Washington State Department of Social and Health Services

Transforming Lives

REPORT TO THE LEGISLATURE

Best practices for co-occurring conditions:
Serving people with intellectual and developmental disabilities and mental health conditions

ESSB 5092 Sec. 203 (1)(f)(I)
Chapter 334, 2021 Laws PV

ESSB 5268 Sec. 10 (1)(a)
Chapter 219, 2022 Laws PV

ESSB 5693 Sec. 203 (1)(f)(I)
Chapter 297, 2022 Laws PV

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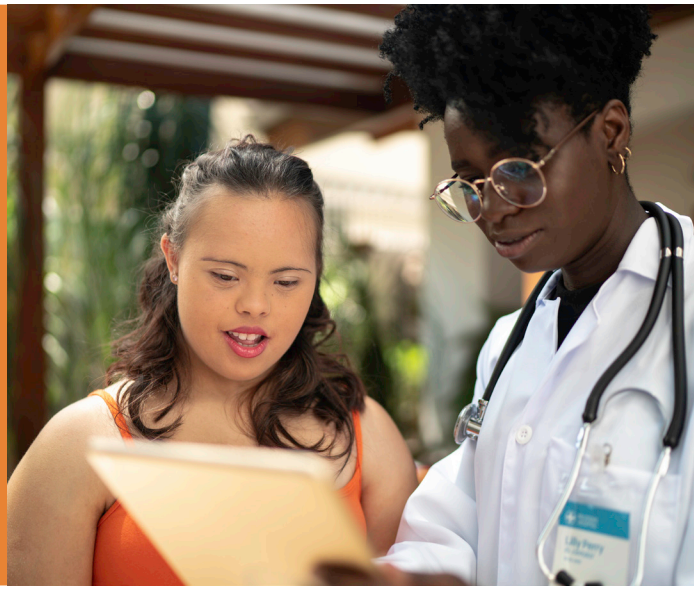
Contents

One recommendation of this report is to train medical, dental and mental health providers on how to recognize and treat people with co-occurring IDD and mental health conditions, also known as co-occurring conditions.



Executive Summary

This report identifies current best practices and makes recommendations for new efforts to improve services and treatments for people with co-occurring conditions. The Developmental Disabilities Administration was directed to **"Coordinate collaboration efforts among relevant stakeholders to develop and disseminate best practices related to serving individuals with co-occurring intellectual and developmental disabilities and mental health conditions."** The Developmental Disabilities Administration gathered input from the Washington State Developmental Disabilities Council, stakeholders and other state agencies providing services for people with intellectual or developmental disabilities to identify gaps in obtaining needed treatments and social services. Through the process outlined and a literature review, we identified recommendations to improve treatment and service delivery. Best practices are procedures that are accepted as being the most effective. Best practices take time to develop and are evidence based. This report identifies existing best practices and their dissemination and recommendations on actions that will lead towards better social services and health care for people with co-occurring conditions. We will continue to work to identify new best practices and disseminate beyond this compressed reporting timeline.

Recommendations

- Train medical, dental and mental health providers on how to recognize and treat people with co-occurring IDD and mental health conditions, also known as co-occurring conditions.
- Designate persons with IDD as a medically underserved population.
- Fund providers who support people with co-occurring conditions to complete training and become certified. Provide higher rates for residential providers that maintain certification in co-occurring conditions.
- Establish long-term community based residential supports with providers trained to support people requiring enhanced behavioral supports.
- Allow healthcare and mental health providers flexibility to spend more time in appointments with complex patients or patients with different modes of communication and the ability to bill for that time.
- Add capacity to the Washington Partnership Access Line so that clinicians can call on experts when treating individuals with a co-occurring condition.
- Incentivize community mental health providers to learn and adapt treatment practices for people with co-occurring conditions. Currently people with co-occurring conditions may be turned away for treatment if they have an intellectual disability or need support with personal care.
- Ensure hospitals have subject matter experts in IDD to provide person-centered treatment and services.
- Create hospital-based psychiatric emergency and short-term programs to increase community crisis and stabilization capacity capable of serving people with cooccurring disorders.
- Fund student loan repayment and forgiveness programs for medical, dental, mental health and direct support providers who treat and support people with IDD.
- Develop an online directory of professional treatment providers with expertise in diagnosing and providing treatment to people with co-occurring conditions.

