

Individuals with Intellectual/Developmental Disabilities and Mental Health Needs (**DUAL DIAGNOSIS**)



Utah Transformation Transfer Initiative Project White Paper

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Target Audience:

- ❖ Utah Department of Human Services/DHS
- ❖ Utah Department of Health/DOH
- ❖ Utah Division of Substance Abuse and Mental Health/DSAMH
- ❖ Utah Division of Services for People with Disabilities/DSPD
- ❖ Utah Policymakers

Introduction

This white paper is written to inform policy makers and Department/Division leadership about the issues concerning the lack of identification and treatment options for those with co-occurring Intellectual/ Developmental Disabilities (IDD) and Mental Health (MH) issues. Because of the many challenges that continue to occur with accessing appropriate services for this population in Utah, this white paper will outline some of the barriers and propose some recommendations to improve the current landscape.


When individuals and families find they have an overwhelming complex need they often do not know where to even begin to address their situation. Do they accept this complex life, or do they start to ask for help? Where do they go to get help? Is the issue only concerning the primary disability or is it something more? Can anything be done to address the needs? When individuals with IDD find they have a need for mental health services, they are often referred to behaviorists to treat the symptoms not the underlying cause.

Often people with IDD are not able to receive mental health services at a Local Mental Health Authority (LMHA), because of the insufficient number of adequately trained mental health professionals. Finding a mental health provider that is qualified to understand the additional possible causes underlying what is seen as a behavior, including possible mental health can be challenging. This type of support, meaning familiarity with co-occurring IDD and MH needs, is rarely an available option in most areas of the state. Individuals and families are often referred back to DSPD (if they are receiving services) for behavioral support which does not help in getting the correct diagnosis and treatment options.

“For example, the need for an individual with IDD to leave a certain situation due to behavior may not be a discipline issue, but a possible manifestation of anxiety. Or a person with IDD may be unable to move onto a new activity until he has put things in place from the current activity, and while he may be considered stubborn, it is actually an obsessive-compulsive disorder that has compelled him to go back and arrange items to his satisfaction before attempting a change of activities. In such cases, the underlying need for therapy, or medication with therapy, is not usually considered. This can be due to the fact that the therapist has not received applicable training in this area, the therapist may believe that ‘this’ individual cannot benefit from traditional therapy due to their lack of cognitive ability, and/or there is possibly a misunderstanding that an individual with IDD cannot receive services from two separate funding streams.”

DEFINITION

It is becoming more accepted to use the term “Dual Diagnosis”¹ to refer to individuals who have co-occurring Intellectual and Developmental Disabilities (IDD) and Mental Health diagnoses (MH), or emerging mental health needs not formally diagnosed. Dual Diagnosis also commonly refers to those having both MH and Substance abuse, and many professionals may be more familiar with that usage.



“Despite the widely varying prevalence rates, existing studies confirm that individuals with mental retardation are susceptible to the full range of mental health disorders. Experts generally agree that the most likely prevalence rate of mental illness among people with mental retardation ranges from 20 to 35 percent².

The Diagnostic and Statistical Manual of Mental Disorders: Fourth edition – Text Revision (APA 2000), however suggests that individuals with mental retardation are three to four times more likely to experience mental health difficulties than individuals without mental retardation. Although the exact prevalence of mental illness is unknown, it is generally accepted that individuals with mental retardation are at increased risk for developing mental illness³.”

What we Know/The Utah Experience

1. People with IDD are at a higher risk of having a mental health diagnosis and of needing mental health supports⁴. Studies have shown prevalence rates anywhere from 5% to 100% depending on definitions and study methods.

More recent large-scale research states, *“It has been reported that individuals with IDD who also have a mental illness may constitute one of the largest underserved populations in the United States . . . And that 40-50 % of people with IDD (also) have a psychiatric disorder⁵.”*

We do know that children/individuals who have IDD are far more likely to also experience mental health needs than the general population. There are various proposed explanations of why mental illness might be more prevalent in individuals with IDD. Widely accepted factors include:

- Day to day life is very challenging for individuals with IDD, leading to the experience of stress (such as rejection, segregation, lack of control over one’s life, limited social support, limited vocational opportunities, poor self-image, limited social skills, labeling, etc.⁶)

- Individuals with IDD have a limited capacity to cope, so smaller stressors may be experienced more intensely
- Individuals with IDD have physical damage to the brain, digestive system, etc. (It is now accepted that many neurotransmitters are produced in the gut.)⁷
- There are increased rates of abuse and neglect among the IDD population⁸.

2. Families and professionals have not been educated to understand that a child/young adult with IDD can also have a Mental Health diagnosis, and vice versa. For example, it is not always understood by the families and professionals that a person with autism can also have depression/anxiety/OCD.

The usual initial reaction for families is to believe the diagnosis and prescribed treatment until they come upon additional information offering possible alternatives. This can lead to a level of distrust between family members and professionals. Family members may also feel like they are being given limited information on available medical treatment instead of being listened to and creating an individualized plan that explores other options.

Mother was reluctant to seek out mental health because she is not sure if it's needed or if "it" is a part of his disability. She has said she has gone over to the local behavioral health building during operation hours and the building has been closed and cannot get anyone to follow up with her or schedule a therapist.

Her son struggles with anxiety and communication.

Communication

... diagnosis is often based on self-report. A person with IDD and limited verbal skills would have more difficulty in expressing his/her symptoms or feelings, which could make diagnosis more difficult and/or contribute to diagnostic overshadowing. For instance, an individual with Down syndrome and limited verbal expression could be considered stubborn, when he/she is actually experiencing anxiety. It is critical to consider alternatives to verbal expression for communication.



