



**Utah Parent Center**  
Special needs, extraordinary potential

## Topical Journal

# Dual Diagnosis

## Developmental Disabilities Plus Mental Health Needs

Welcome to the topical e-journal on Dual Diagnosis. This e-journal is part of a series published by the Utah Parent Center (UPC). This material has been prepared to provide information and resources to both parents and professionals.

Any person with disabilities is at higher risk for having mental health diagnoses for a number of reasons. In this journal you will find information about some of these reasons and also about medical issues that may cause behaviors that cause us to suspect there are mental health concerns. You will become more aware of some of the signs to look for. You will also find some stories of families who have dealt with the challenge of dual diagnosis and some tips from families about things that have been helpful to them. Lastly, you will find information on some resources and places to go for more information.

We hope the information in this issue is helpful to you and your son or daughter who might have mental health challenges in addition to a disability. An electronic copy of this journal along with supporting information is available on or through the UPC's website at [www.utahparentcenter.org](http://www.utahparentcenter.org). If you need resources specific to a certain area of the state or other types of resources or if you would like to speak to one of our parent consultants about questions regarding school services or other topics, please contact us at 801-272-1051 or toll free at 1-800-468-1160.

Our Family to Family Health Information Center can provide information about how your primary care physician can help and about the importance of a medical home for your child. Often if you can clear up some of the medical health issues you can manage the disability better.

The Utah Parent Center has been serving Utah families of children, youth, and young adults with all disabilities since before 1983. We provide free resources such as publications, workshops, and individualized assistance to help families make decisions about education, support services, vocational training, employment, and other services for the child and family.

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# Dual Diagnosis: The Facts about Having Mental Health Needs and an Intellectual or Developmental Disability

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*If your child has received a Dual Diagnosis or may be at risk for a dual diagnosis, it can be very helpful to understand some basic information. Let's start with some common terms and their definitions.*

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## Developmental Disability

Many different terms have been used to describe developmental disabilities. The familiar terms include "learning disability", "developmental disability", or "intellectual disability". We sometimes even still see the term "mental retardation" in scientific and clinical articles. Often these terms are used interchangeably, but there are also subtle differences between the definitions of each term. Intellectual and developmental disabilities are disabilities that cause significant limitations in multiple areas of functioning. Developmental and intellectual disabilities have many things in common. They both occur before age 22. They are both chronic and are almost always lifelong. They both cause significant functional limitations in multiple areas of life, such as self-care, communication, mobility, learning, self-direction, capacity for independent living and self-sufficiency.

Sometimes people use the term "developmental disability" to include intellectual disability, and sometimes the term is used to differentiate the two (which is how it is used here). An intellectual disability (also known as mental retardation) is characterized by significant limitations in BOTH intellectual functioning and adaptive behavior. Intellectual disability ALWAYS includes significant limitations in intelligence or mental capacity. On the other hand, a developmental disability may involve mental OR physical limitations, or both of these. These mental and physical limitations may not affect intelligence or mental capacity, but cause substantial limitations in multiple areas of life nonetheless. An example of a developmental disability that involves mental limitations but that may not impact intellectual functioning is autism. While some people with autism also have an intellectual disability, others do not, but in either case it may cause substantial limitations in multiple areas of life. An example of a developmental disability that involves significant physical limitations is Cerebral Palsy. While some people with Cerebral Palsy also have an intellectual disability, many do not, but the Cerebral Palsy may cause substantial limitations in multiple areas of life nonetheless.

It is critical to recognize that people with disabilities are defined by their own individual identities, personalities and their own choices, and not their disability. It is important to understand the disability to provide good support to people, but it is much more important to get to know who each person is as an individual and what he or she wants from life.

The use of a particular term can be influenced by where one lives, the policies and the regulations of a particular locale, as well as the discipline or background of the speaker.

Another description of people with Developmental Delay is children, youth and adults who have significantly greater difficulties than most people with intellectual and adaptive functioning and have had such difficulties from a very early age (or the developmental period prior to age 18). ('Adaptive

functioning’ means carrying out everyday activities such as communicating and interacting with others, managing money, doing household activities and attending to personal care.)

The definition of developmental disability also includes children, youth and adults with developmental disorders such as Fetal Alcohol Spectrum Disorders or Autism Spectrum Disorders.

### **Mental Health or Mental Illness**

Mental health (or well-being) is an ideal that we all strive for. It is a balance of mental, emotional, physical and spiritual health. Caring relationships, a place to call home, a supportive community network, and work and leisure all contribute to mental health. However, no one’s life is perfect, so mental health is also about learning the coping skills to deal with life’s ups and downs the best we can.

*Mental illness is a serious disturbance of thoughts, feelings and perceptions that is severe enough to affect day-to-day functioning.*

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Some types of mental illness are:

- ✧ **Depression** – intense feelings of sadness and worthlessness – so bad that you have lost interest in life
- ✧ **Bipolar** – cycles of feeling of intensely happy and invincible followed by depression
- ✧ **Anxiety Disorders** – panic attacks, phobias, obsessions or post-traumatic stress disorder
- ✧ **Trauma** – a person surviving trauma may carry any psychiatric diagnosis and may carry several different diagnosis
- ✧ **Impulse Control Disorders** – – failure to resist an impulse, drive, or temptation to perform an act that is harmful to the person or others
- ✧ **Attachment Disorder** – rare but serious mental health condition in which infants and young children don’t establish healthy bonds to caregivers or parents. Note that some children whose symptoms do not rise to the level of a clinical diagnosis may have developmental attachment problems or anxiety conditions that need to be treated.
- ✧ **Schizophrenia** – hearing voices, seeing things, having false beliefs

### **Dual Diagnosis**

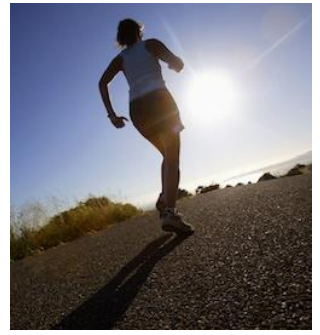
People with developmental disabilities and mental health needs have variously been referred to as having a dual diagnosis, a concurrent disorder or a co-morbidity. Sometimes for the sake of clarity, the longer definition, “*children, youth and adults with a lifelong developmental disabilities and mental health needs*” is preferred. For simplicity, we are calling this “dual diagnosis”. (Please note that you may see the term used that way in other literature.)

