Suicidal Behaviors in People with Intellectual and/or Developmental Disabilities: Strategies for Positive Health Outcomes

Mirian Ofonedu, Ph.D., LCSW-C
Director of Training, Maryland Center for Developmental Disabilities
at Kennedy Krieger Institute

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Training Description

People with intellectual and/or developmental disabilities (I/DD) are at increased risk for undetected suicidal thoughts and behaviors and for developing suicidal thoughts and behaviors, which usually creates high anxiety for professionals, parents and caregivers caring and working with them.

This training aims to increase participants' knowledge and skills to recognize risk and protective factors, warning signs, and suicidal behaviors in people with I/DD, and to facilitate early referral of those at risk for suicide.

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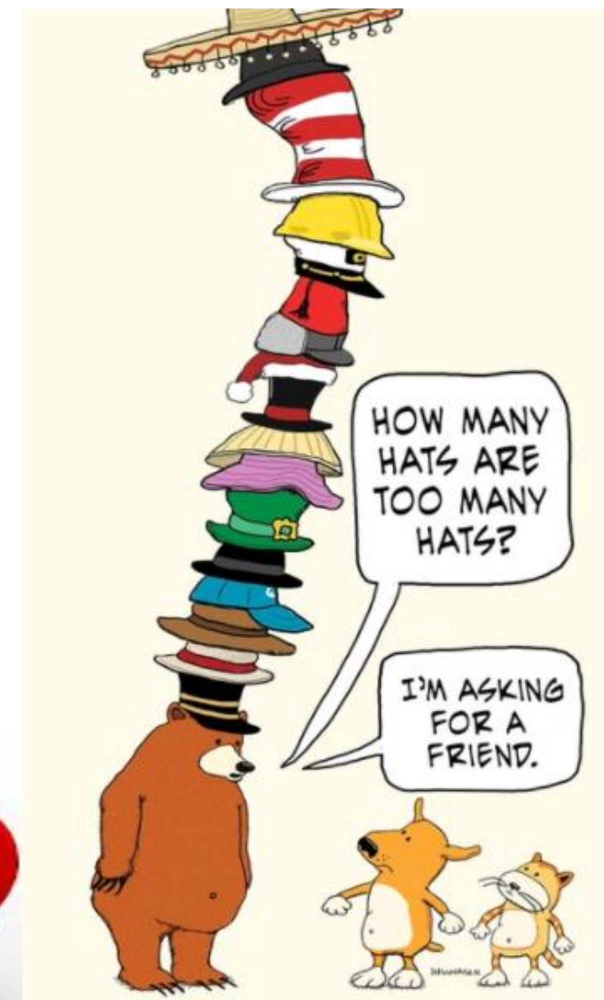
What is your role?

In the chat, please respond to this question

- What is your role with individual with intellectual and/or developmental disabilities? For example:
  - Psychologist
  - Social Worker
  - Educator
  - Direct Service Professional
  - Parent
  - Student
  - Medical/Clinical Staff
  - Other



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Definition of Terms (1 of 2)

Intellectual disability (ID) is a neurodevelopmental disorder that is typically diagnosed before the age of 18 and is characterized by significant limitations in intellectual functioning (i.e., IQ below 75). ID is highly associated with deficits in adaptive skills (e.g., conceptual, social and practical skills) and cognitive functioning.

Developmental disabilities (DD) is a broader category used to describe disabilities that present at birth and that negatively affect the trajectory of the individual's physical, intellectual and/or emotional development.

- In this training, we focused on the people with intellectual disability and/or developmental disability (I/DD).
- We used the term "ID" to describe people with only intellectual disability and "IDD" for those with intellectual disability and other types of developmental disability together.

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Definition of Terms (2 of 2)

Suicide: A self-injurious act associated with some intent to die.

Suicidality: A term that includes suicidal ideation, suicidal planning, suicidal attempts and death by suicide.

Suicide-related behaviors include:

- **Suicide ideation:** Having thoughts to engage in behavior with the intent to end one's life.
- **Suicide Plan**: Planning to use a specific means to end one's life.
- **Suicide Attempt:** Harming oneself with the intent to die.

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Suicidal and Self-Harm Behaviors

Suicidal behaviors: Acts done with the intent to end one's own life.

