Mental Health Guidebook for Families\textsuperscript{1} of People with Developmental Disabilities

For many years, mental health symptoms for children and adults with developmental disabilities were hard to recognize. We now know that children, teens, and adults with developmental disabilities actually have mental health conditions at least as often as others in the community. Mental health disorders, also called psychiatric illnesses, are medical problems that affect emotions, behaviors and the ability to think realistically (Icovino & Esralew 2008). Some common mental health disorders are anxiety, depression and psychosis. When a person has both a developmental disability and mental health disorder, it is often called “dual diagnosis”.

Doctors and therapists used to think that any behavior challenge in a person with developmental disability was due to the developmental disability. Now we know that this is not the case. Behavior changes can be signs of medical conditions, developmental conditions or mental health conditions. It can sometimes be very hard to tell which of those is causing the behavior change. One step you can take to understand if your family member has a mental health condition is to see a primary care doctor or mental health professional for a mental health assessment.

Mental health disorders can seriously affect the activities of people with developmental disabilities. Some symptoms of mental health problems include behavioral outbursts, including aggression, self-injury, property destruction, impulsive behaviors and/or elopement (Icovino &

\textsuperscript{1}By families, we mean in the broadest sense, all caring, loving people surrounding the individual with dual diagnosis.
Esraleyw 2008). Others with challenging behaviors may have increases in frequency or severity. Dual diagnosis can make it hard to have relationships and friendships. Dual diagnosis can make it hard to be successful in school, work or day programs. Dual diagnosis can even affect residential placement. Many families face the decision of placing a family member in out-of-home care because of dual diagnosis. Because of this, it is very important to recognize, diagnose and treat mental health conditions as early as possible for people with developmental disabilities.

No one understands exactly why people with developmental disabilities are at high risk of mental health problems. Some factors include stress and negative social conditions, like social rejection, stigmatization and lack of acceptance (NADD 2014). It may be harder for people with developmental disabilities to cope with these stressors. Spoken language difficulties and not enough social supports also make it hard to be resilient. In addition, some causes of developmental disabilities, such as some genetic syndromes, also put people at risk for mental health disorders. Most of all, it is important to remember that no one is to blame for these symptoms.

The following information may help you understand mental health conditions, how to get mental health care, how to assess mental health conditions, and some treatment options. This guidebook also has a stepwise checklist to help you talk with primary care and mental health professionals and advocate for your family member’s needs.
How to tell if someone has a mental health problem?
It is easy to recognize when someone has a fever. A fever is a symptom that something is physically wrong. There are also symptoms that could indicate mental health conditions in people with developmental disabilities. Ask yourself the following questions or look for these symptoms:

1. Has there been a strong demonstration of non-compliance with routine tasks?
2. Have there been big changes in appetite or sleeping as compared to usual?
3. Has there been mild aggression that has increased in intensity?
4. Have there been quick bursts of energy, like pacing back and forth?
5. Have there been changes in demeanor that could indicate anger, frustration, confusion, fear or general threat?
6. Have there been displays of violence to oneself or others, like hitting, biting, kicking, pulling hair, etc.?
7. Has there been any type of inappropriate behavior that appears to become more frequent and intense than usual?

Your observations are important. If you are concerned by your answers to the above questions, it may be important to have your family member evaluated. Mental health problems can be recognized and treated before your child is in a crisis situation. Caring families and professionals working together can make the difference.
How do I find out if my family member has a mental health condition?

Where Do I Start?
There are many “starting points” that you can choose in order to have symptoms evaluated. Where you start is often a matter of personal preference, insurance coverage, existing relationships you may have with a family doctor or other professionals, or the severity of symptoms. Occasionally, someone else (such as the school, police, or your family doctor) may refer for evaluation.

Here are some suggested starting points:

1. Primary Doctor. A number of physical conditions can mimic or lead to mental health problems. Schedule an appointment with your doctor and be prepared to talk openly and honestly about symptoms. Your doctor will examine your family member and may order some tests. This doctor is making sure that there aren’t any known physical reasons for experiencing mental health symptoms.

2. Neurologist. If no apparent physical causes are found by a primary doctor, a referral to a neurologist may be needed. A neurologist is a specialist who can check brain structure or brain functioning by using a variety of tests.

3. Psychiatrist. A psychiatrist is a medical doctor who will use a variety of psychological tests and techniques in order to evaluate
your child's mental health symptoms. A psychiatrist can prescribe medicine, if necessary.

4. Psychologist. A clinical psychologist is licensed to diagnose and treat mental health problems. He/she may use a variety of psychological tests and techniques to evaluate for mental health conditions and can use “talk therapy” to treat some mental health conditions. However, a psychologist cannot prescribe medication.
Preparing for your first visit to a mental health professional

Some families hesitate to seek help. They may be afraid about what will happen at the first visit to a professional, or about what the professional might say is the problem, especially with having already faced getting a developmental disability diagnosis. They may be afraid about what others may think or say, even other family members. If you are reading this information, you have already taken the first step in preparing to get help.

