

Suicide prevention for people with intellectual and developmental disabilities

Isadora Rodriguez-Legendre, NH Council on Developmental Disabilities
Austyn Blais-Cameron, Person with Lived Experience

1

Introductions

- Isadora Rodriguez Legendre is Executive Director at the New Hampshire Council on Developmental Disabilities. At the DD Council, Isadora works to eliminate barriers and promote opportunities for individuals with intellectual and developmental disabilities (ID/DD) through advocacy, capacity building and systems change activities in line with their 5-year state plan. She has a Master's degree in Social Work and is dedicated to supporting all people with the resources and services they need to live full and meaningful lives in the community. She is committed to addressing the whole needs of a person for community integration and has lived experience navigating mental health, addiction/recovery and suicide prevention resources.
- Austyn Blais-Cameron is a young professional whose disabilities and lived experiences with mental health treatment has informed a life of education and advocacy. She is dedicated to eliminating stigma behind suicidal ideation and disabilities. When she is not connecting her peers to resources that can help them live better lives, she is traveling with her husband and catching up on true crime podcasts.

2

NH DD Council

- Mission: We are dedicated to dignity, full rights of citizenship, cultural diversity, equal opportunities, and full participation for all New Hampshire citizens with developmental disabilities.
- A Federally funded State agency (5-year state plan)
- Support public policies and initiatives that remove barriers and promote opportunities in all areas of life
- We do this through advocacy, capacity building and systems change work
- We mostly collaborate with other entities (and provide grants) since we do not provide direct services
- At least 60% of our membership must have lived experience with developmental disabilities (Federal definition) – includes physical, cognitive and mental disabilities or a combination of these

3

Learning Objectives

- Recognize the importance and need for suicide prevention for people with intellectual and developmental disabilities (ID/DD)
- Identify tools and resources available to address the needs of a person with ID/DD and mental health needs

4

Some Background

- For a long time it was thought that people with developmental disabilities lacked the capacity to have mental health issues.
- It was thought that all behavioral issues were due to their disability diagnosis.
- This is in part why systems of services have historically been provided in silos; separate systems for medical, developmental and mental health services.
- In NH developmental services and community mental health services have also typically been separate. In fact, some developmental services providers report very few clients that have mental health needs, which is highly unlikely.

5

More background

- One resource provided is an informative PowerPoint entitled: *Substance Abuse and Suicide in People with ID and Autism*

It covers a lot of background information including:

- Substance abuse and ID/DD
- Co-occurring mental health issues
- Issues with traditional treatment options including 12-step recovery and potential modifications that can be made for people with ID/DD
- Depression and Autism Spectrum Disorder
- Suicide risk factors and how these may be manifest in people with DD
 - Including increased isolation, loss, barriers to accessing mental health services, stigma, less family support, less reciprocity in relationships, more rejection, more co-morbid physical disabilities, more stress loneliness
- How suicidal threats are treated in people with ID/DD
- Promising treatment options

6

Persons with Dual Diagnosis

Prevalence of IDD/MI:
National Core Indicators Data

Approximately one third of persons with IDD have a co-existing psychiatric disorder.

Year	Prevalence (%)	Sample size
2006-07	27.2%	12,000
2007-08	31.2%	11,400
2008-09	34.4%	11,500
2009-10	36.1%	11,000
2010-11	33.2%	8,000
Avg.	32.4%	

AUTISM
Nearly 50% of adults with Autism will experience depression

From: Suicide in People with Intellectual Disability and Autism (txcouncil.com)

7

Recognizing that there is a capacity issue is the first step

Some of the areas needing attention:

- There is not enough information available or data collected on the needs of people with ID/DD and MH support needs.
- There are not a lot of clinicians with expertise providing mental health services to people with ID/DD – training is essential
- Available resources typically available don't always meet the needs of people with ID/DD
- Family and natural supports are sometimes triggering so other community-based systems of support and crisis planning engagement is also important

8

DD Council funding for a demonstration project

- *Our last 5-year state plan had the following objective: The Council will collaborate with key partners to promote and strengthen best and emerging practices related to supports for individuals who experience developmental disabilities with co-occurring mental health/behavioral needs.*
- As a result, we developed an RFP to provide financial support for a demonstration project and the following was awarded:
 - \$50,000, over two years, to **Center for Life Management and Community Crossroads** to implement new strategies that address the needs of individuals with intellectual/developmental disabilities and mental health needs; their model is called the **Continuum of Collaborative Care**. This will include training to increase capacity in the system and data collection in hopes of expanding this innovative service approach throughout the state of New Hampshire.

9



Continuum of Collaborative Care™

Mission: To create, support, and coordinate team-based care, integrating continuity of care efforts for whole-health needs of those experiencing Intellectual/Developmental Disability and/or Acquired Brain Injury and mental health needs.

Taking a proactive vs reactive approach to care, we have set an expectation of collaborative supports in Region 10, with the goal of making an impact for continuity of care for those with dual diagnoses throughout NH



Developed in partnership by Center for Life Management and Community Crossroads, the Continuum of Collaborative Care has made strides in achieving equality in access to mental health services for those who experience dual diagnoses of ID/DD and/or TBI and mental health needs.