Non-suicidal self-harming behaviors: Acts done without the intent to end one's own life.

In this training, we only focused on suicidal behaviors or self-inflicted injury with the intent to die.

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Common Terminology

Incorrect

- Completed suicide
- Committed suicide
- Failed suicide attempt

Correct

- Died by suicide
- Death by suicide
- Non-fatal suicidal behavior

DSM-V Diagnostic Criteria for ID

An individual must have an intelligence quotient (IQ) score of 70 or lower.

They must display deficits in intellectual functioning (e.g., reasoning and academic learning).

There must be significant deficits in adaptive functioning as determined by performance on an adaptive behavior assessment.

- Specifically, the individual would not be able to meet social or developmental standards that are needed to support personal independence.
- Finally, the adaptive functioning deficits must require some form of continual support to support daily functioning, or the deficits must be severe enough to limit daily functioning when it is not available (American Psychiatric Association 2013).

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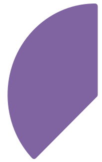
Suicide and IDD Population



I/DD

Suicidal behavior in people with I/DD has been a relatively neglected phenomenon despite evidence in the literature that this population also thinks about, attempts and dies by suicide.

Among 98 adult participants of a qualitative study, 11 reported a history of suicide attempts (Lunsky, 2004).

Ten cases of suicide in a cohort of **2369** people with intellectual disability over 35 years reported (Patja, 2001).

Despite this knowledge, there is still lack of data on population-based prevalence of suicidal behaviors among this group, commonly excluded in studies examining suicide risk.

Values and Attitudes: A Reflection

What are your thoughts and feelings about the following statements?

- People with I/ DD do not have suicidal thoughts.
- People with I/ DD do not die by suicide.
- People with I/ DD cannot engage in suicidal behaviors.
- People with I/ DD cannot make suicidal plans.
- People with I/ DD cannot attempt suicide.
- People with I/ DD do not think about hurting themselves with the intent to die.
- Providers should only ask for and rely on others for information about a person with I/ DD.
- Providers should feel pity for people with disabilities and work to fix their problems.

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Myths about Suicide

1. Most suicides happen suddenly without warning.

2. Talking about suicide directly may provoke and encourage suicidal behaviors.

3. People with I/DD are incapable of suicide.

4. Suicide is only the product of psychological problems.

5. Once an individual has suicidal thoughts, he or she will always remain suicidal.

6. People who choose suicide are selfish and take the easy way out.

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Facts about Suicide

1. There are some clues and warning signs of suicidal behaviors.
2. The individual may feel relieved and better understood by talking about suicidal thoughts.
3. Persons with IDD are at high risk of suicidal ideation and behaviors.
4. Many stressors within family, interpersonal relationships, community and society can lead to suicide.
5. The suicidal ideation can be specific to situations and times, and can be modified.
6. People choose suicide as an approach to end their suffering rather than simply not wanting to live.

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(Sternheimer, 2013)

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IDD and Functioning Levels

People with mild, moderate or severe/profound I/DD also have social interaction, initiation and verbal skills, and therefore can have suicidal thoughts and behaviors.

Levels of functioning can range from mild ID (Intelligence Quotient [IQ] 55-70) to profound ID (IQ < 25), and there exists no clear evidence on association of higher IQ and suicidal ideation and behaviors in a cohort of people with ID.

While functioning level is an important consideration during screening, assessment and intervention, it has no established relationship to suicidal thoughts and behaviors.

Specific characteristics need to be considered for each individual.

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Functioning Level

“The intellectual age below is a global classification which has no absolute limits and which is based upon the arrangement according to levels of development used by Piaget (1954) and others.”

Functioning Level	Intelligence Quotient (IQ)	Intellectual age (years)
Mild	55 – 70	7/8 – ±12
Moderate	40 – 55	4/5 – 7/8
Severe	25 – 40	±2 – 4/5
Profound	<25	0 – ±2

Caution: The intellectual age is not the sole determinant of a person’s functional abilities. The socio-emotional development and other factors should also be considered.