Methodology

Listening sessions. The Developmental Disabilities Administration invited GovDelivery subscribers signed up to receive general information, project updates, provider information and training events to stakeholder listening sessions. The stakeholder listening sessions were co-hosted by the Developmental Disabilities Council and the Developmental Disabilities Administration. Two sessions were held with one in January and the second in February 2022. Each listening session provided attendees the opportunity to speak directly to DDA staff members and comment on seven program topic areas.

Literature Review. DDA completed a limited literature review using HealWA medical database, ERIC, JSTOR, Science Direct, NIH, Google Scholar and Google using the terms: intellectual disability, developmental disability, co-occurring, mental health, behavioral health, best practice, guidelines and best practice protocol to identify:

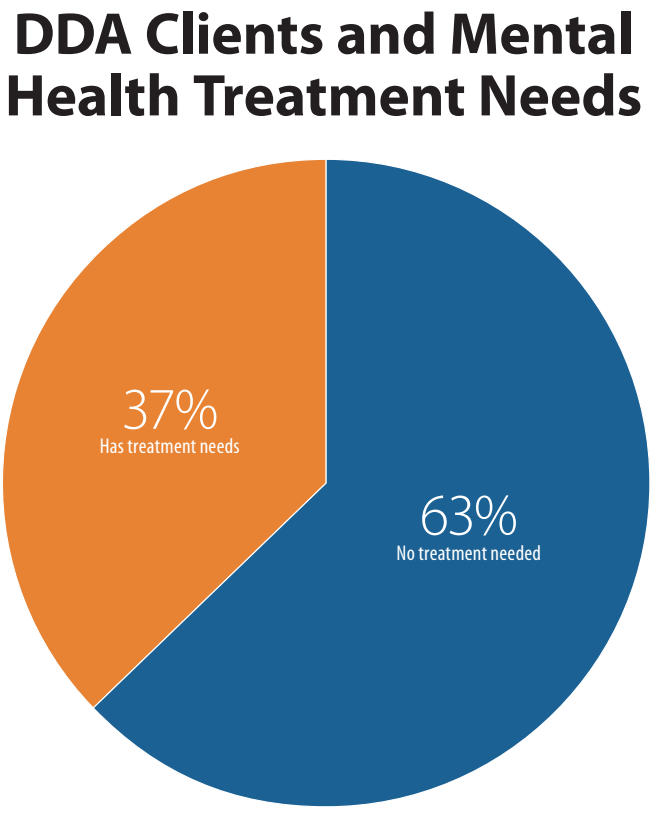
- Gap reports.
- Position statements.
- Best practice statements, guidelines and programs.

DDA reviewed bibliographies for similar documents. Abstracts were reviewed and documents that could be obtained online were downloaded.

Practices of other states:
DDA worked with the National Association of State Directors of Developmental Disabilities Services to learn what other member states consider best practices. Louisiana and Missouri provided information on what their states are doing to support people with co-occurring conditions.

Background

In Washington state, RCW 71A.10.020 defines developmental disability as meaning the conditions of intellectual disability, cerebral palsy, epilepsy, autism, or another neurological or other conditions similar to intellectual disability with onset before the individual reaches age 18. For the purposes of this report a mental illness is a condition that affects a person's thinking, feeling, behavior or mood. Examples of mental health conditions include anxiety disorders, attention deficit and hyperactivity disorders, bipolar disorder, borderline personality disorder, depression, dissociative disorders, eating disorders, obsessive-compulsive disorders, post-traumatic stress disorder, psychosis, schizoaffective disorder and schizophrenia. Studies consistently show that the prevalence rate of mental health occurs at higher rates for people with IDD than within the general population.[1, 3, 4, 7, 9, 25] A review of currently eligible Developmental Disabilities Administration clients found that 37% had an identified need for mental health treatment.



37% of Developmental Disabilities Administration eligible clients have an identified mental health treatment need. Data source: Department of Social and Health Services Research and Data Analysis.
DSHS Research and Data Analysis Division, April 29, 2022

Dissemination of Best Practices

DSHS' Developmental Disabilities Administration regularly consults and shares best practices on supporting people with co-occurring conditions with other states and national organizations.

