the client
  - Is someone non-compliant or does he have a desire to be independent?
  - Does someone ask everyone the same questions because he is manipulative or because he has trouble trusting people?
  - Is this family sabotaging or do they need more information in order to make an informed decision?

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### WHAT is an Ecomap?

- A graphic representation of a person's connections to other people and/or systems in their life. It helps us to identify how reciprocal interaction exists between the person and the system

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### WHAT is an Ecomap?

- Ecomaps:
  - Express the strength and effect of each relationship
  - Serve as a tool to highlight different relationships and human resources in a person's life
  - Are a starting point when addressing a person's needs
  - Allow the consultant to successfully identify barriers and develop a working hypothesis as to how to affect change within the system

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### WHY Do We Use Ecomaps?

- As a TOOL to inform systemic analysis and consultation
- The main purpose of systemic consultation is to support the team with the development of a common understanding and goal in order to support the person as effectively as possible. We use ecomaps to:
  - Aid in the development of a working hypothesis that explains how and why the system works as it does
  - Identify the types of relationships that exist within the system
  - Identify current roles of the individuals within the system
  - Identify the client's connectedness to his/her system as well as the larger environment

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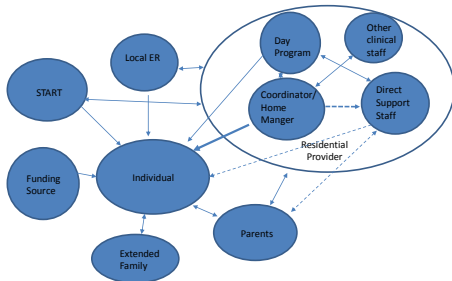
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# Structural Systemic Interventions Applied to Crisis Situations



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## A crisis is.....

- A stressful event without the tools to address it
- Unplanned
- Unpredictable
- More than simple stress
- More than just mental illness

"There cannot be a crisis this week. My schedule is already full"

-Henry Kissinger

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## Components of a crisis experience

- Precipitating events
- Factors that make a person(s) vulnerable
- The actual crisis event/active crisis state
- recovery

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### The role of the clinician

**\*\*Address distress, impairment and instability.\*\***  
"In a crisis, give help first, then advice."

- Respond quickly to make critical safety and treatment decisions
- Develop rapport
- Focus on the here and now
- Rapidly address the presenting problem
- Develop a disposition plan
- Follow-up

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**85% of referrals to emergency services are precipitated by aggression.**

**Why?**

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### Intervention Planning- A Systems Perspective

- If you want to teach people a new way of thinking, don't bother trying to teach them. Instead, give them a tool, the use of which will lead to new ways of thinking"
- Fostering dialogue
- Facilitating
- Providing support--being present
- Cross-systems planning

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### Who is in Crisis – the Person in Need or the System?

It doesn't matter!

A crisis is a crisis is a crisis.....

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### Positive Psychology Approaches to Crisis Intervention

- The assumption is that when conditions to promote wellness are undermined, problem behaviors may occur
- Empathy and rapport are key
- Health/mental health – identification and understanding behavior in the context in which it occurs includes an evaluation of biomedical and mental health issues as vulnerabilities that perpetuate challenging behavior

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### Positive Approaches to Crisis Intervention

- Communication - looking at an individual's behavior as a form of communication that has function and meaning
- We can often turn things around with heightening exposure to fun and stimulating activities not contingent on behaviors-humor
- Nutrition, exercise, sleep all contribute to health and can create irritability when undermined

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### Positive Approaches, continued

- The need for rewarding experiences: Reinforcement - advocating intense non-programmatic and non-contingent reinforcement that occurs on a frequent basis
- The environmental social context of wellness: Redirection - changing aspects of the individual's environment and interaction pattern; capitalizing on stimulus change opportunities
- Coping - teaching methods and skills to handle stressors and friction

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### Trauma Informed Crisis Intervention

- People with IDD experience trauma at higher rates
  - Increases risk of MH conditions
  - Increases risk of emergency service interface
- Actual crisis events are traumatic in and of themselves

Things to consider:

- How do you answer your crisis line? Office phone?
- How is your office set up?