Meeusen-van de Kerkhof, R., van Bommel, H., van de Wouw, W., & Maaskant, M. (2006). Perceptions of Death and Management of Grief in People with Intellectual Disability. Journal of Policy and Practice in Intellectual Disabilities, 3(2), 95–104

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(Meeusen-van de Kerkhof, et al., 2006)

Overcoming Negative Attitude

Instead of focusing on disability as a problem of fixing bodies and minds, focus on changing disabling built and social environments.

Instead of only caring *for* people with disability, adjust the social and attitudinal aspect of caring *about* them.

Instead of devaluing friendship between people with disabilities in the name of successful social including, encourage and support it.

- **Remember that group association is not only formed around a shared social context (e.g., faith, recreation, projects) but also around disability.**

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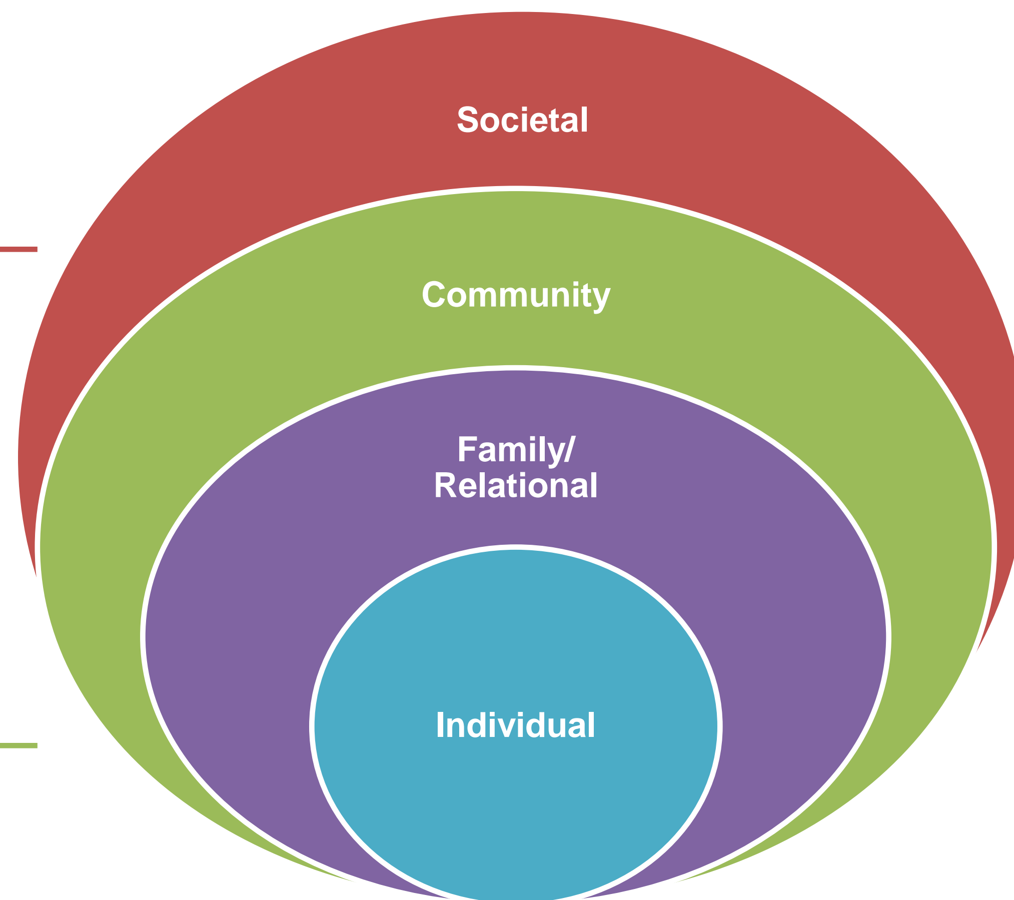
Social Ecological Model

The social ecological framework was used in this training to illustrate the interplay between individual and environmental factors (risk and protective factors) in the health and well-being of people with I/DD.

The model accounts for influence at four levels (individual, family/ relational, community and society [CDC (b), 2019]), and supported our multilevel approach for suicide prevention in the I/DD group.



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Overview of Risk Factors

- People with I/DD are at risk for comorbid psychiatric disorders, which correlates with elevated suicidal ideation and behavior.

- They experience more abuse, neglect, social disadvantage, stigma and peer exclusion than their peers without such disabilities.