DDA's clinical director continues the administration's work in positive behavior support principles. The work focuses on building person-centered systems and supports encouraging skill development. Person-centered practices and positive behavior support enables an individual to live in their community, achieve their personal goals, participate in the workforce and contribute to the community.

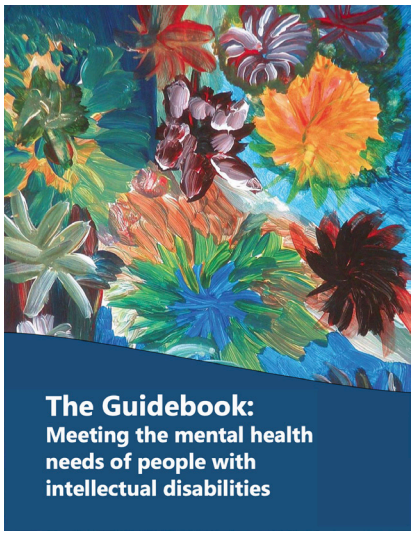
DDA and partner agencies disseminate best practices to families and providers. Below are selected examples of best practices that are disseminated by DDA and other agencies.

1) Developmental Disabilities Administration Home Survival Guide

DDA developed and presented the *"Home Survival Guide"* webinar in May 2020 to over 400 participants. The webinar provided hands-on tips for adapting to the requirements of being locked down during the COVID-19 pandemic. English and Spanish versions of the slides and handouts were sent to participants and posted on an administration's web page. The webinar was offered in three virtual Town Hall meetings after the initial broadcast and is available online.

2) The Guidebook

In 2017, the Developmental Disabilities Administration published, *"The Guidebook: Meeting the mental health needs of people with intellectual disabilities"*. The Guidebook was developed by a team of mental health and DDA professionals currently serving people with intellectual disabilities in the community. The Guidebook talks directly to the needs of people with co-occurring disorders of mental illness and IDD in obtaining competent mental health care. It is a resource for social service and mental health providers serving people with co-occurring conditions. The Guidebook was disseminated again in June 2022 via GovDelivery.



3) Trainings produced by the Developmental Disabilities Administration

- For support professionals, families or community partners:
  - Positive behavior support and functional assessment.
  - Supported independence model.
  - Active listening.
  - Avoiding power struggles.
  - Dual diagnosis.
  - Ecology of behavior.
  - Behavioral phenotypes of genetic disorders.
  - Anatomy of a meltdown.
  - De-escalation techniques.
  - Psychological first aid.
  - Relocation trauma.
  - Dialectical Behavioral Therapy adapted for people with intellectual disabilities.
  - Suicide recognition and prevention.
  - Visual aids for calendars, schedules, social stories, choice boards and communication systems.
  - Autism spectrum disorder (2020): Prevalence, functioning impacts and supports.
  - Person centered planning.
- For law enforcement:
  - Improving communication skills.
  - Augment Crisis Intervention Team training with information on IDD including specific disorders and useful strategies for recognizing and interacting with people.
  - Roll call videos to inform and start conversations at roll call.

DDA and partner agencies disseminate best practices to families and providers.

4) Developmental Disabilities Administration Regional Clinical Teams

- Provide support to administration staff, providers and system partners to:
  - Address barriers to discharge.
  - Assist with stabilizing complex cases.
  - Connect with community resources.
  - Act as a bridge between community facility support to community supports.
  - Provide crisis stabilization services.
  - Provide client specific training and technical assistances.
  - Consult on complex cases.
  - Participate in the Client Critical Case Protocol.
- Partner with state hospitals and providers in treatment discharge planning.
- Assist with cross-systems crisis planning.
- Psychiatric Nurse Practitioners assist with physical and mental health bridge services.
- Field Services Psychologists and psychology associates consult on behavioral and mental health needs.
- Mental Health Case resource managers provide intensive case management.

5) Collaborative Efforts to Support Complex Cases

- DDA and Health Care Authority meet with managed care organizations and hospitals to discuss people in acute care setting who are identified as failing to discharge.
- Client Critical Case Protocol to review and assist providers in preserving services to clients in their home settings.
- Complex case staffing with Health Care Authority, Department of Children, Youth and Families, Behavioral Health Administration, Developmental Disabilities Administration and community providers to address barriers to discharge.