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### Stages of Crisis Intervention

- Establish rapport quickly
- Conduct a biopsychosocial assessment/assess imminent risk
- Identify major problems/crisis precipitants
- Encourage exploration of feelings and emotions
- Generate and explore alternatives
- Restore functioning through implementing an action plan
- Follow up and debriefing

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### Effective Crisis Intervention

- Our job is to support the desire to deal with frustration that is an inevitable part of life in the context of their vulnerabilities and abilities
- Intensity - the frequency and quality of interactions with individuals during the course of the day needs to promote a wellness approach rather than behavior management
- Change – crisis intervention techniques require educated flexibility on the part of staff and the system of support- requires Cross-Systems collaboration

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### Do Not Focus On a "Cause and Cure Approach"

- Think in terms of acceptance
- Sometimes have to live with problems we cannot completely resolve
- Job is to improve life experiences
- Support makes human frailty bearable
- Even in the treatment of medical illnesses, it has been found that the quality of a person's life is important

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### An Effective Cross-Systems Crisis Intervention Plan

- Instructs: Action-oriented based on consensus amongst partners in the systems
- Relies on mutual definitions of how to reach a goal
- Ongoing interaction is needed, review and modify
- Requires a tool to foster communication and service linkages
- Clear, concise, relevant
- Must easily and accurately communicate relevant issues/results

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### Lessons Learned: Effective Crisis Intervention Plans

- Consistency - one cannot implement an effective plan on a part-time, haphazard basis. Protocols of support should be established to promote a positive, methodical response to the problematic behavior
- Portability - the plan must have the ability to move with persons in the various settings in which they interact - staff and family in all locations must be trained in the interactional approaches

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### IDD and Mental Conditions

- Across the United States approximately 1.5% to 2.5% of the population has an intellectual developmental disorder (IDD).
- The (DSM5) defines IDD as a disability that involves impairments of general mental abilities that impact adaptive functioning
- Epidemiological studies have established that the prevalence of mental health conditions for people with IDD is typically 2 to 3x the general population
- Mental health conditions often contribute to challenging behavior. For people with IDD, aggression and self-injurious behavior are two of the most common reasons for referrals for mental health services.

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### Barriers in IDD System

- "Troublesome" behaviors considered unacceptable in many support and service venues
- The last and least served
- Continued concept of "primary" vs. "secondary" disorders: were not trained in MH or health practices that could contribute to challenging behavior were sent to be "fixed"

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### Barriers in the MH System

- Stigma
- Much more likely to use emergency services
- Lack of training (diagnostic overshadowing)
- Lack of expertise
- Medication issues
- Believed that challenging behavior was a result of developmental issues alone
- "Did not have the IQ for depression"
- Primary vs. secondary diagnosis instead of presenting issue

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### Communication and Understanding Between Systems

- MH "language" vs. IDD "language"
- Treatment vs. Support
- The person's perspective vs. the provider's perspective
- What are people and systems telling us with their behavior?
- What do families need, do we listen
- The need to develop a common language begins with checking our assumptions and integrating approaches

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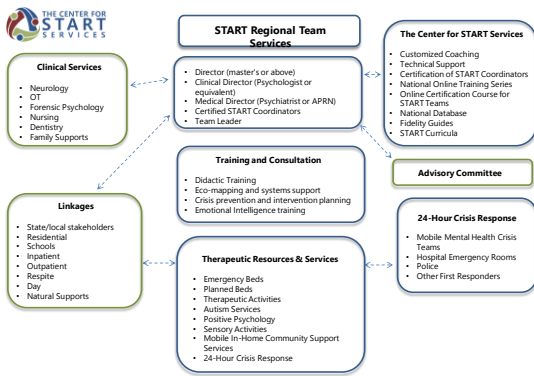
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## START Practices

- The START Network is a group of individuals with a common repertoire of knowledge about the ways of addressing similar (and often shared) problems and purposes.
- This collective practice is made accessible to newcomers through the START training forums: activities through which individuals develop ways of thinking and reframing their views.
- The apprenticeship of START coordinators is aimed to reproduce practices through which the next generation START coordinators is developed. We need to teach coordinators to act like START coordinators.

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## 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

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## START Assessments and Training

- 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

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## 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

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## Positive Psychology

- Shift in perception, reframe and refocus
- 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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**START**

**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 in-home services, inpatient and START Resource centers

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**Finals Thoughts and Questions**

- If you have questions or I can be of any support, please email at any time! [andrea.caoili@unh.edu](mailto:andrea.caoili@unh.edu)

Thank you!

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