- Stigma and lack of disability-responsive programs and services make it difficult for a person with disability to participate in social activities that promote health.

Both micro (individual level) and macro level risk factors such as socio-economic conditions, access to health and support services (community level), and guiding law, policies and socio-cultural norms (society level) should be considered in suicide prevention efforts.

(U.S. DHHS, 2012).

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Risk Factors

Risk factors are defined as factors that may increase the likelihood for suicidal thoughts and behavior in individuals (CDC [c], 2019).

Mental and physical health problems

Late identification of suicide risk factors

Barriers to health and mental health services

Previous suicide attempts

Conflict relationships and non-supportive environment

Risk Factors

Social isolation

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Risk Factor Levels

Individual

*Previous suicide attempts

*Mental/ physical health problems

*Psycho-social stressors

*Trauma

Family

*Psychiatric disturbance within family

*Family discord

*Conflict relationships

Community

*Barriers to health care and employment

*Lack of supportive environment

*Lack of social networks

Societal

*Cultural and social norms

*Social isolation

*Lack of eligibility for related services

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Warning Signs

Warning signs are behaviors and symptoms that may indicate that someone is at risk for suicidal attempt or suicide.

*Warning signs should not be confused with risk factors.

*Recognizing the warning signs and being prepared to address them are crucial to suicide prevention.

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Common Warning Signs

Behavioral and verbal warning signs include:

- Worrying about being a burden to others.
- Talking about wanting to die or end one's life.
- Looking for a way to end one's life.
- Making statements of hopelessness.
- Talking about being in unbearable pain.
- Increasing alcohol or drug intake.
- Acting more agitated and showing rage.
- Becoming less socially engaged and active.
- Abrupt change in health and behavior.

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Responding to Warning Signs

Do Not

- Ignore the person.
- Say that everything is going to be OK and for them to take their mind off it.
- Say you also feel the same way sometimes.

Do

- Talk to the person.
- Express concern about what they have just shared with you.
- Connect them with someone who can help keep them safe.

Knowing When to Take Action

Suicide prevention is everyone's business. It is important to know when to take action and seek help.

Take action when…

- self-harming behaviors with intent to die are present.
- one plans to take one's own life.
- one imagines being better off death than alive.
- one shows warning signs which indicate that a suicidal crisis may be developing.
- **your gut feeling is telling you to take action.**

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Who Can Take Action?

Anyone in a trusting relationship with someone at risk of suicide can help someone at risk of suicide or in immediate crisis or who displays suicidal behaviors and/ or expresses suicidal thoughts.

- You do not have to be a clinical staff member to help.
- **Suicide prevention is everyone's business.**

Action Steps:

- Refer the person to emergency room or local crisis centers and/ or connect them to mental health resources.
- Ask them if they are thinking about killing themselves. Doing so will not make it more likely that they will attempt suicide or put thinking about suicide into their head.

Case Discussion

A 15-year-old girl, Maria, with moderate intellectual disability (ID), tells her parent that she wants to jump off her room window and runs to her room which is in the second floor of the house. There is a report of recent death in the family. Maria has experienced prolonged episodes of screaming and crying that are atypical for her.

How would you respond?

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Social Ecological Approach

Risk-factor knowledge within the social-ecological framework is used to better inform suicide prevention strategies. Two most important steps include:

- Recognizing the existence of multiple levels (individual/micro, family/meso, community and society/macro) of influences on individuals and the interaction between them, and
- Targeting the different risk and protective factors at different levels during assessment and intervention.

Both will facilitate sustainable suicide prevention at all levels and successful mental health care outcomes.

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Protective Factors

Protective factors are defined as factors that promote strength and resilience and buffer individuals from suicidal thoughts and behaviors (CDC [c], 2019).