"Providers should be given the tools needed to support people with behavioral health issues. A database where providers can access training, best practices and other provider contacts would be helpful." – Listening session participant

6) ECHO Wraparound: University of Washington and Health Care Authority Collaboration projects

- DDA staff contribute to each of following University of Washington -Extension for Community Health Outcomes projects:
  - ECHO parent education pilot is a partnership between the Developmental Disabilities Administration and the Haring Center to offer parent education focused on teaching principles of challenging behavior.
  - Centers of Excellence Provider training: Trains individual and agency providers to become centers of excellence in diagnosing autism spectrum disorders.
  - ECHO Intellectual and Developmental Disability Wraparound: Introduces wraparound providers to the autism to network of providers and provides in-service training and case consultation
  - ECHO Psychiatric Care: Graduates of the beginner sessions may sign up and continue case collaboration and in-service training for more difficult cases.
  - ECHO Intellectual and Developmental Disability Resources: Attendees are exposed to programs and services, network and receive advice on how to proceed with referrals for services.
  - ECHO Autism: Communities Symposium is an opportunity for professions to learn from leading professionals to improve knowledge and practice on specific topics to enhance services, access care and advocacy.

"Providers need to give clients the time they need to process and articulate."
– Listening session participant.

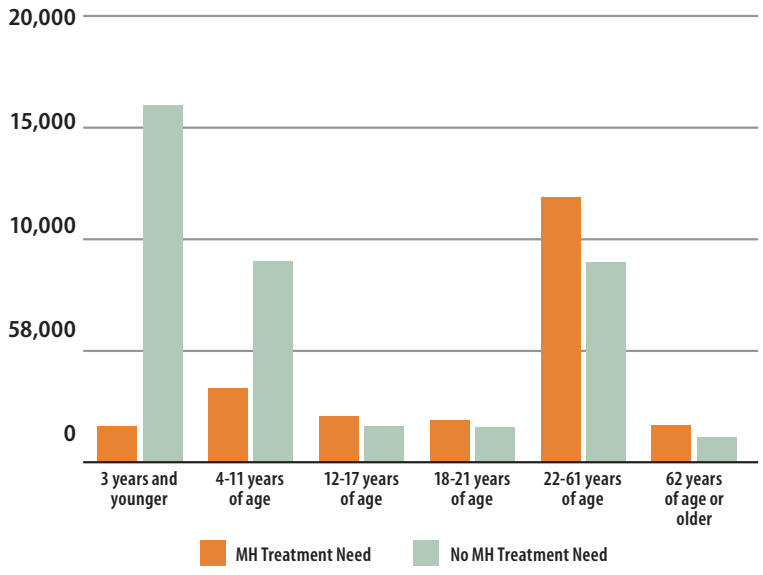
Stakeholder Feedback on Mental Health Treatment

Stakeholder experiences vary when trying to access to mental health services. Access depends on the person with IDD's ability to communicate using spoken words or sign language. When a person does not use standard verbal or sign language, the individual can be denied access to an accurate diagnosis, treatment, medication management, case management and coordinated treatment planning. People who do not use standard verbal or sign language are denied because they are seen as unable to participate.[14] Most people with IDD are helped by a parent or a paid caregiver to access mental health services.[4] The family member or paid caregiver often ask for services by describing changes in the person with IDD's behavior.[4] When the family member is unable to get services at the community mental health provider, they travel to the local emergency room seeking help.[6]

"One of the things we have difficulty with is getting behavioral diagnosis if they have a developmental disability – some may be non-verbal. Talk therapy is often the gateway to medication management, but obviously doesn't work with people who cannot talk." – Listening session participant

This family member's comments were reiterated by several other participants. Experiences like these shared by stakeholders have caused the American Medical Association to support policy changes designating people with IDD as a medically underserved population.[1] People with an IDD have more severe mental health issues that are difficult to diagnose and manage.[1]

DDA Eligible Clients Mental Health Treatment Need by Age



DSHS Research and Data Analysis Division, April 29, 2022

People with IDD have the same physical, social, emotional, cultural and other needs that all people have.[4] People with IDD do not experience treatment based on their strengths and that accommodates their needs[4, 11] like people without IDD. Instead, people with IDD are expected to comply with the professional's treatment orders and not allowed the right to disagree or refuse treatment.[11] Washingtonians call for mental health professionals to understand the diagnostic and treatment needs specific to people with co-occurring conditions. In June 2022, the Developmental Disabilities Administration disseminated information about training and other resources available through the Mental Health and Developmental Disabilities National Training Center. This training hub offers resources for health care providers, clinicians, direct support providers, individuals and families.