CLM Center for Life Management | NEW HAMPSHIRE COUNCIL ON DEVELOPMENTAL DISABILITIES | Community Crossroads | Continuum of Collaborative Care™

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10

Wellness Support and Response Planning

The Continuum of Collaborative Care utilizes proactive vs. reactive strategies, to promote strengths base, wellness focused client-centered care.

Collaborative strategies between Area Agencies and Community Mental Health Centers includes:

- Merging of treatment planning/service planning meetings
- Collaborative meetings and team discussions for all aspects of care
- Sharing of necessary documentation
- Collaborative health history review
- Clinically Informed Behavior Services
- Primary Care Integration
- Collaborative and proactive wellness (crisis) planning
- Flagging/Alerting Emergency Services to existing Crisis Plans from partner agencies
- Caregiver support and education
- Bookends Therapy: Engaging supports in the clinical process, engaging the client in teaching their skills and encouraging collaboration in wellness planning

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11

Outcomes

Since implementation of the Continuum of Collaborative Care, roughly **8.5 years** ago we have...

- ✓ Supported over 280 individuals with ID/DD and/or TBI and mental health needs at CLM, including those with and without Area Agency services
- ✓ Successfully advocated for changes in interpretations in HeMs, resulting in over a 65% increase in those served having access to wrap-around mental health services
- ✓ Maintained **ZERO** psychiatric hospitalizations and/or prolonged psychiatric ER stays for those fully receiving all Continuum of Collaborative Care services between CLM and Community Crossroads

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12

Resources and Trainings

The Continuum of Collaborative Care offers consultation, along with the following training opportunities...

- Continuum of Collaborative Care Training Series
- Introduction to Dual Diagnosis
- Practical Clinical Skills
- Clinically Informed Service Coordination
- Bookends Therapy
- Stigma and Diagnoses
- Behavior and Mental Health
- Traumatic Brain Injury and Mental Health
- Grief and Loss and ID/DD
- Assessing Mental Health Eligibility for those with ID/DD and/or TBI
- Completing and Utilizing the Waiver Process
- Collaborative Documentation
- Preventing Provider and Caregiver "Burnout" Through Collaborative Support
- And more...

For more information or to schedule training or consultation, please contact ccc@clmmh.org or

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13

The power of personal stories

- Hearing from those with lived experience can help us identify service gaps and resources
- It can reduce stigma and 'normalize' that people with and without disabilities sometimes need to seek support to maintain good mental health
- It can be a powerful source of peer support for someone who is struggling
- It can help clinicians better identify tools that are most beneficial when working with the ID/DD community (promising practices)

14

Austyn's Story

- Tell us a little about yourself.
- How would you describe some of your challenges growing up?
- When did you discover that you may also have some need for mental health services?
- What sorts of resources did you find and how did you find them?
- If you are speaking to others with disabilities who have identified suicidal ideation, what do you share with them?
- What do you think mental health professionals and clinicians should know about working with people with disabilities?
- What is it about trauma-focused therapy that you believe is helpful for working with people with disabilities?

15

Messages from Austyn

- We can find help.
- Advocating for ourselves is so important.
- Mental health professionals can do their part by being open minded and willing to learn about the unique challenges that people with disabilities bring to the table.
- I would also like to highlight trauma-focused therapy because I think, even without lived experience with suicidal ideation, people with disabilities can benefit from it.

16

Some Resources Identified by an individual with Autism and Mental Health Needs

- One individual reported using the following resources:
 - <https://warmline.org/> - peer support "providing mental health help before a crisis"
 - <https://centerforstartservices.org/locations/new-hampshire-nh-start-teams-provide-the-following-services>:
 - Community partnerships and systems linkages
 - Systemic and clinical consultation and training
 - Community training and educational opportunities
 - Award-winning Clinical Education Team training opportunities
 - Cross Systems Crisis Prevention and Intervention Planning
 - On-call crisis support 24/7 by a certified START coordinator (603) 931-2123
 - Psychiatric and Interdisciplinary consultation and evaluation in connection with Dartmouth-Hitchcock Medical Center
 - Virtual Therapeutic Groups
 - START Therapeutic Resource Center for planned and emergency support

17

Resources

- <https://warmline.org/>
- <https://centerforstartservices.org/locations/new-hampshire>
- [Home - MHDD National Training Center \(mhddcenter.org\)](http://Home-MHDDNationalTrainingCenter(mhddcenter.org))
- [Suicide Prevention Resource Center \(sprc.org\)](http://SuicidePreventionResourceCenter(sprc.org))
- American Foundation for Suicide Prevention: www.afsp.org
- Psychology Today (Can search for providers familiar with developmental disabilities like autism as well as different modalities): www.psychologytoday.com
- Eunice Kennedy Shriver National Institute of Child Health and Human Development (great tool for people with developmental disabilities to help with healthcare resources and up to date research): www.nichd.nih.gov
- To Write Love On Her Arms (non-profit focused on eliminating stigma and matching people with resources: www.twloha.com)

18

Additional
Articles and
Information:

- Suicide in People with Intellectual Disability and Autism (txcouncil.com)
- Supporting Individuals with Intellectual/Developmental Disabilities and Mental Health Needs (citizenshealthinitiative.org)
- Understanding and Preventing Suicide in People with IDD: Experiences Learned from a Collaborative Research Project (aaidc.org)

19

Contact
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20