Healthy emotional and physical well-being

Early identification of suicide risk factors

Access to health and mental health services

Availability of disability-related supports

Supportive and caring relationship and environment

Protective Factors

Social inclusion

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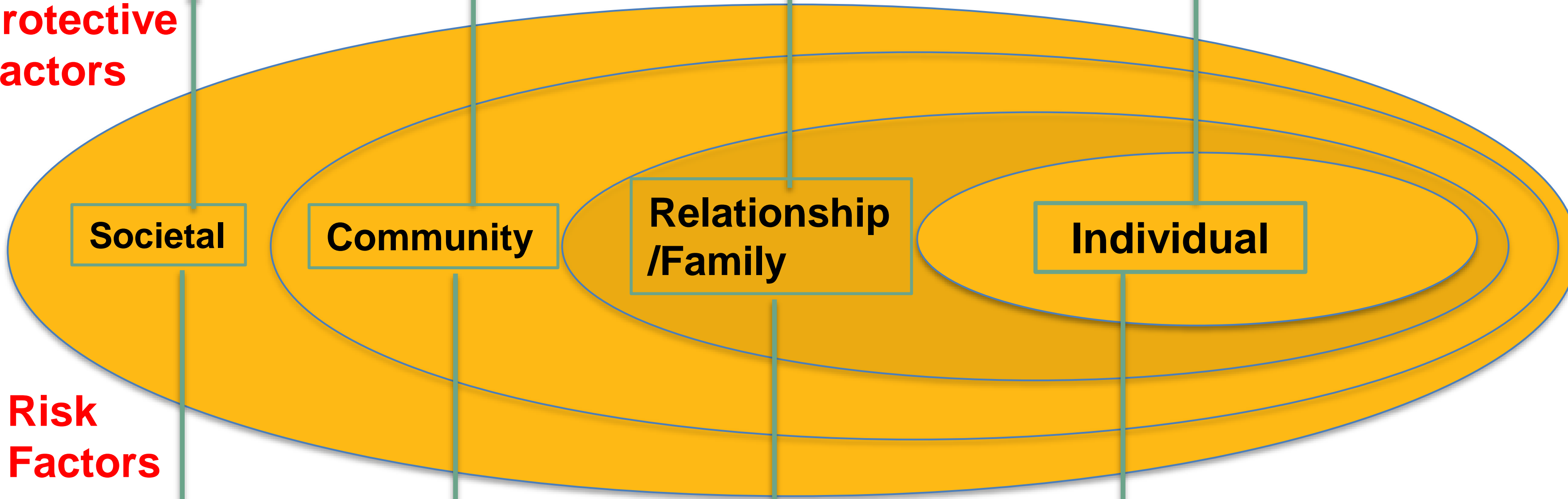
- Social inclusion.
- Available health care.

- Supportive environment.
- Community awareness.

- Supportive relationships with family, peers and care providers.

- Healthy emotional wellbeing.
- Healthy physical wellbeing.
- Coping skills.

Protective Factors



Risk Factors

- Cultural and social norms
- Social isolation.
- Few resources of health care

- Barriers to health care
- Few sources of supportive relationship.
- Neighborhood Disadvantages.

- Psychiatric disturbance within family.
- Family Discord
- Conflict Relationships
.

- Previous suicide attempt.
- Physical health problems.
- Mental Health Problems.
- Psychosocial stressors.
- Trauma.

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Knowledge Assessment

True or False

- It is important to target the different risk and protective factors at different levels during assessment and treatment.
- A good practice is to organize special social activities just for individuals with I/DD.
- Emotional support should be provided to people with I/DD only when their parent or caregiver feels that they need it.

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Best Practices Include:

Being adaptable (i.e., engage in person-centeredness care—the person at the center of care delivery) and modifying approach to respond and meet their needs.

Using person's preferred style of communication (see tips for communication below).

Allowing time for rapport and trust building to understand how a person experiences their IDD and mental health.

Involving family, friends and other key informants in treatment, and work to shift from illness to wellness.

Apply trauma-informed practice and policies and engage in ongoing professional development.

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Tips for Mental Health Promotion

Provide the opportunity for people with I/DD to live a full and normal life.

Encourage their involvement in meaningful activities and supportive relationships that promote independence.

- Supportive relationship means making efforts to get to know a person and being reliable, responsive and respectful.

Provide opportunities (verbal and non-verbal) for emotional expression and encourage having someone to talk to, which helps with managing difficult situations and emotions.

Provide supportive physical and psychological environment that contributes to better management of challenging behavior and quality of life.

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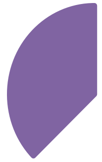
Preparing for the Unexpected



I/DD

- Teach coping skills and strategies.
- Remove access to means of suicide.
- Monitor medication and alcohol intake.
- List things to be hopeful for and reasons to live.
- Maintain a current list of mental health providers, crisis centers, nearby hospitals and their phone numbers, address and hours of operation.

