



RUTGERS HEALTH

**The Boggs Center
on Disability and Human Development**

Robert Wood Johnson Medical School

THE BOGGS CENTER ON DEVELOPMENTAL DISABILITIES

New Jersey's University Center for Excellence in Developmental Disabilities Education, Research, and Service

Understanding Behavior Change and Mental Health in IDD

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Session Objectives:

1

Recognize indicators of a possible mental health condition

2

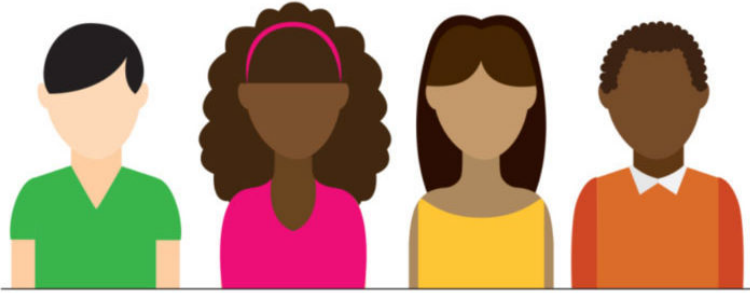
Recognize barriers to assessment and diagnosis of mental health conditions in people with IDD.

3

Describe the impact of mental health symptoms on behavior and quality of life

4

Share tools and resources on disability and mental health



1 in 4 Americans suffers from a diagnosable mental disorder. Minority populations are less likely to receive diagnosis for their behavioral health issues and have less access to mental health services.

ADULTS WITH DISABILITIES REPORT FREQUENT MENTAL DISTRESS ALMOST 5 TIMES AS OFTEN AS ADULTS WITHOUT DISABILITIES

Screen patients for mental health concerns

CDC.GOV bit.ly/MMWRMentalDistress MMWR

The infographic features a teal silhouette of a human head in profile, facing right, with a red brain icon inside. The background is a gradient of orange and yellow. A dark blue curved banner at the top right contains the main headline in white and teal text. Below the banner, the text 'Screen patients for mental health concerns' is written in black. At the bottom, there is a teal bar with the CDC.GOV website, a link to the MMWR report, and the MMWR logo.

Prevalence of Mental Health in IDD

Two to four times a typical population (Corbett 1979)

