

Wisconsin Public Psychiatry Network Teleconference (WPPNT)

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Mental Health Among Individuals with Intellectual/Developmental Disabilities:

Practical Guidance for Practice

Stefanie Primm

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Wisconsin Public Psychiatry Network Teleconference

About Stefanie Primm

- Stefanie graduated from UW-Madison in 2008 with a Masters of Social Work. She is a CAPSW (Certified Advanced Practice Social Worker).
- Stefanie is currently the Executive Director of Living Our Visions Inclusively (LOV Inc.) and a Field Faculty Associate at UW-Madison's Sandra Rosenbaum School of Social Work.
- Stefanie helped found LOV Inc. in 2008 and has been with the organization ever since, working to unite adults with disabilities and their families to build their best lives.
- Stefanie's older brother Jeremy is the kindest person in the world, and lives with autism, depression, anxiety and obsessive compulsive disorder.

About LOV Inc.

- Living Our Visions Inclusively was founded in 2008 by a small group of families who had adult children with intellectual/developmental disabilities.
- We envision a future where our loved ones with disabilities are seen as essential members of society, and lead enriching lives filled with relationships, productive activity and joy.
- We currently support families in 13 Wisconsin counties, including members of two tribes, Spanish-speaking families and rural families, though our base group is in Dane County.
- We engaged nearly 200 families in 2019 and continue to grow each year.

Outline for presentation

- Definitions and terms
- Statistics
- Programs and services
- Considerations for practice with dually diagnosed individuals
- Engaging natural supports in MH treatment/recovery
- Recommendations for future planning

Terms

Intellectual/Developmental Disabilities: IDD or I/DD

Physical Disability: PD (May co-occur with I/DD, but the presence of one does not indicate the presence of another)

Mental Health: MH

Mental Illness: MI

Functional limitations: bathing, meal prep, hygiene, communication, mobility

What is the definition of I/DD?

From the Federal Definition: “individuals who have a severe, chronic disability that meets all of the following conditions:

- A. It is attributable to:
 - a. Cerebral palsy or epilepsy, or
 - b. Any other condition, other than mental illness, found to be closely related to intellectual disability because this condition results in impairment of general intellectual functioning or adaptive behavior similar to that of persons with intellectual disability, and requires treatment or services similar to those required for these persons.
- B. It is manifested before the person reaches age 22.
- C. It is likely to continue indefinitely.
- D. It results in substantial functional limitations in three or more of the following areas of major life activity: self-care, understanding and use of language, learning, mobility, self-direction, or capacity for independent living.

What conditions are associated with I/DD?

May include:

- **Cerebral palsy:** a brain disorder that affects muscles and body movement
- **Epilepsy:** a disorder that disturbs nerve cell activity in the brain, causing seizures
- **Autism:** a disability that causes social, communication and behavioral challenges
- **Down Syndrome:** a condition where a person has an extra copy of chromosome 21
- **Fragile X:** a genetic condition that causes intellectual disability
- **Traumatic brain injury:** Brain dysfunction caused by an outside force, usually a violent blow to the head
- **Prader-Willi Syndrome:** Caused by deletion on chromosome 15, leads to intellectual disabilities, insatiable appetite and short stature
- **Intellectual Disability:** defined by significant limitations in intellectual functioning and adaptive behavior
- **Fetal Alcohol Spectrum Disorder:** Symptoms can include behavioral and learning challenges

What about???

Learning Disabilities

Attention Deficit Hyperactivity Disorder

Muscular Dystrophy

Cystic fibrosis

Spina bifida

Metabolic disorders

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Terms to avoid when discussing I/DD

- Mental disability: unspecific and vague, could be confused with mental illness
- Mentally challenged: unspecific and vague, also could be confused with mental illness
- Slow, not quite right: overgeneralization and pejorative
- Mind of a 3-year old: Insulting to anyone over age three, everyone's mind is the same age as their body. Can be more specific, i.e. "lacks complex problem solving skills"
- Imbecile, idiot, moron: Outdated terms to categorize people, now pejorative
- Mental retardation: Outdated term that has become pejorative

Terms in early childhood

Developmental or cognitive delay

Missing milestones

25% delay

These are markers that might indicate the need to assess for I/DD, but they are not themselves a diagnosis, and could have multiple other causes, like trauma, environmental hazards, abuse/neglect

How prevalent is I/DD?

According to the CDC, in 2016 nearly 7% of children aged 3-17 had been diagnosed with a developmental disability. This statistic is based on data collected in the National Health Interview Survey. They look at a broad definition of developmental disability, and include developmental delay, so this could include children who never meet the Federal definition for I/DD.