Professionals need to understand that families bring a unique expertise about their child and are competent to understand information that is shared and that they are equal partners with professionals. Another misconception is that the family needs to be protected from information regarding a disability or diagnosis. As stated above, parents should be considered the experts on their own children and their desire to find the best treatment path/person centered plan should be honored.

3. Diagnostic overshadowing⁹ continues to be an issue for professionals when considering diagnosis and treatment. Diagnostic overshadowing refers to attributing a person's symptoms to a primary diagnosis/condition, rather than the person having a primary diagnosis/condition with a co-occurring illness. This results in the co-occurring illness remaining undiagnosed and poorly treated or untreated while behaviors are falsely attributed to the disability¹⁰.

4. Individuals with dual diagnosis are being refused appropriate clinical mental health treatment due to the lack of skills and training of clinicians.

Client was denied seeing a therapist because client has a diagnosis of autism. Mother wanted child seen due to his OCD disorder. The LMHA still would not do an intake. The family became frustrated and stopped working with ALL agencies.

Family Resource Facilitators (FRF), Utah Family Voices, the Utah Parent Center and other advocates have little success at gaining access to dual diagnosis mental health services for the individuals/families they work with. Typically, an individual on Medicaid seeking mental health services is referred to the Local Mental Health Authority (LMHA). However, the expectation for a LMHA to provide comprehensive services to individuals with dual diagnosis has not been customary in the past.

It has actually been acceptable for LMHA's to indicate that they do not treat individual with dual diagnosis. These mental health professionals explain away the mental health symptoms as a manifestation of the person's primary IDD diagnosis (ie: Down syndrome = stubbornness; Autism=anxiety), or to state that the person won't benefit from treatment because they cannot cognitively understand the process. This puts a burden on the caregiver, with little support from others, to prove that the person needs clinical mental health services.

The FRFs and Utah Family Voices have been successful in providing peer-to-peer or family-to-family support to help them access non-clinical supports in the community and give them some hope; but entry to the 10 mandated mental health services and clinical treatments have been restricted or denied.

Currently, when a child/young adult with IDD is on the DPSD waiver and in need of mental health services, the standard Medicaid system of supports are with the Local Mental Health Authorities (LMHA). When the individual contacts the LMHA they are told

that they are not able to provide services because of their IDD diagnosis. This leaves the family vulnerable and at increased risk of crisis which leads to higher costs interventions including emergency room visits and/or out of home placements. This has created a failure to provide appropriate services that Medicaid has in place to protect this population.

Client is in need of mental health services, but due to his level of care and need no therapist will see him. Due to their lack of training with his level of aggression.

At this time, there is one location in the state that is able to support individuals with dual diagnosis: the UNI Home Program. However, most family members are not able to access the UNI Home Program due to waiting lists, location and capacity.

An important note There are more than 7 million Americans with IDD. On average, each must contact as many as 50 physicians before finding one with training and experience to treat him/her¹¹.

Results and Recommendations

After examining statistics, and reviewing individual experiences, we became convinced that the current practices do not adequately address the problems identified. This white paper will argue in favor of the following proposed solutions because it would increase capacity within the system of supports for individuals with dual diagnosis and their families throughout the state.

- ❖ **Allow for access** to clinical and non-clinical supports for children/young adults who experience IDD and mental health services regardless of entry into any system for any individual with IDD. Funding streams must be modified as necessity dictates. If an individual has qualified for Medicaid services, then the person should be able to get the necessary services regardless of funding issues. It is important to note that the services needed by these children/young adults do not end when they become 18 years old or age out of Early and Periodic Screening, Diagnostic and Treatment/EPSDT services the needs are across the life span.
- ❖ **Mandate training from DSAMH**, providing CEU credits, to increase ability to support individuals with dual diagnosis and their families/caregivers including how to talk with parents about assessment scores, IQ, perception of 'parents in denial', parent blame, and/or 'red flags' to increase capacity for staff in LMHAs. Creation of the CEU training outline should be done in partnership with family organizations and/or community partners.
 - Offer additional training on how to adapt current therapies such as Cognitive Behavioral Therapy (CBT), Dialectical Behavior Therapy (DBT) and other preferred practice therapies for all individuals needing therapy.

- ❖ **Develop planned mentoring opportunities** for peer-to-peer support for professionals from LMHAs who have knowledge about treatment options, building on their successful experiences. This will broaden knowledge and expertise to professionals and mentoring opportunities around their shared knowledge base to increase capacity across all LMHAs as well as utilize strengths currently available in successful LMHAs. Have Uni Home provide TA to LMHAs
- ❖ **Provide peer-to-peer support for families** through the training provided by family advocacy organizations. Continue implementation of the curriculum “Dual Diagnosis - What Families Need to Know When a Family Member has Developmental Disabilities Plus Mental Health Needs” beyond the scope listed in the TTI grant with supports and funding in place for long term training opportunities.
- ❖ **Build capacity and increased competency** by implementing the nationally recognized NADD Certification programs. NADD offers three competency-based certification programs for personnel, including 1) Clinical Certification 2) Direct Support Professional Certification and 3) Specialist Certification (for case managers, service coordinators, supervisors, managers, residential and vocational staff, etc.)
- ❖ **Increase the strength of collaboration** with agencies, advocacy groups, and family members to provide successful outcomes as measured by person centered and family driven plans of focus.
 - Cross system coordination and team approaches must be developed, outlined, implemented, and monitored for effectiveness¹².
- ❖ **Involve Utah with other Centers of Excellence** that are making progress with the dual diagnosis services in their state/area.

References:

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