People with dual diagnosis have more severe symptoms, are more likely to have co-occurring medical conditions and have fewer resources (access to education, social and economic supports). They are also more likely to require long-term hospitalization.

“Challenging behaviors” is a term that has been used to describe aggression, self-injury, and destructive, disruptive or non-compliant behaviors that can be an expression of symptoms related to physical or mental health needs. Unfortunately such responses may also expose individuals to threats, excessive force, and caregiver anger. As a result they may then experience even further isolation as families, significant others, caregivers and communities struggle to respond to these complex dynamics.

## One Parent's Story

I recently ran a race that I felt I had trained well for. I felt I was prepared. I studied the race route, knew where the hills were and the elevation of each hill, ran my miles and got ready for race day. As I approached another hill on mile 5, I looked up and realized that this hill was steeper and longer than what the race route had said. As I changed my race pace to push through this part of the race and work to finish well, I thought about how being the parent of a 21 year old young man with multiple disabilities, including intellectual disabilities and mental health needs, was like this race in that we often looked up and saw changes that we didn't think we were prepared for and yet we did what needed to be done.



Our first training about Dual Diagnosis started when our son was 10 years old and my husband and I were seeing some first signs of what looked like anxiety: Holding onto doorways in new situations, a different 'look' in his eyes that looked a bit frightened, and just a little less of his usual social self. I came to the training not knowing what Dual Diagnosis meant, what Dual Diagnosis included or what I could do to help our son as we went forward. That was the start of what has turned into 13 years of attending conferences to talk and learn with the best as the questions of what our son experienced increased and changed. I learned from many professionals about how to help our son decrease the need for medications in those early years by working to understand what a behavior could tell us at home. I have been able to talk with physicians about increased seizure activity, medication side effects and early signs of dementia. I have learned from these same professionals that quality of life and personal preferences are to be respected in a person with a disability even during difficult behaviors and at the end of life. I have learned that professionals in the Dual Diagnosis field are open and willing to answer questions from other professionals and family members in the same manner and with the same integrity. I learned that other parents are a great resource and support as I learned about Dual Diagnosis for our son.

There have been times when we have gone to further trainings, learned new skills, looked ahead to possible events and thought we were ready for any of the possible upcoming changes with our son's medical and mental health world. I then found that I was facing a change that was more difficult than expected. Recently, our family moved into a new home because our son had gotten weaker and had started falling, especially falling down the stairs. The move did reduce that fall risk but brought other challenges: our son had increased dementia like confusion including forgetting daily routines and skills, increased difficulty with transitions, return of the anxiety attack and a 30 pound weight gain because of not having stairs to go up and down each day for exercise - to name a few.

As we moved on with these new events, I found myself remembering the many opportunities and the advice I had been given from people at the conferences and trainings. I also asked myself "Is there someone who has a trick up their sleeve?", "Would they share that trick?", "Are there others who have been here and done this?", and "What is coming our way next?" And then we realized that the trainings, conferences and networking with professionals and parents were still needed as I looked forward to all that would come to us, including the challenge of running the next event, even if it might have unexpected hills.

And with it all, we learned that it is important to trust our instincts as parents, to speak about what family's needs are when working with professionals, to present things that worked with our son, especially in communication supports, so others attending a training or conference could learn from him to understand that we all need to work together to improve the lives of children and adults with a Dual Diagnosis.

Julia Pearce - NADD Board member, NADD Family Issues Committee Chair, Family to Family Network

## Some of the Challenges

People with dual diagnosis may suffer the “double jeopardy” of stigma, further marginalizing and isolation. One result is that their mental health needs are often missed – for a number of reasons:

- Challenging behaviors, as a result of an emerging mental health need, may be misinterpreted as another manifestation of the developmental disability.
- A diagnosis of developmental disability can over-take a person’s entire identity where new symptoms are seen as an extension of the disability rather than evidence of a physical or mental illness.
- Similarly, recent changes in behavior that may signal a mental health need can be dismissed or ignored.
- In many cases, people with developmental disabilities are already prescribed psychiatric medications to address the challenging behaviors. Over-medication may mask a real mental health need that requires assessment, diagnosis and perhaps a different regimen of medication.
- People with developmental disabilities can develop competencies and skills in an effort to appear normal and in order to avoid rejection or bullying. Caregivers may be lulled into thinking nothing is wrong – when these skills, once adaptive, now serve to conceal real pain.
- Some people with developmental disabilities have exceptional talents or abilities that can divert caregivers from seeing that they have physical and mental health needs.
- People with developmental disabilities often have communication difficulties and are unable to tell caregivers what, exactly, is wrong.

As a result there is a tendency toward inaccurate mental health diagnosis, inappropriate treatments (such as too many or too much medication(s)), complicating and confounding side effects to over-medication, frequent contact with police and hospital emergency rooms, and failure in community programs.

This is a group that has complex needs yet most service systems are not well equipped to deal with complexity. Education, health, community and developmental service professionals are not trained in responding to people with developmental disabilities and mental health needs. They are also not used to working in inter-professional care teams where the many professionals needed to respond to complexity are available in one location. Individual services can also do a poor job in communicating with one another leaving families scrambling to coordinate services themselves. Government policies that affect people with developmental disabilities, in general, are scattered across multiple levels and (states) with no harmonization. Often there is no specific policy for this group.

### Recovery:

***What people with a dual diagnosis, and their families, look toward is what recovery will look like for all involved. Each individual and his or her experiences and abilities, will be factors as treatment begins and life goes forward.***

“Recovery defines consumers not as passive objects or treatment but as active participants – along with their families and caregivers – in creating and maintaining their own mental health. Recovery focuses on wellness rather than illness. Recovery is not a cure. It is living life to the fullest despite challenges.