"Behavioral health providers need to understand intellectual or developmental disabilities, as well as behavioral/mental health. Training on IDD is needed." – Listening session participant

As this participant's comment notes and is repeated in research, professionals do not have a basic or advanced knowledge of the needs and complexities that come with the co-existence of an intellectual disability and mental health condition.[1, 2, 7, 9] A person with co-occurring disorder may find attending appointments difficult because of the professional's office procedures, waiting areas, exam procedures and the ways they communicate. These procedures and practices prevent equitable access to services.[6, 11] Simple accommodations like providing paperwork prior to the visit, pre-visit check-in, waiting in an exam or therapy room, using visual communication aids and other simple accommodations are not available options for an office visit.[9] Using trauma informed practices during the examination like allowing a friend, family member or caregiver in the treatment room, telling the person with an intellectual disability what is going to be done before something is done or the person is touched and asking the person's permission are often not used in physical or mental health settings.[16, 22]

"Providers need training on how to listen to people who don't use words to communicate." – Listening session participant

Supports a medical or mental health professional may offer to meet an individual's needs might include: communication boards, communication books, illustrated books without words such as Books Without Words™, augmentative communication systems and non-verbal or non-language communication techniques.[9, 11] Most importantly, the professional to must familiarize themselves with the person's needs and accommodate those needs to provide competent care.[13, 21] If the person with IDD requires more time to process words, the time reserved for the appointment needs to be longer than the standard appointment. People who are sensitive to noise and how close people are should be allowed to wait in the exam or interview room. Professionals need to understand the complexities co-occurring conditions bring to the clinical picture and change office procedures to enable people with co-occurring conditions to access the care they need.

Picture Exchange Communication System sentence, "I want an apple."

Medical and behavioral health providers are trained in techniques that work for the general population. This training helps to create very specific problem when working with people with IDD or a co-occurring disorder. It is call "diagnostic overshadowing."[4] This happens when a value or belief prevents the professional from accurately assessing, diagnosing and treating the underlying condition because the professional believes the symptoms are caused by something else. This is often seen when the professional is told about a change in a person with IDD's behavior and the professional says the change in behavior is a part of the person's IDD.[4] To combat diagnostic overshadowing, professionals must reframe what they know about behavior.[4] Professionals must obtain specialized training in how physical and mental health conditions combine to produce specific behavior patterns that are commonly missinterpreted.[7, 20] IDD in combination with these physical and mental health conditions complicate the diagnostic picture and require specialty consultations to accurately diagnose the cause of the behaviors.[1, 9, 13, 14, 16, 18, 20] Improved preprofessional training, continuing education for practicing professionals and in-service training with specialists in the field can increase capacity and provide high quality care for people with IDD.[13] Without specialized training and consultations, people with IDD will continue to experience professionals prescribing psychotropic medications,[3, 13, 14, 18] police called to intervene when experiencing a crisis,[1] having to go to emergency rooms for crisis stabilization services, social isolation in the community[2] and being referred for behavior modification.

Several standard mental health treatment methods used by the existing workforce are easily modified to accommodate people with IDD.[4] Louisiana Department of Health's Office for Citizens with Developmental Disabilities authored seven white papers telling clinicians how to modify cognitive behavior therapy, dialectical behavior therapy, trauma-Focused cognitive behavior therapy, eye movement desensitization and reprocessing, multisystem therapy, assertive community treatment and the Positive Parenting Program- to meet the needs of people with IDD.

Missouri is increasing its existing corps of behavior health provider capacity by developing a clinical best practices application for the clinician's phone or tablet. Other initiatives include tele-mentoring, tele-coaching and competency-based trainings to increase awareness and clinical skills of existing mental health professionals.

These interventions and efforts are consistent with the best practice of person-centered planning and developing a comprehensive, collaborative treatment plan.[9, 13]

"It's important to think about the intersectionality with behavior and developmental disability." – Listening session participant

Stakeholder Feedback on Developmental Disabilities Administration services

Stakeholders are keenly aware of significant issues in supporting people with co-occurring conditions. Their comments spoke of issues that address the balance between competing interests, such as: dignity of risk versus need for protection, client rights versus restricting client rights and full access to community services versus development of specialized segregated services. Stakeholders were acutely aware of capacity and system barriers.