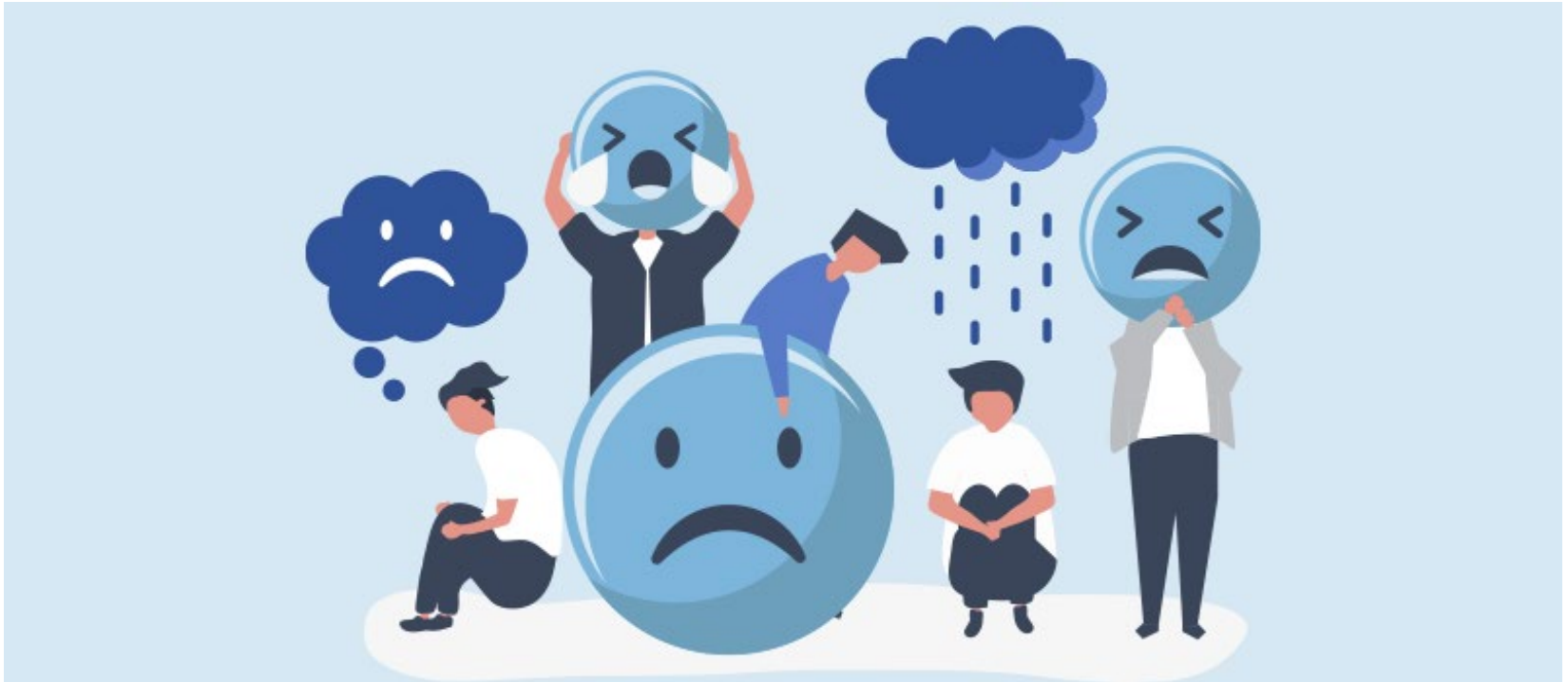
32.9% of people with IDD have co-occurring MI (National Core Indicator data)

55% of people with IDD have MI (National Core Indicator data, 2012)