Practice Considerations

Parents and caregivers form bridges between people with IDD, their families and other professionals.

Parents, support staff and people with I/DD are primary data source during assessment and treatment (Matson & Shoemaker, 2011).

Early prevention and help-seeking behaviors depend upon family members and staff caregivers detecting signs and risk factors of suicidal behaviors.

Everyone plays a key role in early detection of warning signs and risk factors of suicidal behaviors, and in early referral and intervention.

(Costello, 2006)

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(Costello, 2006)

Tips for Communication

First step is to determine the person’s preferred communication style.

Use accessible and preferred style of communication and ensure that communication pace is responsive to the person and their family’s preferences.

Allow plenty of time and provide conducive communication environment (e.g., remove physical barriers; adjust position for communication; ensure relaxed, comfortable and noise-free space).

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(Cooper, 2013)

Tips for Verbal Communication

Engage in active listening and avoid passing judgment or leading questions (e.g., *"You're not thinking about suicide, are you?").*

Use plain language and short sentences, and avoid use of jargon and complex concepts.

Ask clarifying questions to check your understanding and the person.

Articulate clearly, repeat and rephrase.

Use open-ended questions as much as possible.

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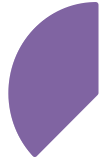
(Cooper, 2013)

Tips for Non-Verbal Communication



I/DD

- Use eye communication with the person.
- Use intonation, gesture, body language and posture.
- May use pictorial and symbolized material.
- May use sign language (personal/standard).
- Use assistive technology and devices and other specialists.

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(Cooper, 2013)

Screening and Assessment Overview

Screening is a process of using standardized tools or instruments to identify a person who may be at risk for suicide.

Screening for suicide risk helps with suicide prevention. Risk factors for suicide may be or look different in people with I/DD than those established with the general population.

Despite the need for greater screening efforts for suicidal behaviors and understanding of symptom presentation in this population, there is still a lack of suicide risk screening and assessment tools specific to people with I/DD.

Below, we provided some resources on assessing mental health problems both in the general population and in the I/DD population.

Screening Tools: I/DD

- **Columbia-Suicide Severity Rating Scale (C-SSRS)— Cognitively Impaired Lifetime/Recent** is used to assess lifetime and recent history of suicidal ideation and behavior in people with cognitive impairment.
  - **Resource link:** http://cssrs.columbia.edu/the-columbia-scale-c-ssrs/cssrs-for-communities-and-healthcare/#filter=.general-use.english

- **Moss-Psychiatric Assessment Schedule (Moss-PAS [Diag ID])** is a semi-structured clinical interview for adults with intellectual disabilities. It consists of separate sets of questions for people with I/DD and the informants.
  - **Resource Link:** https://www.pavpub.com/mental-health/assessment/moss-pas-diag-id
- **The Reiss Scale** is used to screen mental health problems for individuals aged 4 to 21 with intellectual disability.
  - It takes about 10 minutes to administer, and it is completed by parents, teachers or other caregivers who know the person well.
  - **Resource link:** http://www.idspublishing.com/scales/

- **The Nisonger Child Behavior Rating Form (NCBRF)** is used to assess the behaviors of children aged 3 to 16 with I/DD. There is both a teacher and parent version of the form, and it takes about 15 minutes to complete.
  - **Resource link:** https://psychmed.osu.edu/index.php/instrument-resources/ncbrf/
- **Ask Suicide-Screening Questions (ASQ**) helps providers to screen youth at high risk of suicide in medical settings.
  - **Resource Link:** https://www.nimh.nih.gov/research/research-conducted-at-nimh/asq-toolkit-materials/asq-tool/asq-screening-tool.shtml
- **Suicide Assessment Five-step Evaluation and Triage (SAFE-T)** is used by clinicians to identify risk factors and protective factors; conduct a suicide inquiry; determine risk level & intervention; and document a treatment plan step by step.
  - **Resource link:** https://store.samhsa.gov/product/SAFE-T-Pocket-Card-Suicide-Assessment-Five-Step-Evaluation-and-Triage-for-Clinicians/sma09-4432
- **The Patient Health Questionnaire (PHQ-9)** is a 9-items instrument that helps with making criteria-based diagnoses of depression and other mental health disorders in primary care settings.
  - The 9 items are based on actual criteria of DSM-IV diagnosis on depressive disorders.
  - The 9th item asks about suicidal ideation.