Stakeholders expressed frustration with the ability of providers to support people with behaviors that place the person or others at risk of harm, significantly damage property, or are generated by the person's mental health conditions. This means a provider is more likely to serve a person who does not have a history of risky behaviors.

"There needs to be training to get away from punishment mentality… you're misbehaving because you're bad." – Listening session participant

The 2020 report to the legislature Continuum of Care for Youth and Adults with Developmental Disabilities, determined, "The curriculum in the basic training for the Home Care Aid Certification needs to provide better information for supporting people with intellectual and developmental disabilities."[8] Stakeholders commented the basic training overly emphasized the physical care of medical conditions and significant physical needs and less on providing supports to physically capable people with co-occurring conditions. Stakeholders want content to address supports for people with significant challenging behaviors and those with co-occurring conditions. Support staff need access to continuing education.[4] Support staff need a way to know when and where training options are available.

Several listening session participants commented on applied behavior analysis as not the preferred intervention based on their experiences. Applied behavior analysis looks at the behavior to be changed and its immediate environment to develop a plan to change the behavior. Commenters identified positive behavior support as a preferred intervention. Several participants expressed displeasure that DDA no longer provides positive behavior support plan writers and now they must access state plan service providers who wrote applied behavior analysis plan.

Positive behavior support uses comprehensive lifestyle changes, taking a lifespan perspective. Positive behavior support uses techniques that are consistent and work in the settings the person finds themselves in. The person with IDD and family members are key to designing the positive supports that will change behavior.[5] Positive behavior support is a natural outcome of the movements to support people with IDD in their community and use person-centered values in all aspects of designing supports.[5] Positive behavior supports align with the techniques and dispositions of "Gentle Teaching" practices by John McGee, Ph.D. and Marge Brown, MS.[4] Gentle teaching core beliefs highlight how some community held beliefs work against a person with IDD or co-occurring condition, and were heard in listening session comments:

- Disability is an attribute – not a problem.
- It is you who see me as deviant or helpless.
- I am not broken, don't try to fix me.
- Don't see me as a client. I am your fellow citizen, neighbor, potential friend or helper.
- Be still and listen. What you see as inappropriate may be my attempt to communicate in the only way I can.
- Be a person who listens and does not try to take away my struggle by trying to make it all better.
- I have the right to power as a person – don't try to control me.
- Respect me, for respect presumes equity.
- Listen, support, follow – don't tell, correct or lead.
- Work with me – don't work on me.

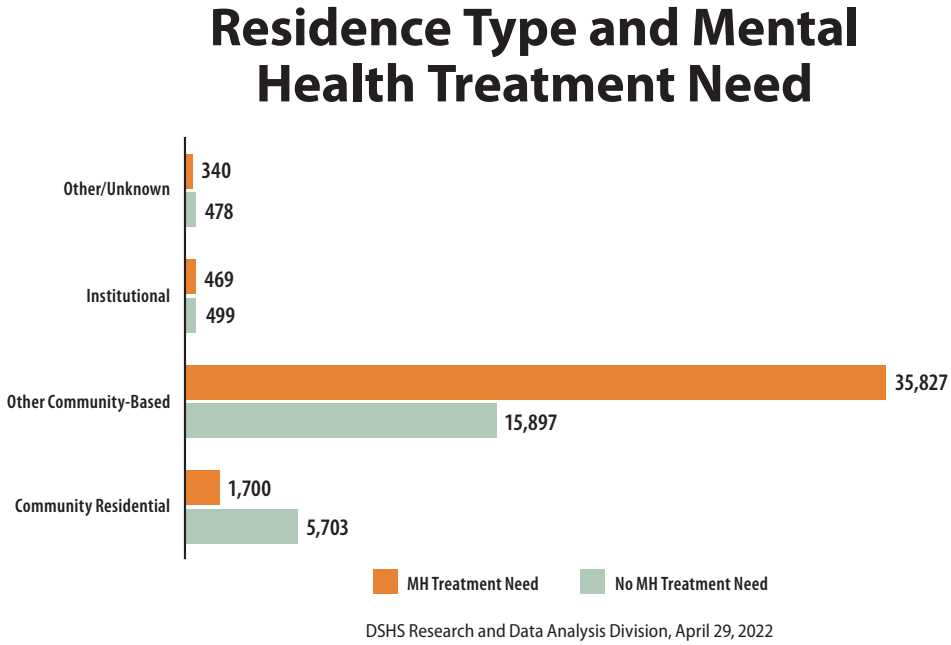
"Resources to address requests for technical assistance are needed." – Listening session participant