Evaluation
It may take several visits and a number of tests for the doctor or therapist to decide on a “working diagnosis”. An accurate diagnosis is needed to determine the best treatment options. However, diagnosing mental health problems is difficult especially with a co-occurring developmental disability. There are no blood tests or X-rays that will pinpoint a diagnosis as with many physical conditions. It may take time and patience before all symptoms and behaviors are evaluated and understood. In addition, diagnoses change over time and need re-evaluation.

Diagnosis
Some of the more common mental health diagnoses that you may hear are:

1. Anxiety Disorder. This is a disorder that causes persons to be afraid, worried or uneasy so that it becomes difficult for them to function. There is a higher prevalence of anxiety disorders in people with developmental disabilities.
2. Attention Deficit Hyperactivity Disorder (ADHD). This disorder is characterized by greater than normal periods of inattention, impulsivity and/or hyperactivity. These symptoms often cause significant problems in social situations, at home and at school or work. There is some overlap between ADHD and autism spectrum disorder (ASD) symptoms.

3. Bipolar Disorder. Also called manic-depression, bipolar disorder generally involves cycles of depression and elevated mood. Mood switches can occur rapidly or can be more gradual.

4. Depression. This disorder refers to a combination of emotional and physical symptoms that affect ability to sleep, eat, concentrate and enjoy life. Because of the tremendous social stress and rejection, people with developmental disabilities are more at risk for depression.

5. Obsessive-Compulsive Disorder (OCD). This is a disorder where the person becomes trapped in a pattern of repetitive thoughts and/or behaviors. Obsessive thoughts may include thoughts, words or pictures that keep coming into his or her head, without the ability to get rid of them. Compulsive behaviors may include repeated hand washing, counting, or rearranging objects. These may overlap with some characteristics of autism spectrum disorders (ASD).

6. Oppositional Defiant Disorder (ODD). This disorder is defined as a recurring pattern of negative, disobedient and hostile behavior that persists for a long period of time.
7. Post-Traumatic Stress Disorder. This disorder can develop in after people have personally experienced or witnessed a serious traumatic event. Because of the high rates of trauma and abuse of people with developmental disabilities, PTSD is common.

Treatment
Treatment options for mental health problems may include a combination of:

- Therapy
- Behavior Management
- Medications
- Hospitalization (rare)

Over the years, many treatments have been tried, some more effective than others for people with developmental disabilities. It is best to find treatments that have some evidence that they are effective, called “evidence-based” treatment or practices. Remember that many people with dual diagnosis respond well to the right treatments.

You and your doctor and/or therapist will work together to decide what type of treatment will work best for your family.

Psychotherapy
Psychotherapy can be done in individual, group or family settings. Psychotherapists may use a number of therapy theories or schools to assist in treating, such as behavioral, cognitive behavioral, dialectical behavioral, psychodynamic, family systems, nondirective, etc. Psychotherapy that is “talk therapy” is more likely to be used for people with mild to moderate intellectual disabilities. In groups,
therapy might include social skills, sexuality training, anger management or safety training to prevent abuse.

**Behavior Management**
Inappropriate behaviors can be addressed using functional behavioral analysis to understand which approaches would work to change the behavior. A behavior management plan can be created with the input of the individual with dual diagnosis.

**Medication**
The medications used today for the treatment of mental health problems can dramatically improve the quality of life. Just as a pair of glasses can help a person to see better, medication can help a person with mental health problems see the world more clearly. When medication is effective, the results can be significant.

However, medication is not the solution to all mental health problems, nor is it the answer for everyone. It can be a difficult process to know exactly which medication (and dosage) will work best for any individual. Often, trial-and-error is the rule, which requires multiple medication trials until the right combination of drugs is found.

For those that it does help, medication can make the mental health symptoms less severe, but it does not “cure” the problem. Medication should only be used under close medical supervision, and only as a part of a comprehensive treatment program that includes a careful diagnostic evaluation, education and therapy.

There are many types of medications used to treat mental health problems. There are too many to list them here. But, like any medication, for any condition, you will want to become very familiar
with the risks, benefits and side effects. Work with your doctor, and observe and monitor closely whenever a medication is started or stopped, or if the dosage is adjusted. Be sure that you understand how and why taking the medication is needed.

*Crisis Intervention Services/Hospitalization*

It is always best to treat mental health problems in the "least restrictive" setting. This means that your family member will most often receive treatment in the most natural environment available, such as in the office of a doctor, therapist, a Service Coordination Unit, or even at home. However, there are some situations when your family member may need the most intensive treatment available. Generally speaking, a person would only need crisis intervention services or be admitted to a psychiatric hospital or the psychiatric unit of a full service hospital if:

- He/she is a clear danger to him/herself (threatening or trying to commit suicide).
- He/she is a danger to others (threatening or trying to hurt others).

If you observe the above behaviors, call a doctor or therapist immediately. If you don’t have a doctor or therapist or if you can’t reach one, go to the nearest emergency room:

- **call an ambulance [911],**
- or
- **call LA County Crisis Emergency Services [phone: 800 854-7771 or TTY for Hearing Impaired 562 651 2549]**

The decision to hospitalize should not be taken lightly, but it may be the best option at a given time in order to keep safe.