1 out of every 100 Wisconsin children utilize services based on a disability diagnosis. Many more may qualify but choose not to enroll.

3.6 out of every 500 Wisconsin adults utilize services based on the Federal definition of I/DD. More may qualify but choose not to enroll

Prevalence of dual diagnosis of I/DD and MI

Based on a 2010 study, 33% of individuals with I/DD also have a MH diagnosis, much higher than the general population. This is described in the study as a conservative estimate.

Other sources suggest the prevalence is as high as 40%.

Much more research is needed in this area to determine prevalence.

Prevalence of dual diagnosis of I/DD and MI

I have worked with and met hundreds of people with I/DD in my career, and can think of very few who displayed no symptoms of mental illness.

The most common, in my experience, is anxiety and depression, mirroring the general population.

More severe mental illnesses impact people with I/DD. I personally know people with I/DD and schizoaffective disorder, personality disorders and bipolar disorder.

People with I/DD tend to be more socially isolated than their peers, with fewer protective factors.

Challenges in treating individuals with I/DD and MI diagnosis

- Finding a therapist and psychiatrist with experience treating people with I/DD, and willing to accept MA insurance payment. This limits the ability to get a diagnosis as well as ongoing treatment.
- Determining if symptoms are caused by MI or I/DD diagnosis
 - Would treatment be the same regardless of cause of symptom?
- Difficulty following MH treatment plan due to I/DD limitations
 - Missing doses of medication, too much/too little sleep, substance use
- Symptoms may present differently in individuals with I/DD (example: suicidal ideation, anxiety)
- Challenges with communication can lead to not being able to describe MH symptoms in an easily recognizable way. Some individuals may describe it as physical pain, or may not have language to describe it.
- What does recovery look like? Intellectual/Developmental Disabilities are lifelong and the need for support is also lifelong, though MI needs may vary during their lifetime.
- Behavior may be the only form of communication available to a person with I/DD and the same action might be related to physical or emotional discomfort.

Long-Term Support for People with I/DD

Children's Long Term Support Program

Family Care

IRIS

Children's Long Term Support Program (CLTS)

Eligibility: Age 0-22, eligible for Medicaid, diagnosed with intellectual disability, experiencing substantial functional limitations and needs active treatment.

More information: <https://www.dhs.wisconsin.gov/clts/cltsloc.pdf>

Enrollment Process: Contact County intake and arrange for a functional screen interview. <https://www.dhs.wisconsin.gov/clts/contact.htm>

Waitlist: Since 2017, Wisconsin is working toward making this program an entitlement. There are over 11k children enrolled, and ~1000 waiting (8/30/20)

Services Funded: Dependent on needs of child, examples include home modifications (ramp, fencing, bathroom), augmentative communication device, respite caregivers, specialized camps or day programs. Most families are required to cost-share with their services in CLTS, based on their income.

Also serves: Children with physical disabilities

Katie Beckett Program

Disability does not discriminate based on socioeconomic status. To qualify for Medicaid however you typically need to be making less than a certain % of the Federal Poverty Level.

Children with I/DD often require expensive support and treatments beyond the normal cost of childcare. The dollar amount widely varies, but could be an additional \$3,000 to \$30,000 (or more) per year in expenses that could be covered by CLTS.

Children may be able to qualify for Medicaid through Katie Beckett, even if their family's income and assets are too high to be eligible for traditional Medicaid.

Family Care

Eligibility: 18+ years old, functionally eligible based on support needs, and financially eligible, like through Medicaid eligibility.

Enrollment Process: Contact your County's Aging and Disability Resource Center (or Disability Resource Center in Milwaukee County) to request a functional screen.

Waitlist: Most parts of the state have no waitlist, and it is expected to be eliminated statewide by 2021.

Services Funded: Dependent on needs of individual, but can include caregivers at home, job coach at work, transportation for non-drivers, technology to increase safety, augmentative communication devices. A cost share is often required.

Also serves: Frail elders and individuals with physical disabilities.

IRIS (Include, Respect, I Self-Direct)

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Also serves: Individuals with physical disabilities and frail elders.

Comparing IRIS and Family Care

IRIS

IRIS is supported by IRIS Consulting Agencies (ICAs) and paid for through Fiscal Employer Agencies (FEAs). Participants decide where to spend their IRIS funds with support from an IRIS Consultant, who authorizes the FEA to pay for services based on the plan.

IRIS Budgets are determined by the functional screen performed annually.

There are multiple ICAs and FEAs to choose from in all parts of the state.

8,164 participants enrolled on 7/1/2020.

Family Care

Family Care is run through Managed Care Organizations (MCOs) and functions similar to an HMO, with in-network providers and limited choice about who will provide service or how much support you receive.