Consumers say that recovery is much more than dealing with the symptoms of mental illness. People have other life experiences that have affected their mental health. Recovery acknowledges and validates all these experiences and opens the door to a broader base of coping mechanisms than simply diagnosis, medications or therapy.”

### Resources:

- CARE-ID Advocacy Toolkit Documents including Dual Diagnosis Factsheet and Dual Diagnosis Backgrounder <http://care-id.com/dual-diagnosis/>
- Medical Home Portal - <http://www.medicalhomeportal.org/medical-home>

*For more information regarding definitions and terminology consult:*

- The American Association of Intellectual and Developmental Disabilities [http://www.aamr.org/Policies/faq\\_mental\\_retardation.shtml](http://www.aamr.org/Policies/faq_mental_retardation.shtml)
- The Canadian Association for Community Living <http://www.cacl.ca/english/aboutus/definitions.html>
- Centres for Disease Control and Prevention <http://www.cdc.gov/ncbddd/dd/dd1.htm>
- The Developmental Disabilities Assistance and Bill of Rights Act of 2000 [http://acl.gov/Programs/AIDD/DDA\\_BOR\\_ACT\\_2000/p2\\_tI\\_subtitleA.aspx](http://acl.gov/Programs/AIDD/DDA_BOR_ACT_2000/p2_tI_subtitleA.aspx)
- Fletcher, R., Loschen, E., Stavrakaki, C., First, M. (2007) Intellectual Disabilities. In Diagnostic Manual – Intellectual Disability: A clinical guide for diagnosis of mental disorders in persons with Intellectual Disability. Editors: R.Fletcher, E. Loschen, C. Stavrakaki, M. First. NADD Press.

## Mental Health and Mental Illness Treatment

Most experts agree that treatment requires a comprehensive plan with several components. An interdisciplinary evaluation of the individual is necessary to obtain an accurate diagnosis and to establish habilitation and treatment needs. A thorough medical and neurological evaluation should be included to identify acute or chronic conditions that may need attention. A psychiatric evaluation can determine if medication is appropriate. Follow up interviews are required to monitor the individual’s response to various treatments. **When the person with a disability is not able to report what he or she is feeling for any reason (due to being non-verbal, functionally non-verbal or any other reason) at any time during the evaluation process, a parent or caregiver will be able to interact with the interdisciplinary team about observations regarding changes seen in the home.**



### What treatments are available?

- **Psychopharmacology:** medication treatment is appropriate for many psychiatric disorders (ie: mood disorders and psychotic disorders). Medication should not be a total treatment approach per se, but rather part of a comprehensive bio-psycho-social-developmental treatment approach
- **Psychotherapy:** Individual, group and/or family psychotherapy may be included in the treatment plan. Psychotherapists may draw techniques from many theoretical orientations, including behavioral, cognitive, cognitive-behavioral, gestalt, psychodynamic, nondirective, or systems... Group therapies include skills training groups such as social skills, dating skills, assertiveness, and anger management training.

Other therapy groups may focus on specific developmental tasks such as independence or bereavement. The groups may be structured or unstructured, time limited or ongoing. Verbal psychotherapies are most appropriate for persons with mild to moderate intellectual disabilities.

- **General Wellness/Medical Treatment:** Medical evaluation and treatment may help get to the origins of some problems. Your medical professional can help you consider sleep problems, diet and nutrition, toileting problems, engagement in fitness activities, engagement in recreation activities, stress management, and social and relational connections and perhaps other health considerations.
- **Behavioral Management:** Through your child's special education Individualized Education Plan (IEP), you can work with the IEP team to provide positive behavioral supports at school. Behavior management plans are developed to deal with inappropriate behaviors and to teach adaptive skills. A functional analysis of behavior is conducted to determine the best approaches to use in the behavior plan. For more information about how to work with your child's school or about the IEP process, you may wish to contact the Utah Parent Center and speak to one of our parent consultants.

Systematic behavior programs may be implemented by individuals in the person's environment. The person who has a dual diagnosis may participate in the design of the behavioral program.

A behavioral assessment may also show that a behavior is what a person is using to communicate a change in his/her needs in regards to mental health/mental well-being.

Many treatment modalities and approaches have been tried, with varying degrees of effectiveness, with persons with intellectual and developmental disabilities. Evidence based treatment approaches are those that have been empirically tested and proven effective for persons with intellectual and developmental disabilities. It is considered best practice to use evidence based treatments.

- **Day Treatment:** Day treatment, or partial hospitalization, programs for persons who have a dual diagnosis have been established in many communities. The programs serve individuals with intellectual or developmental disabilities who have difficulty functioning in a traditional school or vocational program due to behavioral or psychiatric problems. Day treatment programs are generally designed for both rehabilitation and, and education, and include small group activities that focus on independent living skills, interpersonal skills, vocational preparation, and enrichment activities. Small group and individual psychotherapy are usually scheduled as part of the weekly program.
- **Social Skills Training:** Social skills training is usually a time limited approach that helps persons to improve the quality of their life by enhancing interpersonal interactions. Individuals are taught effective and appropriate social behaviors.
- **Residential Services:** Residential treatment programs have also been developed. These include inpatient units with intensive treatment programs for those individuals who require 24-hour supervision in a secured environment. In community settings, a range of residential options is available, although the demand often exceeds the available supply. Community placements include group homes, foster care, and supervised apartments, as well as programs that provide in-home family services and respite care.
- **Crisis Intervention Services:** Additional services may be called up in emergency situations. These services are designed for short-term use to stabilize immediate crises.