  - **Resource link:** https://www.mdcalc.com/phq-9-patient-health-questionnaire-9

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A Screener Card for Parents

- **Resource link:** http://cssrs.columbia.edu/wp-content/uploads/Community-Card-Parents-2018c.pdf

	Past Month	
1) Have you wished you were dead or wished you could go to sleep and not wake up?		
2) Have you actually had any thoughts about killing yourself?		
If **YES** to 2, answer questions 3, 4, 5 and 6 If **NO** to 2, go directly to question 6		
3) Have you thought about how you might do this?		
4) Have you had any intention of acting on these thoughts of killing yourself, as opposed to you have the thoughts but you definitely would not act on them?	**High Risk**	
5) Have you started to work out or worked out the details of how to kill yourself? Do you intend to carry out this plan?	**High Risk**	
Always Ask Question 6	**Lifetime**	**Past 3 Months**
6) Have you done anything, started to do anything, or prepared to do anything to end your life? *Examples*: Collected pills, obtained a gun, gave away valuables, wrote a will or suicide note, held a gun but changed your mind, cut yourself, tried to hang yourself, etc.		**High Risk**

NATIONAL SUICIDE PREVENTION LIFELINE™
1-800-273-TALK (8255)
suicidepreventionlifeline.org

Any YES indicates the need for further care. However, if the answer to 4, 5 or 6 is YES, immediately ESCORT to Emergency Personnel for care, call 1-800-273-8255, text 741741 or call 911.

DON'T LEAVE THE PERSON ALONE. STAY WITH THEM UNTIL THEY ARE IN THE CARE OF PROFESSIONAL HELP

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Screening Challenges and IDD

Clinicians often find themselves at a loss as to how to directly ask an individual with I/DD about current suicidal thoughts, past suicidal behavior, plan formulation and access to means.

Diagnosis overshadowing: The presence of intellectual disabilities may overshadow signs of mental health problems and lead to under-identification of emotional problems.

Standardized evaluation of suicidal thoughts and behaviors is challenged by the lack of appropriate measures developed specifically for persons with I/DD.

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Screening Considerations

Risk factors and warning signs for suicide should be assessed together and be person-specific instead of independent.

Screening, assessment and referrals should be embedded within all health care programs and records.

Family and community-based service providers should be included during assessment and care.

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Screening Tool Use Considerations

When using screening tools developed with the general population, it is important to consider their limitations, which may include:

- Advanced reading and comprehension level requirement.
- Complex and confusing response format.
- Complex questions and vocabulary.
- Thoughts and past events recollection requirement.
- Focus on observable and sudden behavioral and emotional changes.

Resources

National:

- National Suicide Prevention Lifeline: https://suicidepreventionlifeline.org/
  - Online chat: https://suicidepreventionlifeline.org/chat/
  - Video relay service/voice/caption phone- Dial 800-273-8255
  - TTY: Dial 800-799-4889
- Crisis Text Line: text HELLO to 741741
- 911
- Suicide Prevention Resource Center: https://www.sprc.org/
- National Institute of Mental Health (NIMH): https://www.nimh.nih.gov/health/topics/suicide-prevention/index.shtml
- Substance Abuse and Mental Health Services Administration: https://www.samhsa.gov/
- The Society for the Prevention of Teen Suicide (SPTS): http://www.sptsusa.org/
- Action Alliance for Suicide Prevention: http://actionallianceforsuicideprevention.org/resources
- American Foundation for Suicide Prevention (AFSP): https://afsp.org/find-support/resources/
- Hotlines, Organizations, Websites, Resources, Survivor Support Groups, and Training/ Education https://dmh.mo.gov/mental-illness/suicide/links
- American Association of Suicidology: https://suicidology.org/
- American Psychiatric Association Suicide Prevention Page: https://www.psychiatry.org/patients-families/suicide-prevention