There are multiple options for MCOs in most parts of the state.

Each individual is assigned a social worker and a nurse by the MCO, and it is their job to direct care planning for the individual.

23,992 participants enrolled on 7/1/2020.

Participants can switch between IRIS and Family Care at any time by contacting the ADRC.

Dual enrollment in I/DD and MH services

Children and adults with a dual diagnosis of I/DD and MI can enroll in both long-term support programs (CLTS, IRIS, or Family Care) and mental health programs like Comprehensive Community Services.

Some tension exists between the goals of the support programs. Long-term care is designed to care for individuals with lifelong conditions, and while support needs may vary over time, the individual is not expected to be cured or recover. Mental health programs have a recovery focus, and want to see progress in order to continue treatment.

Case Examples

My brother has always had a low food drive. He also has limited skills with food preparation. Not eating affects his physical health (low sodium levels have caused seizures) and can trigger anxiety and depression or be a symptom of depression. He's a very picky eater, and has a limited set of foods he enjoys that also offer nutritional value. When he gets tired of eating a type of food, he struggles more with getting enough nutritional food. His CCS team do not feel that better eating habits are related to his recovery since he's unable to change some of his behaviors related to food. Through IRIS, he can get help to go to the grocery store and prepare food, but the supporters are lower skilled workers and may not help him navigate the complexity of his food issues.

Case Examples

Nick and Elisa are a couple who met in an autism support group. Both experience a great deal of anxiety and agoraphobia, along with significant hoarding behavior. They also routinely engage in power struggles with their families around hygiene and their home's cleanliness. The relationship between the two is rocky at times and they have had major arguments leading to Nick physically assaulting Elisa. Elisa then goes to stay with her mom for a few days or up to a few weeks before returning to Nick and the relationship. Both Nick and Elisa's family's are actively involved in their life, and they have support through IRIS and CCS, but their life looks almost identical to how it looked two, three or even five years ago. Both want a better life for themselves, but are difficult to engage in treatment.

Natural Supports

As I mentioned earlier, individuals with I/DD tend to be more socially isolated and have fewer protective factors for MH.

Many individuals with I/DD may only have strong relationships with family members, and some connections with paid caregivers and coworkers.

Family members of individuals with I/DD provide a lot of unpaid support well into adulthood for their loved one. Being a major part of a MH treatment plan may strain the caregiver or relationship further (example: being on a list of people to call when feeling suicidal).

Some individuals with I/DD do not want their family members (especially parents) to be as deeply involved when they are adults.

Natural Supports

People with I/DD have a more difficult time making friends due to social skill limitations and difficulty finding peers they mesh with.

People with I/DD miss out on a lot of informal interaction at school due to being segregated in Special Ed rooms, or having an adult aid with them throughout the school day.

They also don't follow their peers to college, most of the time, and get left behind after high school.

As adults, very few supports focus on developing bonds among people with I/DD, or between them and their neighbors and peers.

Tools to build natural supports

Seek out recreational opportunities designed for people with I/DD: Special Olympics, local Arc chapter, other family-based organizations like LOV Inc.

Seek out recreational opportunities based on the person's interests: bowling leagues, faith communities, computer clubs, craft groups, book clubs, etc.

Over the past 11 years, LOV Inc. has found that community groups are incredibly welcoming of anyone who shares their interests, regardless of ability.

We have also found that having a person whose job it is to help you build those connections and then fade their support is critical to the long-term success of these relationships.

Peer Support Networks with a professional facilitator help individuals with I/DD develop social skills and relationships to one another that can extend beyond the group meetings.

When natural supports contradict recovery plan

It's key to balance need for support and connection with other parts of the recovery plan. For example:

- Participating in a regular social event, even if it impacts your sleep that night.
- Making friends even if they sometimes let you down and lead you to feel disappointed.
- Joining an art club, even if you make dark and depressing art that disturbs some people.
- Meeting someone to have a romantic relationship with, even if it might fail in the future.

Future planning for caregivers

76% of adults with I/DD live with a family caregiver and 25% of those caregivers are 60+ years old. Average age of the care recipient is 38 years old. (Family Caregiver Alliance)

Future planning is more than financial (not just writing a will and setting up a trust)

- Who can fill my shoes as a caregiver?
- Who will remember their birthday?
- Who will take them to the doctor if they are sick?
- Who can they call in a crisis?

These are topics that require a major investment of time and preparation, which can be hard for families to tackle in the midst of life.

The Arc has a free toolkit on their website: <https://thearc.org/our-initiatives/future-planning/>

LOV Inc. offers workshops where families can get support to complete a Fearless Future Plan.

Questions?

Follow up questions?
Feel free to reach out!

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<https://lovinc.org>

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