## When There's A Crisis:

Many families who have children with a dual diagnosis have experienced crises related to behavior or “meltdowns”. As sons and daughters grow up—sometimes to be larger than their parents—the possibility of behavioral problems causing safety issues becomes even more of a concern. While there is no simple fix for this type of crisis, there are some things that families have done or can do to be more prepared in case there is a crisis. You may wish to consider taking some of the following actions if you think they apply to your situation:



- Take a class or get training to help you understand why meltdowns happen—the brain science behind why your child may lose control. Learn how to de-escalate behavior while keeping yourself and others safe.
- Learn to communicate with and teach your child in a calm teaching moment. People do not learn well in the heat of the moment when emotions are high. Save the teaching for when the child is receptive.
- Plan ahead about what you might do in a specific crisis. Share plans with other family members or people in your child's circle of support.
- Know where your child can go to be stabilized in case of a crisis. It might be the emergency room at your local hospital or other health care facility.
- Find out if your local police department has officers who have been trained to help people with mental health challenges. Many police departments in Utah have CIT (Crisis Intervention Team) officers who have received such training. If you need to call the police for help, be sure to ask for a CIT officer. If your local department has not had this training, encourage them to contact the Salt Lake city Police Department to request training.
- Let your local police and emergency personnel know about your child's needs. Is the child a frequent runner? What would they need to know in an encounter with your child? Many communities have a system where they can “flag” your home and post information so that anyone responding to a call there will be aware of the child's situation.
- Educate your family and neighbors about your child so they know what help might be needed in an emergency. Most people are glad to help if they know what to do.
- Keep a list of important emergency contacts in an easy to access location or multiple locations.
- Store your child's medical records and other important information in a way that they can be quickly accessed and taken with you in case of a disaster. Make sure others know where they are.
- Other services provided to individuals with intellectual and developmental disabilities and mental health needs may include physical therapy, speech therapy, art therapy, occupational therapy, and assistive technology among others, depending on individual needs. The coordination of services is an essential task.

### Resources:

- NADD – an Association for Persons with developmental and intellectual disabilities and mental health needs [www.thenadd.org](http://www.thenadd.org) - Information on Dual Diagnosis
- Digest on Dual Diagnosis – Intellectual Disability + Mental Illness [www.geisinger.org/services/comm\\_health/hcqu/Digest\\_on\\_Dual\\_Diagnosis.pdf](http://www.geisinger.org/services/comm_health/hcqu/Digest_on_Dual_Diagnosis.pdf)



## Heather Bowman's Dual Diagnosis

Heather Bowman was in a near drowning accident when she was 22 months old. She miraculously survived, though the odds were stacked heavily against her. She has significant disabilities, but her recovery far surpassed the expectations of the medical personnel who attended her after her accident.



Heather was a very sweet and compliant child, but when puberty hit, things began changing. She started having seizures (some of them grand mal) and she also began to start having firm opinions about how things should be said and done. Her behavior became more difficult to manage and she started having violent outbursts. It did not help that her first experience in a Junior High School was miserable. The special education class she attended was not used to serving children with disabilities as significant as hers, and the teacher was not very accommodating or cooperative.

We hoped that changing to a different junior high school would help her recover her former happiness, and while her new teacher was a good one and very helpful, Heather was not the same. When she began attending High School, I learned at a State Family Council parent meeting (the forerunner to the Family to Family Network) that many people with disabilities also have mental health issues, such as depression, obsessive compulsive disorder, etc. This was explained as a "dual diagnosis." I wondered if this might be the issue with Heather!

I took Heather to her doctor and after evaluating her, we decided to try some anti-depressant medication. It took tweaking, but after a number of months, Heather seemed happier and less prone to outbursts and violence. We saw more of the sweet and happy Heather and less of the out-of-control, miserable Heather.

We have continued to tweak her medications from time to time. Heather is now 30 years old, and we are grateful that these medications are available to help her feel better and keep her moods more stable!

## Ruling out Medical Concerns

It is very important for parents to be aware that other medical concerns may also be part of what we need to understand when trying to meet the needs of people with Dual Diagnosis.

There are a large number of other medical conditions which have significant psychiatric overlay in the general population. Robert Taylor, MD refers to this as "Psychological Masquerading". (Taylor, 2000) The list of such conditions is extremely long, including headaches, hypothyroidism, menstrual problems, dental problems, and gastro-intestinal disturbances such as ulcers, kidney dysfunctions, etc.

According to Dr. Ruth Ryan, the relationship between medical concerns and mental illness takes different directions, depending on the medical diagnosis. Medical illness can:

- Cause the actual symptoms which meet full criteria for a psychiatric disorder
- Cause a feeling state or symptoms which influence behavior
- Confer treatment resistance

People with developmental disabilities are more likely to have such medical problems. Data collected in both Los Angeles and Colorado indicated that more than 70% of the people referred for dual diagnosis evaluation are found to have one or more medical problems which contribute to their mental health

problems. Also, many of the genetic syndromes discussed above include specific medical conditions. For example, people with Down syndrome are more likely to have hearing impairments, vision problems, congenital heart defects, seizures, respiratory problems, and thyroid dysfunction.

We must also remember medication side effects, which can also present as behavioral symptoms. Since people with developmental disabilities are more likely to utilize medications, they are at greater risks for side effects and potential behaviors caused by side effects.

In summary, medical health impacts on mental health and people with developmental disabilities have more medical problems.

It is helpful to try to look beyond the Behavior and rule out medical issues when a new behavior or a change in behavior is noticed.

**Sometimes we must look at things differently. We may think we immediately know the reason why something is the way it is without even considering alternatives.**

For example, if a person is hitting, biting, spitting, pulling our hair, engaging in self injurious behavior, or being "non-compliant" we may immediately label it as a "behavior." We may make such comments as "she is just doing that for attention", "he's just lazy", "she just likes to cause trouble" or "he's always been like that." However, there may be an underlying condition causing or making the behavior we are seeing worse.

A study conducted by Neurologist Ruth Ryan emphasizes the real possibility of a medical condition appearing to be a behavioral health problem.



In the abstract of the study it is reported that "a total of 1135 people with mental retardation referred for mental health assessment were medically evaluated according to a two-step protocol which included a screening evaluation of all persons and expanded testing, depending on clinical status. The workup was considered complete when the person was either improving clinically or had a specific terminal diagnosis and was as comfortable as possible. Medical co-occurrence was about double that of people referred for mental health assessment who do not have mental retardation (words used in the study). Common conditions presented in unusual ways, and less frequent conditions presented more often... Comprehensive medical assessment discloses increased medical co-morbidity in persons with mental retardation referred for psychiatric evaluation. Comprehensive treatment based on the assessment findings appears to be associated with better clinical outcomes..."