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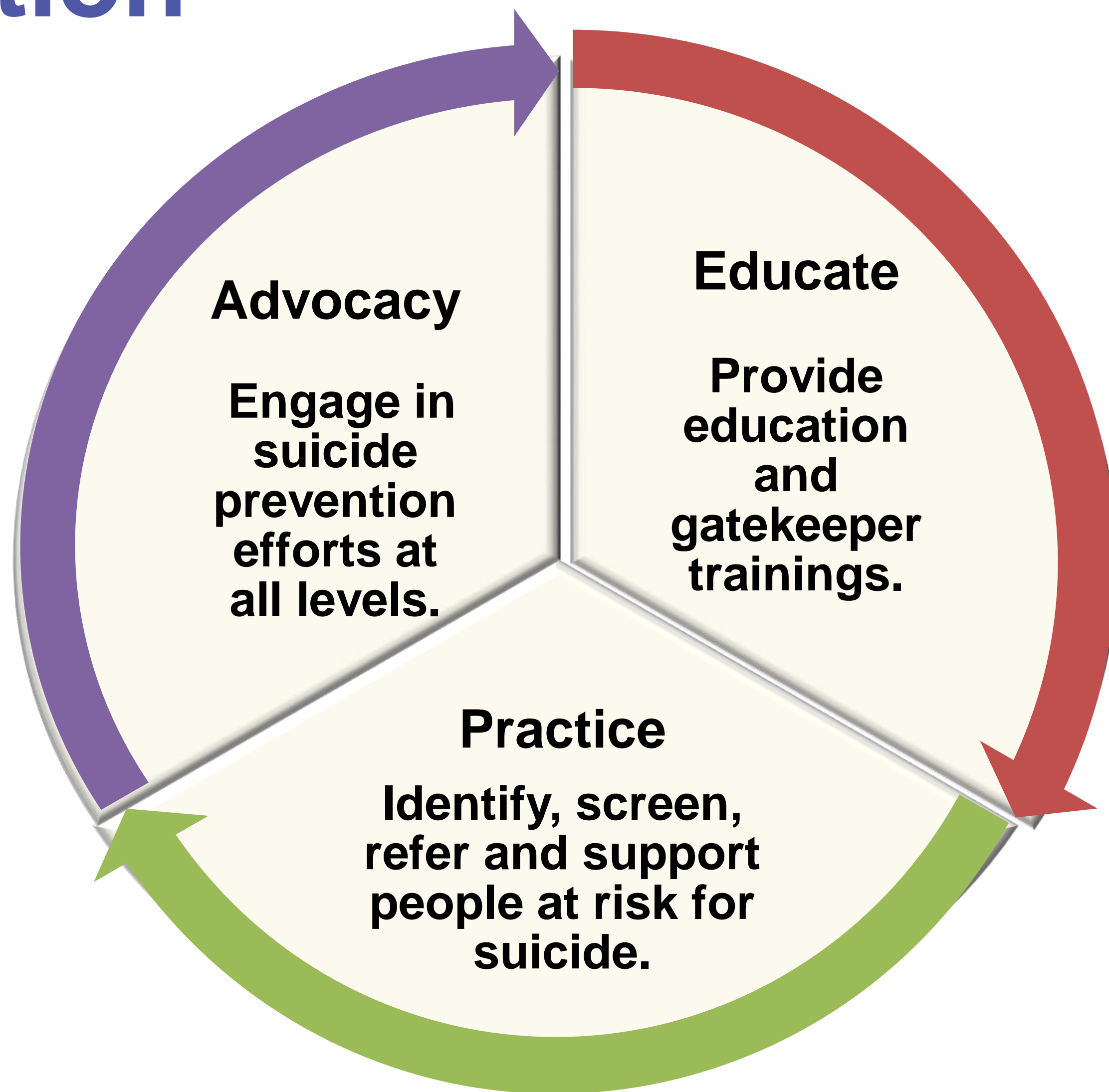
Call to Action



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Presenter Contact Information

Dr. Mirian E. Ofonedu, Ph.D., LCSW-C, Director of Training
Maryland Center for Developmental Disabilities at Kennedy Krieger Institute
Email: Ofonedu@kennedykrieger.org or training.mcdd@kennedykrieger.org
Phone: 443-923-9592 or 443-923-9555

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