SUPPORT COORDINATOR QUARTERLY MEETING

April 25, 2019, 11:00-12:30 p.m.
Multi-agency State Office Building, 195 N. 1950 W., SLC, Room 1020C

Video conferencing:
- Video access if you have a camera and a mic on your computer:
  https://hsconnect.hs.utah.gov/ustepspublic

WHY

THREE FOCAL AREAS
- Communicate changes at DSPD instaffing
- Provide informational updates on DSPD processes
- Engage ways DSPD and support coordinators can better collaborate

AGENDA

1. Staff Changes
   - Emily Crandall, Tricia Jones-Parkin,
   - Anne and Nadia are out

2. Utah Employment and Community Integration Training and Technical Assistance Center through Utah State University

3. Transitioning People into Services
   - Intermediate Care Facilities (ICFs)
   - Waiting List
   - Needs Assessment Questionnaire Rollout
   - MySteps
4. Presentation of White Paper from the *Utah Parent Center* (Individuals with Intellectual/Developmental Disabilities and Mental Health needs (DUAL DIAGNOSIS))

5. PCSP Updates from the workgroup

6. Q&A

Next meeting  17 July 2019 (Wednesday), 10am - 11:30am
Employment and Community Integration
Training and Technical Assistance

The Division of Services for People with Disabilities is contracting with the Center for Persons with Disabilities at Utah State University to offer Technical Assistance providing support and resources for contracted service organizations working towards compliance with the Settings Rule.

What is it?

This TA includes both an informational website with links to a variety of resources, webinars, training opportunities, and direct consultation between the organization and a subject matter expert that has knowledge or experience in the disability services field. All of these opportunities will give guidance to organizations to accomplish the following:

- Determine unique ways to revise policy, financing, staffing, culture, and other practices to be Settings Rule compliant that are financially stable
- Identify approaches to better support community engagement
- Methods to engage and inform individuals and their families about the Settings Rule process

This assistance is available to all providers and support coordination companies contracted through DSPD.

Why participate?

- Progress reports and other plans developed in the TA process can be submitted to the Utah Department of Health to meet Settings documentation requirements
- This assistance is funded by DSPD and generally only requires time from the participating organizations
- Access to resources that will help organizations innovate their services towards compliance with the Setting Rule
- The subject matter experts have gone through the process with their own organization or have helped other organizations through the process, so they can offer real world guidance, ideas, and reassurance

Apply online by May 30th at https://www.uettac.com/technical-assistance
Individuals with Intellectual/Developmental Disabilities and Mental Health Needs (DUAL DIAGNOSIS)

Utah Transformation Transfer Initiative Project
White Paper

Contributing Authors:
- Deborah Bowman – Utah Developmental Disabilities Council
- Gina Money – Utah Parent Center and Utah Family Voices
- Julia Pearce – Parent and Family Leader
- Lori Cerar – Allies with Families
- Tracy Johnson – Allies with Families

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)/Autism 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 experience overwhelming complex needs, they often do not know where to even begin to address their situation. Do they try to accept a complex life, or do they start searching for help? Where do they go to get help? Are the issues a result of the primary disability or are they something more? Can anything be done to address the needs?

When individuals with IDD/autism 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/autism 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/autism 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.

One family’s experience - 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.
What we Know/The Utah Experience

1. Prevalence

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

Individuals with Autism are at a higher risk for mental and behavioral health needs such as:

- ADHD affects an estimated 30-60% of people with autism vs. 6-7% of the general population.
- Anxiety disorders affect up to 42% of people with autism. With contrast, they affect an estimated 3% of children and 15% of adults in the general population.
- Depression affects an estimated 7% of children and 26% of adults with autism. By contrast, it affects around 2% of children and 7% of adults in the general population.

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 disorder.”

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.).

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.)

There are increased rates of abuse and neglect among the IDD population.

2. Family/Professional Partnerships

Families and professionals have not been educated to understand that a child/young adult with IDD/autism 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.

Family Resource Facilitator report: Mother was reluctant to seek out mental health services because she is not sure 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.

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 individualized plan that explores other options.

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 Overshadowing

Diagnostic overshadowing\(^\text{10}\) 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 disability\(^\text{11}\).

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

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 individuals 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 has 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 cost 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.

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/her effectively.