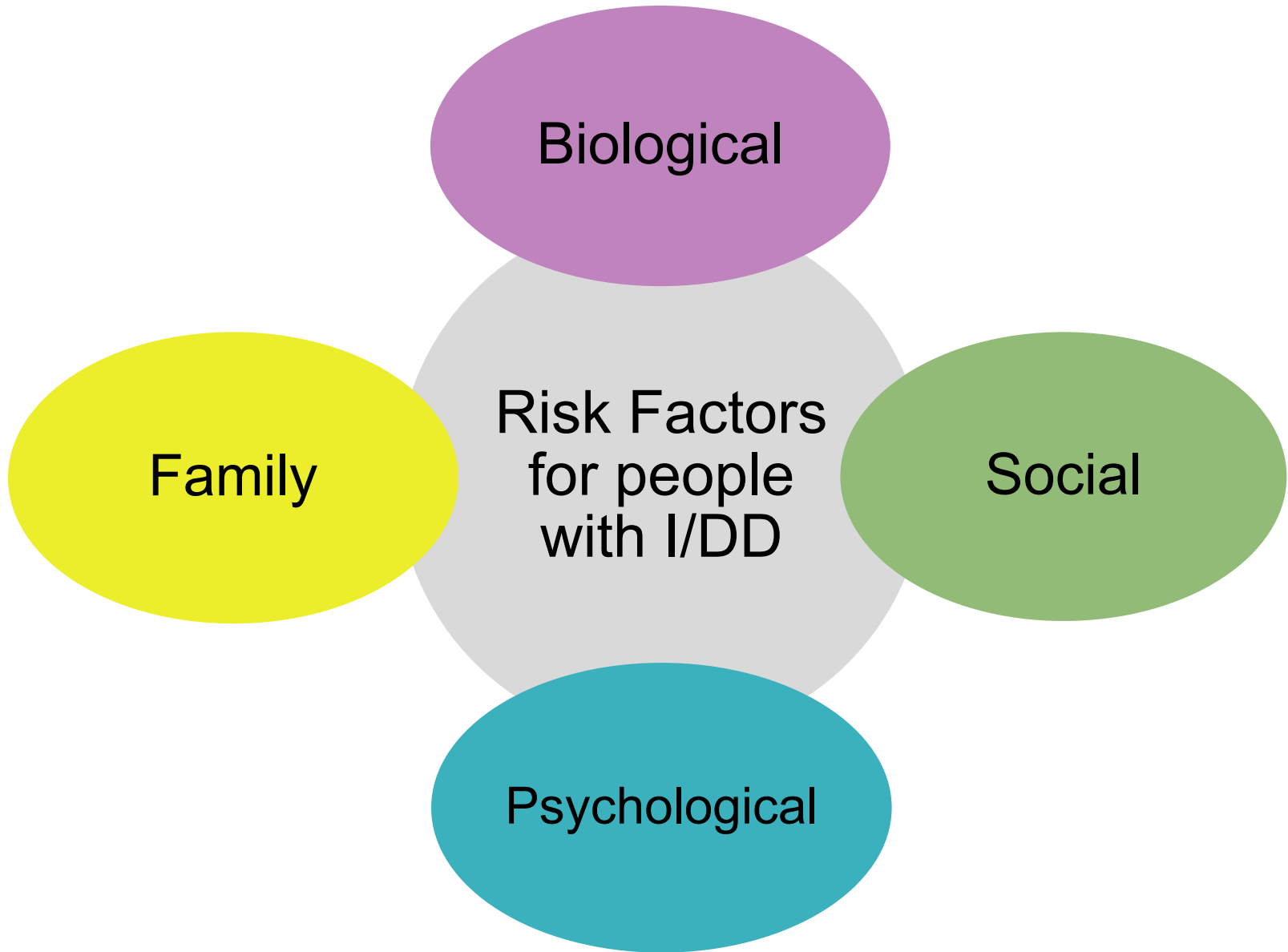
50-60% of people with IDD will have MH (NADD, 2020)



Prevalence of MI in IDD



Why are people with IDD more likely to experience a secondary mental health condition?





Triggers for Emotional or Mental Health Crises

Onset of illness (medical or mental)

Birth of sibling

Onset of puberty/adolescence

Start or end of school

Out of home “placement”

Sex and dating issues

Changes in staff and teacher relationships

Surpassed by younger siblings or peers

Inappropriate expectations of others

Physical, sexual or emotional abuse

Illness/aging of parents

Death of parent, caretaker or family member

Loss of peer or roommate or friend

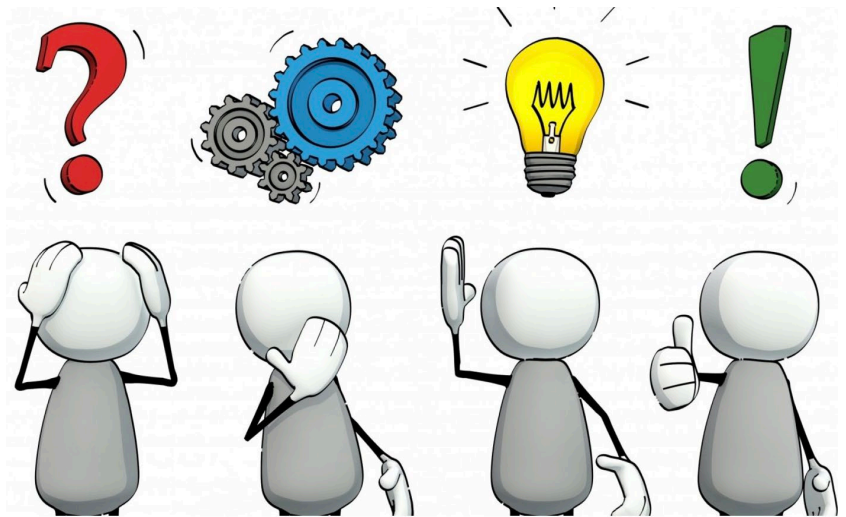
It can be difficult to distinguish whether a change is associated with:

- A symptom of a psychiatric disorder
- An unmet need
- A learned behavior
- A medical condition
- The environment
- Trauma and grief



Assessment Challenges in IDD/MH

- Communication
- Diagnostic Overshadowing
- Acquiescence
- Appearing Withdrawn
- Medications
- Behavioral
- Multiple Diagnoses
- Division of Services
- Presentation of Symptoms



Kelly has been struggling to get ready for work and attend other activities. She has lost weight despite missing tennis lessons and exercising less. She manages chronic migraines with a medication called Topamax. She has new staff who remind Kelly she must follow the same rules as everyone else. This leads to arguments if Kelly chooses to stay behind or skip events.

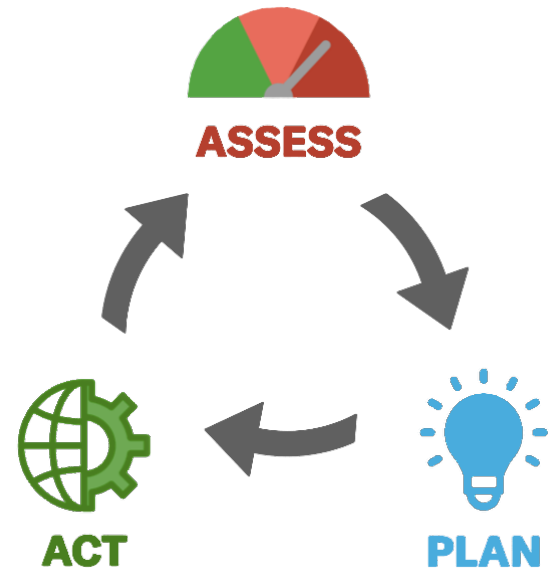
Considerations:

What are some questions we have?

What are potential barriers to assessment?

What is her behavior change telling us?

How can we help Kelly?



Barriers to assessment and planning

- Signs and symptoms can present differently in IDD
- Observation without documentation or communication gets lost
- Mental health symptoms can be overlooked
- Medication can interfere with presentation of symptoms
- Conditions overlooked when we use behavioral lens



Depression: Signs and Symptoms

- Characterized by low mood, slowing of thinking and difficulty concentrating / sustaining energy.
- Can significantly disrupt school, work, family relationships, social life, hobbies.
- A loss of interest in pleasurable activities can be observed, i.e., the person no longer attending the activities from which he/she derived pleasure.
- Other symptoms include feelings of hopelessness or pessimism, appetite and/or weight changes and thoughts of death or suicide; suicide attempts.



Depression Signs and Symptoms

Sadness or
hopelessness

Irritability, anger or
hostility

Tearfulness or
frequent crying

Withdrawal from
friends and family

Loss of interest in
activities

Changes in eating
and sleeping
habits

Restlessness and
agitation

Feelings of
worthlessness
and guilt

Difficulty
concentrating

Physical
complaints (far
more likely in
youth than adults)

Lack of
enthusiasm and
motivation

Thoughts of death
or suicide

Depression: Treatment Approaches



Psychotherapy
(individual and/or
group)