It is now believed that about 75% of behavior problems in those with an intellectual/developmental disability have a connection to some type of physical illness.

## Rule Out Medical Problems First

It is so important that anytime we see behavioral issues we have the person thoroughly examined by a physician to rule out any underlying medical condition that may be the cause or a contributing factor to the behavior. Sometimes this may include having to get a second opinion. Following are some questions you may want to ask to help identify or rule out medical problems.

### Dental Problems:

- Sudden Pain
  - Pain becoming severe over time
  - Pain when biting/chewing
- How do you know if someone you support has a dental problem? Are there changes in eating habits? Irritability? Self-injury in the facial area?

### Ear Problems:

- Pain
  - Fever
  - Fluid from ear
  - Unresponsive to quiet sounds
  - Dizziness
- This may be challenging to detect in a person who has difficulty verbally telling you that his/her ear hurts. What are some ways you think this might be demonstrated? We may see a person who is hitting himself in the ear/head, who is unusually irritable or appears to be "non-compliant".

### Vision Problems:

- Changes in:
  - ADL's (activities of daily living)
  - Mobility
  - Eating/Drinking
  - Reading/Writing
- What changes do you think you will see? ... may include changes or refusal to participate in preferred activities, losing possessions, may turn to produce anxiety, and mismatching clothing. What could be misinterpreted about this person if we did not know the underlying cause for his/her actions?

### Sleep Issues:

- How much do you need?
  - Adolescents – 8.5 – 9.5 hours
  - Adults – 7 – 9 hours
- Imagine what a person would be like if loss of sleep occurred for longer than one night but there was no ability to communicate that verbally. Maybe no accommodations would be made and expectations would remain the same. Or, perhaps, demands are increased because people assumed non-compliance or laziness. How do you think you might respond?

### Headaches:

- More than 150 headache categories
  - Migraines
  - Acute onset
  - Trauma
  - Tension
- Headaches can be aggravating in and of themselves. Is this person engaging in self-injurious behavior involving his/her head? Trauma can involve any blow to the head. Tension headaches are caused by emotional stress.

## Gastrointestinal Issues:

- Constipation
- GERD – Gastroesophageal Reflux Disease
- IBS – Irritable Bowel Syndrome
- Hemorrhoids

Most people do not consume enough fluids which can predispose a person to constipation. In addition, many of the people with Dual Diagnosis are on a multitude of medications. Most medications can have some effect on the gastro-intestinal system, particularly psychiatric medications. Keeping accurate data on bowel movements can be extremely helpful.

## Seizures:

- One in 100 will experience a seizure
- Abnormal electrical stimuli
- Confusion/agitation
- Staring
- Uncontrollable movements
- Loss of consciousness

Seizures can have major impact on behavior. Seizures damage/ kill brain cells. Depending on the region of the brain that is affected we may see varying symptoms. If it affects emotional centers, we may see agitation, aggression, paranoia, delusional thinking, depressed mood or confusion. We may also see memory loss, incontinence, inability to reason, disheveled appearance, fatigue, loss of motivation. Might your son or daughter have a seizure disorder? Does the he/she have periods of staring off into space appearing to ignore you? Does he/she become angry out of nowhere? Has there been a personality change without any other known cause?

## Urinary Tract Infections

- Pain
- Pressure
- Burning
- Delirium

If someone did not communicate by traditional means how do you think that person might communicate to us these symptoms? Perhaps, by grabbing their genitals or pressing their genitals into objects? How might this be misinterpreted? We may conclude that the person is engaging in sexually inappropriate behavior or that he/she is in a hypersexual state. Perhaps the person becomes very aggressive or volatile. The person may become delirious. Delirium usually begins suddenly and progresses quickly. Hallmarks can include inability to pay attention, confusion, changes in awareness, sleep, personality and mood. Delirium can have a multitude of causes including urinary tract infections, dehydration, retention of urine or feces, sensory deprivation, sleep deprivation or stress.

## Medication Toxicity/Polypharmacy:

- Cardiac medications
- Seizure medications
- Psychiatric medications

Many of the people with Dual Diagnosis are on multiple medications. It is vital that all physicians and pharmacists treating a person know ALL medications the person is taking! The more medications a person takes the higher the risk of an interaction. How many medications does your son or daughter take in a day?

## Arthritis:

- Joint swelling
- Fatigue
- Morning stiffness
- Weight loss

How might we see these symptoms communicated in someone with an intellectual/ developmental disability? Could this be the person we see refusing to go to work most mornings? Or, the person who once she is at work refuses to do her job, is irritable or even combative until lunch time? Could we as supporters jump to the conclusion that this person is just being non-compliant or lazy? Arthritis can be very debilitating for some people. It can cause social isolation in some people, particularly, if that person is having a flare. Possibly this person is having pain that prohibits him/her from engaging in activities or with other people.

## Heart Disease:

- Shortness of breath
- Palpitations
- Weakness/dizziness
- Discomfort/pressure/heaviness in chest

Imagine having any of the symptoms listed and not understanding what is going on with your body. Any of these symptoms could produce anxiety, frustration or anger. Many of the different types of heart diseases come with warning signs. These warning signs many times are accompanied by pain. Symptoms can manifest in a number of behavioral ways for the person who is nonverbal or has an intellectual/developmental disability, not the least of which is anxiety.

## Respiratory Problems:

- Upper Respiratory –
  - Congestion
  - Facial pain/pressure
  - Sore throat
  - Irritability
  - Cough
- Lower Respiratory
  - Cough
  - Fever
  - Difficulty breathing
  - Chest pain

Think about how you feel when you have any type of respiratory infection. If someone were to observe your behaviors when you are acutely ill what might they say? Could they say you are being non-compliant when you don't complete your work? Could they say you are being aggressive when you snap at your co-worker? If a person is hitting himself in the face, instead of being labeled as having self-injurious behavior, could it be that he has a sinus infection and the pain and pressure are overwhelming?