An 18 year old with autism and mental health needs went into crisis and was destroying things at home and became physically aggressive to his family. Family was told by the son’s doctor to take him to the ER at Primary Children’s Hospital. The hospital told them to then take him to the University Neuropsychiatric Institute (UNI) but their Medicaid mental health insurance told the family and UNI that they “were inclined to decline because autism is not covered.” It was suggested that excluding the autism diagnosis and only including the OCD, anxiety and depression on the paperwork might help them access the services they so desperately needed but that would exclude treating the whole person and addressing his individualized needs.

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 argues 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/autism and mental health services regardless of entry into any system for any individual with IDD/autism. 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 (for causing issues), 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

- Develop cross system coordination and team approaches that must be outlined, implemented, and monitored for effectiveness.

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.)

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.

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.

Involve Utah with other Centers of Excellence that are making progress with the dual diagnosis services in their state/area to assist in developing a Center of Excellence in Utah.
References:

2. “How Prevalent is Dual Diagnosis”; book “Breaking Down Silos” pg 8)
4. The Dual Diagnosis Primer - page 16, NADD Press, 2006
5. https://www.autismspeaks.org/associated-medical-conditions-0
8. https://www.ncbi.nlm.nih.gov/pmc/articles/PMC5772764/
10. Chapter 1 “Breaking Down Silos” book “Diagnostic Overshadowing: Have We Really Left it Behind”
Background

● Why are we revising the PCSP?
  ○ Modifying the PCSP to be in compliance with the Medicaid Home and Community Based Services “Settings Rule”
  ○ Opportunity to update/modify the PCSP to re-emphasize “Person Centeredness”

● Settings Rule
  ○ Opportunity to be integrated into the community in the same ways as non-disabled peers
  ○ Planning and meeting is lead by the individual
  ○ Emphasis on community based natural supports development
  ○ Documenting human rights modifications in the PCSP
  ○ Building a pathway for community integrated employment
Work Group

- Began meeting in October, 2018
  - Meeting 2x month

- Diverse group members
  - Support Coordinators
  - Traditional Providers
  - Parents
  - Self Advocate
  - Department of Health
  - Disability Law Center
  - Utah Parent Center
  - USU-CPD
  - DSPD
Person Centered Focus

- Emphasis on getting back to being “Person Centered”

- Individual’s Desired Life
  - Person Driven process
  - Individualized
  - Broad picture of the Person
  - Planning with the Person, not for the Person

- Pre Planning
  - Emphasis on getting to know the person
  - Qualitative Assessment

- Input from ALL relevant sources
  - Family and Circle of Support
  - MySTEPS
  - UPI
Changes to current process/structure

- Annual assessment section in the planning process (pre-planning)
  - Emphasis on assessment tools

- Separating the goals from budget lines
  - Remove the dependency of the budget line from the Goals/Supports

- Separating Goals and Goal Supports into a distinct section (Action Plan)

- Separating the Budget or ISP into a distinct section

- Adding a distinct section for “other” supports
  - Medicaid State Plan Services
  - non-DSPD Purchased Services; e.g., Voc Rehab
Tools

- Emphasis on planning “with” a Person instead of “for” a Person

- Charting the Life Course Tools
  - Identifying long term goals and desired life
  - Mapping out a Person’s schedule and support needs
  - Identifying the types of supports a person wants/needs
  - Identifying the support a Person has for making decisions
  - Understanding a Person’s vision in the context of their stage in life

- Other Tools
  - Identifying the relationships in a Person’s life and building a circle of support
  - Employment focus on understanding a Person’s current situation concerning employment and potential directions to further employment
Emphasis on Natural Supports

- Natural Supports will be specifically identified for goals and supports

<table>
<thead>
<tr>
<th>Supports for this Goal</th>
</tr>
</thead>
<tbody>
<tr>
<td>Support:</td>
</tr>
<tr>
<td>Start:</td>
</tr>
<tr>
<td>End:</td>
</tr>
<tr>
<td>Who will provide this support:</td>
</tr>
<tr>
<td>Paid Providers:</td>
</tr>
<tr>
<td><strong>Natural Supports:</strong></td>
</tr>
<tr>
<td>Other Supports:</td>
</tr>
</tbody>
</table>
Plan/Process Going Forward

- Building Software
- Self Advocates

- Pilot testing with Transition Team
- Welcome volunteers to pilot test tools and process

- Utah State University Employment and Community Engagement Training and Technical Assistance Center (UECITTAC)
- National Center on Advancing Person-Centered Practices and Systems (NCAPPS)