Regular exercise



Antidepressant
medication



Engaging in
meaningful
activities



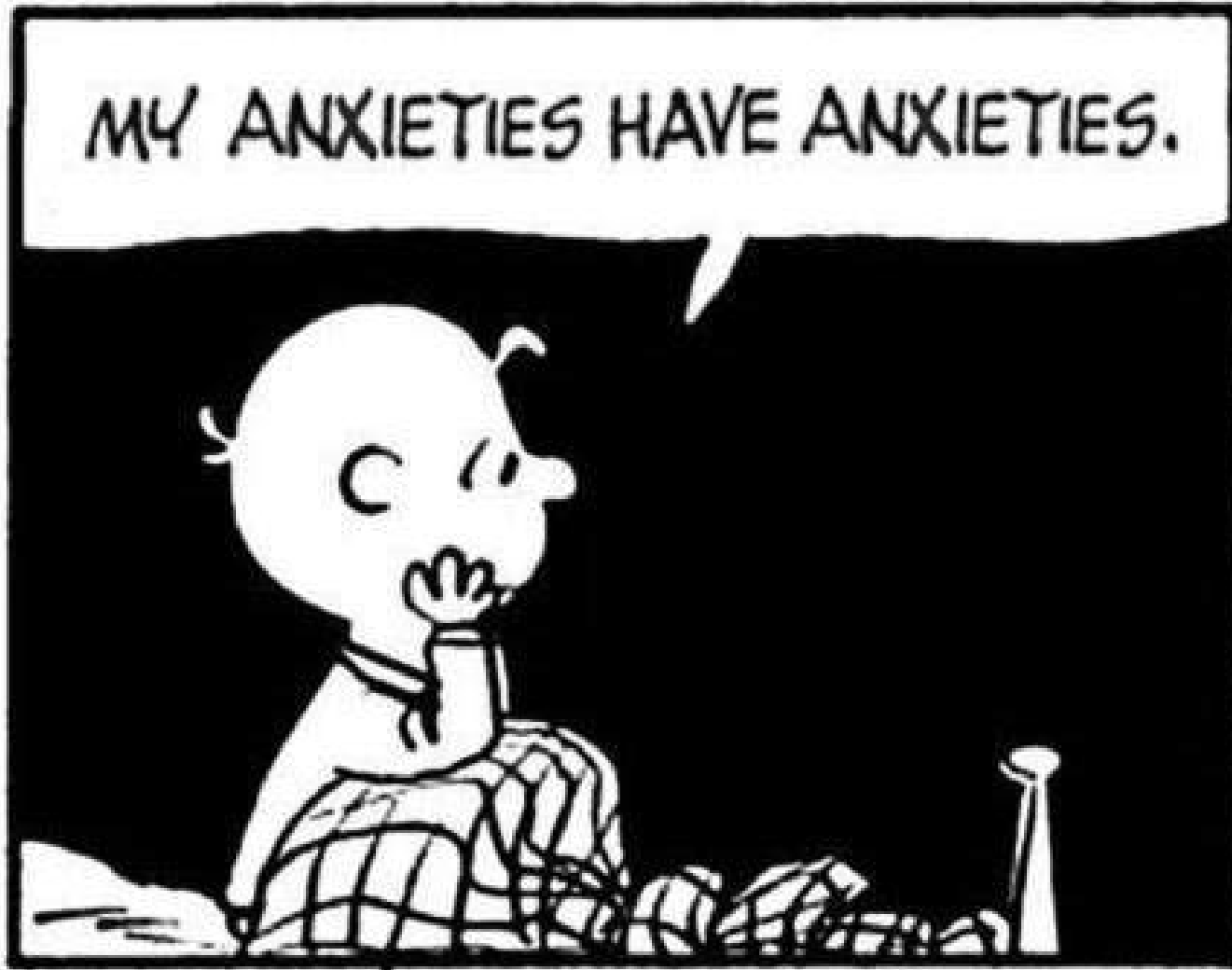
Learning stress
management
strategies




Social skills and
opportunities



Positive
environment and
support strategies



Behavior Change

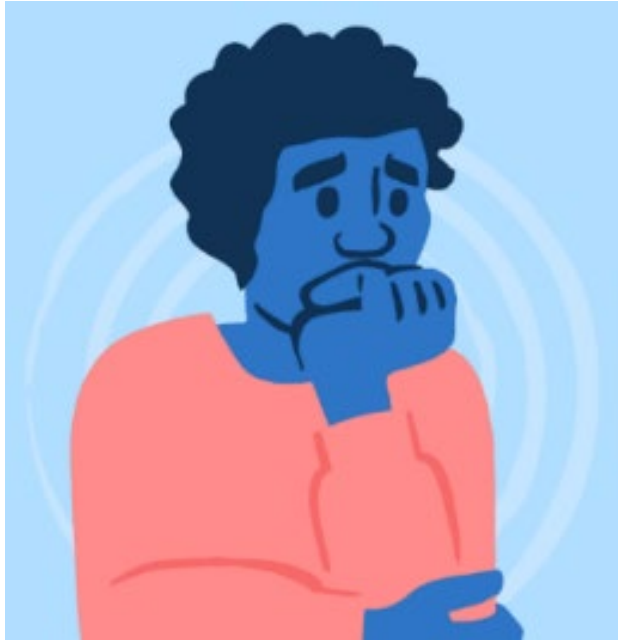


Agitation and aggression
efforts to avoid discomfort
Compulsions
Obsessions

Social-Communication & Perspective
Uncertainty, Discomfort, Trauma
Rule-based, explicit learning style
“Sticky attention” (over focused)
Executive function (poor organization,
sequencing)
Limited coping skills

Anxiety

Anxiety in Youth



Recurring fears and worries about routine parts of everyday life

Irritability

Trouble concentrating

Extreme self-consciousness or sensitivity to criticism

Withdrawal from social activity

Avoidance of difficult or new situations

Chronic complaints about stomachaches or headaches

Drop in grades or school refusal

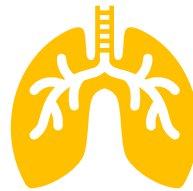
Repeated reassurance-seeking

Sleep problems – too much or too late

Substance use



Anxiety feels different for everyone. There are some outward signs of anxiety that we can observe. Other indicators of anxiety are internal symptoms that a person feels.



Physical feelings of anxiety include rapid breathing, muscle tension, nausea, increased blood pressure, sweating, heart palpitations, and chest pain.



Other symptoms include restlessness, fatigue, irritability, sleep disturbances, difficulty concentrating, muscle tension, and personality changes.