## Pain:

Pain is such a significant consideration. It is vital that we don't just dismiss the possibility. Every medical possibility may be connected in some way with pain and could be linked to a behavioral outcome if it is not addressed.

Sometimes a team approach is needed in order to discover what might be going on with a person we are finding challenging to support. It is so important that we do not exclude the person we support on this journey.

All behavior is a means of communication. For example, if you see me squint what might that communicate to you? It could communicate that possibly my glasses are not strong enough; it could communicate the sun is in my eyes or it may communicate that I have something in my eye. The same behavior but may have several possible meanings. Sometimes we must look at the "puzzle" from multiple angles with multiple sets of eyes to see the complete picture. We need to look at the person's environment. Have there been changes in the physical environment? Are there changes in caregivers or roommates? Could there be sensory sensitivity? For example, does the person become agitated with excess noise?

## Keys to Support:

Are there other medical needs that may need to be discovered and/or addressed? Remember, the main points to remember as you work to understand what is happening are:

- **Listen**
- **Observe**
- **Describe**

Many times our sons or daughters will keep presenting the answers we are looking for. It may help to slow down and listen. It is important that we attempt to keep in the back of our minds that 75% of all behavioral problems likely have a link to a medical problem.



When speaking with your medical professional, it is more effective to describe exactly what you saw the person doing rather than to put your own label on it. Your label may not convey with exactness the details that will give a more complete understanding of the person's symptoms. For example instead of saying, "She was really hyperactive this morning" it may be more helpful to say, "She ran around the room nonstop for 30 minutes and I could not get her to sit down and eat. She was waving her arms and yelling and her face was flushed." You may wish to take notes about what you want to share so you remember to cover all the important concerns.

### *Resources:*

Digest on Dual Diagnosis – Intellectual Disability + Mental Illness

[www.geisinger.org/services/comm\\_health/hcqu/Digest\\_on\\_Dual\\_Diagnosis.pdf](http://www.geisinger.org/services/comm_health/hcqu/Digest_on_Dual_Diagnosis.pdf)

## Families

Those who care for children, youth and adults with developmental disabilities and dual diagnosis also have needs that are often ignored. They suffer significant financial burdens and may have to move to different communities in order to find services for their loved one. They can feel isolated and marginalized from family and community and may have their own physical and mental health problems related to the stresses and constant care. They may feel excluded and blamed by professional providers and find their views and opinions are ignored. Dealing with multiple agencies and service providers, the complications of obtaining funding, and accessing uncoordinated services can leave families, significant others and caregivers feeling frustrated and drained. Respite care and access to their own support services is inconsistently available.

Jo Anne Nugent, Ed D, author of A Handbook on Dual Diagnosis says it well:

*In the past, there has been an unfortunate tendency to assume that the most important element of treatment is the expertise of the medical professional, such as the psychiatrist. In fact, in many situations, support people felt paralyzed until they could access this clinical expertise. Certainly, the clinical professional plays a key role in diagnosis and treatment of a person with a dual diagnosis.*

*However, people who support the individual on a day to day basis have just as crucial a role to play. Some of the key functions they fulfill are:*

- *Listening sensitively to all types of communication, verbal and non-verbal*
- *Teaching skills that enhance the person's quality of life*
- *Observing changes in physical health, mood, behaviors, etc.*
- *Providing habilitative environments*
- *Ensuring that proper care is accessed with respect to medical needs*
- *Monitoring treatments such as medications and behavioral programs*
- *Helping people to develop and maintain social supports*
- *Participating in planning*
- *Contributing accurate and thorough information to the treatment team*

### **Families – some interesting data to consider:**

- US data shows that 80 – 85% of children and adults with developmental disabilities will live with their families until their parents' health declines or they die.
- 77% of adults with developmental disabilities are presently living with parents who are 60 or over.<sup>36</sup>
- In southeastern Ontario, 94% of children with developmental disabilities who receive services live with their parents; 45% of those 18 – 44 years of age and 12% for those over 45 live with their parents.<sup>37</sup>
- US figures show that 60% of children and adults with developmental disabilities live with their families, 13% in their own home and 15% with a spouse.<sup>38</sup> • In England and Wales, ordinary community placements account for no more than 10% of people with developmental disabilities who live outside the families with the remainder in some form of institutionalized or group setting.<sup>39</sup>
- In Australia, 7.8% live in formal residential settings with the vast majority of people with developmental disabilities living with their families or caregivers.<sup>40</sup>
- Families are isolated. UK data reports that less than one in three family caregivers of children with a developmental disability and a mental health problem turn to other family members or friends for help or advice.<sup>41</sup>
- There is an increasing trend in the proportion of individuals in the US with intellectual disabilities and developmental disabilities living with family members. In 1992, 6.3% of Medicaid recipients with developmental disabilities were living at home. In 1999, 22% were living at home. In 2006, 38.8% were living in a home with family members (most often parents).<sup>42</sup>
- Caregivers (mostly mothers) spend 50 – 60 hours per week on caring for their disabled child/adult.<sup>43</sup>
- The prevalence of challenging behaviors among children and adults with developmental disabilities leads to increased stress in family caregivers. It also places the child or adult at greater risk of abuse, neglect and deprivation.<sup>44</sup>

This data shows that families are the main support for many people with an intellectual or developmental disability. This also shows that more needs be done to support the individual with an intellectual or developmental disability and the families, friends and caregivers that support that individual throughout their life.



For more information on the previous statistics, see the following references.