Stakeholders recognize the need for a greater range in providers that specialize in supporting people with co-occurring conditions. Comments suggest a need for technical assistance to help providers build specialized capacity. This was a challenge documented in the *Continuum of Care for Youth and Adults with Developmental Disabilities*.[8] While the DDA provides regular staff training and responds to technical assistance requests, funding is not available to train or accredit residential providers, behavioral health agencies, or medical or behavioral health providers in co-occurring conditions.

There is no incentive to serve people with co-occurring conditions. People with co-occurring conditions bring complexities that require more time in an office visit or therapy session. They require more referrals to settle on an accurate diagnosis. They require more case following to assure a treatment plan is effective. Funding higher rates can encourage residential and professional providers to work with people with co-occurring conditions and complex needs.

Stakeholders were keen on more opportunities for direct care professionals to be trained in de-escalation techniques. Specific issues stakeholders mentioned included direct care professionals must becoming very familiar with the person's support needs, things that cause conflict or crisis. Direct care professionals need techniques that avoid the conflict, turn the conflict around and help the person calm and return to the person's baseline. Participants said generic training on de-escalation techniques was essential, but customized training was more effective when it is centered on the person's individual needs.

Specialized training was requested for police, first responders and designated crisis responders. Stakeholders told stories of how in a crisis the police, first responders and designated crisis responders did not know what to do for the person with a co-occurring disorder, did not know available resources or did not know how to support the person with IDD or system around them.



Conclusion

Washington state is considered a national leader in supporting people with co-occurring IDD and mental health conditions. Washington state has creative services and collaborative relationships between state agencies but, Washington state has a shortage of workers. The shortage is difficult when recruiting for positions in both the direct care and mental health sectors. This means people with co-occurring conditions wait to begin services.

A shortage of affordable housing adds to the employee resource issue increasing the time a person has to wait to start residential supports. Providers struggle to find housing. If the person requires wheelchair accessible doors, rooms large enough for mechanical lifts or locations that reduce noise, the person waits longer. Similarly, a person with complex needs that express by significant behaviors, the person waits longer. Therefore, people with co-occurring conditions and have complex behavioral needs are ready to leave a hospital or in-patient treatment wait longer for housing and staff to support that home.

As the Department of Social and Health Services reported to the Legislature in 2020, "Washington state lacks a full continuum of care"[8] for people with co-occurring conditions.[6] When a person no longer needs in-patient treatment there are no beds ready for the person. There are no less intense treatment or stabilization beds. There are no beds that can be used to transition the person to a residential provider. This capacity does not exist in Washington.

People with IDD struggle finding mental health providers willing to treat them.[1] Many mental health and other healthcare providers do not have training or experience treating people with IDD.[25] This means people with IDD face challenges in gaining an accurate diagnosis.[22] "Psychiatric disorders in persons with intellectual disabilities are typically more severe and more difficult to diagnose than in the general population."[1] Providers with an interest in gaining training and experience to expand their scope of practice to serve IDD have limited continuing education opportunities available. Alternative behavioral treatment modalities for people with IDD in both the psychiatric residential treatment facility settings and mental health community-based settings are needed.[9] Access to care depends on providers making an accurate diagnosis and having a mechanism to provide treatment. "Because the prevalence of psychiatric problems is higher in patients with ID than in the general population, it is critical that psychiatrists obtain more specialized training. There has been a growing appreciation of the issues at all levels of training in medical schools and psychiatry residencies, with a focus on curriculum development that addresses diagnosing and treating ID."[1] The majority of the current corps of mental healthcare providers do not have the training in treatment models that are known to be effective in treating those with IDD.

Training is also essential for staff and families working with people with co-occurring conditions. Supporting people to live in their own home is more complex when a person has a co-occurring condition. They need skilled family or staff to support them successfully in the community.[20] Whether the individual is living on their own, with family, or in a residential setting, training for their support team is essential to the person's stability and longevity in their home.

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