Indicators of a Mental Health Condition



Rapid onset, increase, or change in behavior or symptoms



Changes in sleep or eating patterns



Decrease in living skills or change in appearance or hygiene



Evidence of purposeful self-harm



Signs of hallucination or delusion



Co-occurring substance abuse



Behaviors/symptoms occur across settings

Signs of a Medical or Health Issue

Changes in weight due to physical
discomfort or pain

Changes in sleep habits due to physical
discomfort

Sensitive to touch around certain parts of
the body

Discomfort around certain clothing or
equipment

Change in energy level, digestion, breathing
or consciousness

Unsteady gait, unbalanced walk, recent falls

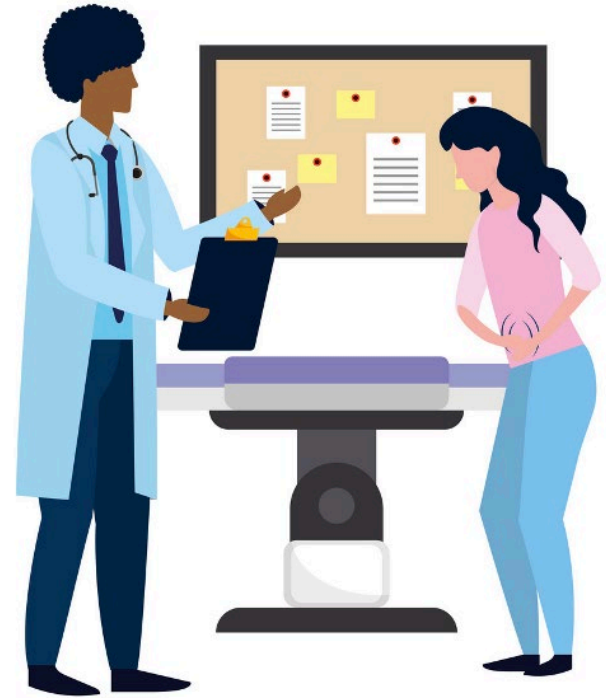
Signs/symptoms occur across settings

Kelly

Something sets me up (<i>setting event</i>)	Something sets me off (<i>antecedent</i>)	So I (<i>behavior</i>)	And I Get/Avoid (<i>consequence</i>)
<ul style="list-style-type: none"> • Grief and Loss • Not motivated by activities • Depression? • Migraines • Staff turnover 	<ul style="list-style-type: none"> • Prompted to get dressed for work, tennis, dinner, movies. 	<ul style="list-style-type: none"> • refuse/choose • argue with staff 	<ul style="list-style-type: none"> • miss events • gets to be alone • break from demands <p style="text-align: center;">Function</p> <ul style="list-style-type: none"> <input type="checkbox"/> Gain attention <input checked="" type="checkbox"/> Escape <input type="checkbox"/> Obtain Tangible <input type="checkbox"/> Sensory
<p>How can we address Kelly's needs?</p>	<p>How can we have more positive, person-centered interactions?</p>	<p>What can Kelly do instead?</p>	<p>What are ongoing supports to meet her needs?</p>

Health and Medicine

- Comprehensive treatment plan
- Positive behavior strategies
- Address pain and medical concerns
- Diet and Nutrition
- Medication and side effects
- Documentation and communication



Therapy and Counseling

- Psychotherapy
- Individual and/or Group
- Focus on understanding and managing symptoms
- Develop self-awareness of feelings and ways to respond
- Learning triggers
- Empowering choice and agency



Lifestyle and Wellness



- Pictures or video sequences
- Relaxation/stress management
- Guided Imagery
- Mindfulness
- Employment
- Recreation
- Exercise
- Friendship / dating / social skills
- Environmental modifications

Wellness Domain	Choices and Opportunities
Social	How can we help people maintain healthy, supportive relationships?
Emotional	List some activities to ensure relaxation and good mental health.
Physical	How can we support fitness/exercise and nutrition goals? What is our role in coordinating with health professionals?
Environmental	Describe a safe, accessible, comfortable space/setting.
Intellectual	What types of activities promote lifelong learning, leisure, and creativity?
Vocational	How can people share their gifts with the community?
Spiritual	How can we honor and explore these preferences? (worship, nature)

Wellness Domain	Choices and Opportunities
Social	
Emotional	
Physical	
Environmental	
Intellectual	
Vocational	
Spiritual	

Resources & Tools

MHDD National Training Center Lessons

<https://www.mhddcenter.org/learn-now/>

Vanderbilt IDD Toolkit Healthcare Checklists & Resources

<https://iddtoolkit.vkcsites.org>

The NADD www.thenadd.org

Positive Identity Dev Worksheets <http://pid.thenadd.org/>

SAMHSA Guide to Wellness

<https://store.samhsa.gov/sites/default/files/sma16-4958.pdf>

Taking Care of your Mental Health

<https://www.nami.org/NAMI/media/NAMI-Media/Infographics/NAMI-Taking-Charge-of-Your-Mental-Health.pdf>

Resources & Tools

Mental Health Disparities: Diverse Populations

<https://www.psychiatry.org/News-room/APA-Blogs?category=163>

Mental Health America: BIPOC MH Resources/Impact of Trauma Toolkit

<https://www.mhanational.org/racial-trauma>

NJ Mental Health Cares (866) 202-HELP

TTY: (877) 294-4356

NJ Hopeline (855) 654-6735

Chat: <https://njhopeline.com/talk-to-us-by-chat/>

National Suicide Prevention Lifeline (800) 273-TALK

The logo features three stylized human figures in red, orange, and blue, connected by a yellow link. To the right of the figures, the word 'THE' is written in blue, 'LINK' in red, and 'CENTER' in blue.

THE LINK CENTER

Bridging I/DD and Mental Health Systems

<https://acl.gov/TheLinkCenter/Resources>

For more training opportunities and resources visit

<https://boggscenter.rwjms.rutgers.edu/>



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