36 Roebuck, R. (2008). Literature review on children and youth with developmental disabilities within a population health framework. Surrey Place Centre. 37 *ibid* 38 Bradock, D. Emerson, E. Felce, D. Stancliffe, R. J. (2001). Living circumstances of children and adults with mental retardation or developmental disabilities in the US, Canada, England and Wales and Australia. *Mental Retardation and Developmental Disabilities Research Reviews*. Vol 7, p. 115 – 121. 39 *ibid* 40 *ibid* 41 Roebuck, R. (2008). Literature review on children and youth with developmental disabilities within a population health framework. Surrey Place Centre. 42 Lakin, K. Charlie, Prouty, R., & Coucouvanis, K. (2007). HCBS recipients are increasingly likely to live with parents or other relatives. *Intellectual and Developmental Disabilities*. Vol 45, pg. 359-361. 43 Roebuck, R. (2008). Literature review on children and youth with developmental disabilities within a population health framework. Surrey Place Centre. 44 Lowe, K. Allen, D. Jones, E. Brophy, S. Moore, K. & James, W. (2007). Challenging behaviours: prevalence and topographies. *Journal of Intellectual Disability Research*, Vol 51(8), pg. 625-636.

## Some things to consider are the following:

Families, friends and caregivers must be included in all activities related to planning, designing and implementing policies and programs for their loved ones.

Families, friends, and caregivers themselves need support and help. This involves access to their own physical and mental health care through education, support groups and respite care. It is important that these services are aligned with what families need and are flexible in their delivery. They also need a choice of meaningful day supports/programs for their loved ones that enhance their lives.



Families, friends, and caregivers need to know that services for people with dual diagnosis are available and accessible close to home. It is unacceptable that families have had to relocate to find services or that their loved ones are sent away because necessary care does not exist in their own community. Families need better guarantees that services for people with a dual diagnosis are widely available, consistent and more accessible.

## A Family-Driven Systems of Care Approach

The children’s mental health system in Utah subscribes to a Systems of Care Approach which should also apply to the treatment of children and youth with Dual Diagnosis. The Systems of Care (SOC) approach must be family-driven with the needs of the child and family driving the types and mix of services provided. “Family-driven” means that families have a primary decision-making role in the care of their children as well as in the policies and procedures governing care for all children in their community, state, tribe, territory and nation. This includes participation in:

- Choosing supports, services and providers to the extent possible
- Setting goals
- Designing and implementing programs
- Monitoring outcomes
- Determining the effectiveness of all efforts to promote the mental and behavioral health of children and youth

Family and youth participation is critical at all levels of the System of Care planning process and extended the same rights, privileges and duties as other members of planning and advisory committees.

## Standards for Family Involvement

Although these standards were developed for the mental health arena, they should also hold true when related to disabilities.

- Standard 1: Families define themselves and their own culture. Families have their own individual strengths and know best what would work for them.
- Standard 2: Families require culturally competent services and supports that reflect their race, ethnicity, gender orientation, language, socio-economic background and family structure.
- Standard 3: Families have their basic needs met. All persons deserve to have their needs met.
- Standard 4: Families have access to information and training. This is vital in the growth of families and their ability to be empowered to take care of their own.
- Standard 5: Family-identified priorities and concerns drive policy and practice. Families take an active role in advocating for family-friendly policies.
- Standard 6: Families share the power to make decisions and responsibility for outcomes. When families partner with professionals and service providers as equal partners, they have a vested interest in policies, services, responsibilities and outcomes.
- Standard 7: Families and their system partners know individual strengths, limitations and fears. Family-Professional partnerships do not happen overnight. Both sides are responsible for teaching and receiving information and forming strong partnerships.
- Standard 8: Families have their own independent organization to speak with a collective voice for system change.

The Utah Family Coalition is a group of family organizations (Allies with Families, NAMI-Utah, and New Frontiers for Families) dedicated to helping children with mental health needs and their families achieve a better quality of life

- Standard 9: Families and their organizations get both respect and protection for their system partners. We are all in this together. By building strong parent professional partnerships, we will have a bright future.

## Questions for Parents to Ask

There are many questions to think about as you work to support your child with a dual diagnosis. Some of them may include:

### Questions for my insurance:

- Contact your insurance regarding Mental Health coverage
- Find out if a referral is needed for coverage
- Find out what the co-pay is
  - In the plan
  - Out of network

### Searching for a Mental Health provider:

- Ask your doctor or other professional you trust for recommendations
- Keep a list of providers approved on your insurance with you
- Ask friends who children have seen a Mental Health provider for recommendations

### **Questions to ask when deciding on a Mental Health provider:**

#### Background:

- What is your degree or certification?
- What kind of training and experience do you have?
- What is your experience/expertise in treating the kind of problem my child is experiencing?
- Are there other areas you specialize in?
- What is your treatment philosophy?
- What are your core values as a practitioner?

#### Treatment:

- What is your approach to treatment?
- What kind of techniques do you incorporate into sessions?
- Do you give children "homework" to complete in between sessions?
- Do you usually work with the child alone or do you conduct family sessions as well?
- How much parent involvement is needed?
- How often do you check in with parents about the course of treatment?
- How do I get help after hours if there is a crisis?
- What is your policy regarding confidentiality?
- What if my child tells you something that sounds risky or dangerous or unbelievable?
- How long does a typical session last?
- How many sessions might be expected overall? Or what do you see was the course of treatment?

#### Psychotropic medications and Psychological testing

- What is your opinion on the use of medication in treatment?
- If you did recommend medication for my child, who would prescribe/monitor this?
- Do you administer psychological testing? If you do not, do you know people who you would recommend and refer me to?

#### Communication with other Professionals

- Will you be in contact with my child's school?
- How do you communicate with the school? Do you attend school meeting, if needed?
- How do you collaborate with other professionals my child sees?
- What is your policy about sharing information?

### **Questions to ask yourself after meeting with a Mental Health Professional**

- Do I feel a sense of rapport (comfort level) with this person?
- Do I feel safe and at ease?
- Do I think this person will be a good match with my child? Does this person seem to understand my child's specific needs and conditions?
- Do I understand how and when I will be able to communicate with this provider? How I would contact him/her in a crisis?
- Do I understand what this person is recommending for my child? My family?
- Are there other questions I want to ask before making a decision?

## Helpful information to provide:

- Early childhood information and history
  - Complications in utero (before birth)
  - Complications at birth
- Developmental milestones
- Previous treatment history and diagnosis
- Disability specific information
- Reasons for your current concerns about mental health (Remember to describe. Don't label)
- Specific changes you have noticed
  - Behavior
  - Affect
  - Mood
  - How it is different to your child specifically
- When you first noticed the change
- How often it happens
- Remember: Describe, don't label!
- Intensity
- How long it lasts (minutes, days, etc)
- Patterns (bedtime, transitions, something new is introduced, etc)
- Family mental health history
- If you, your spouse, or children have used medication previously and what the result has been:
  - With similar genetics it may be a good place to start
  - Recognize that different medications within the same "class" work differently
- Any significant changes in your child or family's lives (puberty, moves, new baby, divorce)
- What you have tried to do to address the concern and the child's response or lack of response
- What response your child exhibited previously to similar "interventions"
- Current treatment or services already being provided for your child

## Questions to ask about medications:

- What are you prescribing this medication for?
- What are the risks of this medication?
- What am I likely to see happen once my child starts it?
- How long should it take before I see a difference?
- What are the possible side effects? What do I need to watch for?
- What if a dose is missed?
- What do I do if it causes problems or my child has a negative reaction to it?
- What follow up is needed?

As you can see, this is a lengthy list and may trigger other questions and thoughts on your part. Remember, that you know your child the best and what you see as changes and concerns are a crucial piece to helping professionals understand what your child's needs are throughout his or her life.

## Medical Home Model

One of the things that a number of families have found helpful is the Medical Home model. A medical home is not a house, office, or hospital, but rather an approach to providing comprehensive primary care. In a medical home a pediatric clinician works in partnership with the family/patient to assure that the medical and non-medical needs of the child/youth are met. Through this partnership, the clinician can help the family/patient access and coordinate specialty care (such as mental health providers), educational services, out-of-home care, family support, and other public and private community services that are important to the overall health of the child and family.

The American Academy of Pediatrics (AAP) describes the ideal Medical Home as one that provides "accessible, continuous, comprehensive, family centered, coordinated, compassionate, and culturally effective care." Recently the AAP has importantly recommended more mental health integration in primary care practices. Key components that have particular applicability to pediatric settings include (from [www.medicalhomeinfo.org](http://www.medicalhomeinfo.org))

- ✧ **Family-centered partnership:** Trusting, collaborative, working partnerships with families, respecting their diversity and recognizing that they are the constant in a child's life,
- ✧ **Community-based system:** Family-centered, coordinated collaborations designed to promote the healthy development and well-being of children and their families,  
See more at: <http://www.medicalhomeportal.org/medical-home>
- ✧ **Transitions:** Provision of high-quality, developmentally appropriate, health care services that continue uninterrupted as the individual moves along and within systems of services and from adolescence to adulthood, and
- ✧ **Value:** A high-performance health care system requires appropriate financing to support and sustain medical homes that promote system-wide quality care with optimal health outcomes, family satisfaction, and cost efficiency.

Often parents or caregivers are the ones who start a conversation about setting up this sort of collaborative approach with the primary care physician. A parent or caregiver is able to do this by asking for the specific support that is needed for their child. One example is when a parent or caregiver begins to notice some changes or signs of a mental health need and then works towards accessing existing care systems only to be told that there is a waiting list to receive services at the location. The parent or caregiver may feel that the only option is to wait on that list, but what if the medical home thought (paradigm) were talked about with the primary care physician? Medical professionals may have contacts within their system for accessing mental health professionals and might be willing to be the one to help you get set up. The questions a parent or caregiver asks are very important. There may be times that a primary care physician is not aware of a new concern until a parents or caregivers talk about observations and questions are asked.



# Medical Home Portal

Information about integrating the Medical Home concept into your family is available throughout the Medical Home Portal. See more at: <http://www.medicalhomeportal.org/medical-home>

## Parent Support

The more complicated and difficult the situation with a son or daughter with dual diagnosis, the more stress may be placed upon the family. It is important that families not feel isolated because they are so busy dealing with all the many needs of the child or because they feel there is no-one who understands. Sometimes it can just take so much effort to help others understand. Parents can plan ahead to take actions so that they receive the support they need. Here are a few suggestions.

Call the Utah Parent Center and receive parent to parent support from one of our trained parent consultants who can help you identify resources for support. Join our email list so you can be notified of events and activities that might be of interest to you. View our online Disability Resource Book for ideas of what is out there to help you.



Attend events in your community or statewide events such as the Family Links Conferences. You will meet other parents who are experiencing similar challenges. Just talking to another parent who has been there can be very helpful. Make the extra effort to keep in touch with some of the parents you connect with.

Join a parent support group. The UPC can refer you to groups based upon your child's diagnosis. Many communities in Utah have a Family to Family Network group that parents of children with all disabilities are welcome to attend. Even though our sons and daughters' needs may be somewhat different, parents still have a lot of needs in common. These groups often have activities, speakers, family picnics and the like. Some of them also connect with Facebook or other online groups. The groups are very responsive to what the parents in the community tell them is needed, so consider getting involved. Contact [www.utahfamilytofamilynetwork.org](http://www.utahfamilytofamilynetwork.org) to find your local group. If you would like to help start a group, please contact the Utah Parent Center for more information.

Find online support. If the only time you have to yourself is at night while your children are sleeping, you may like to participate in an online group. Utah Parent Center staff are aware of some of these groups and may be able to provide a referral. The UPC website also has links to some of the national organizations that support parents.

Let other people in your community know specific information about how they can be supportive. Talk with the leaders of your church about support they might provide. It helps them to know what your needs are.

Apply for services from the Division of Services for People with Disabilities (DSPD). If you are placed on a waiting list, it is important to keep your application updated and to keep your caseworker apprised of changes in your situation that might affect your position on the list. Some families receive one-time money for respite care each year, too. Visit [www.dspd.utah.gov](http://www.dspd.utah.gov) for more information.



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**Our Mission:** To help parents help their children, youth and young adults with disabilities to live included and productive lives as members of the community. We accomplish our mission by providing accurate information, empathetic peer support, valuable training, www/and effective advocacy based on the concept of parents helping parents.

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