Welcome to the Pennsylvania Dual Diagnosis Direct Support Curriculum training on “Naming It”: Mental Health Challenges and People with an Intellectual Disability.
The Commonwealth of Pennsylvania’s Office of Mental Health and Substance Abuse Services (OMHSAS) and the Office of Developmental Programs (ODP) have undertaken a joint initiative to address the needs of people who have an intellectual disability as well as mental health challenges. People who have both of these challenges are commonly referred to as those who have Dual Diagnosis. For the purpose of this training, Dual Diagnosis is not referring to co-occurring mental health challenges and substance abuse or dependence, although people can have substance abuse or dependence issues as well as a Dual Diagnosis of an intellectual disability and mental challenge. The curriculum was designed for Direct Supporters, Supports Coordinators and others who work in either the intellectual disability field or the mental health field.

The ultimate goal of this training curriculum is to provide information that can aid in the understanding of the struggles and the triumphs of those you support or will support. This curriculum was designed to demonstrate the complexity of Dual Diagnosis and the factors that need to be considered to best support those with whom you come into contact. The Dual Diagnosis Direct Support Curriculum was also designed to demonstrate that all people in this world, regardless of their challenges, are much more alike than they are different.
The information presented to you today is to increase your awareness. It is not intended to replace medical advice.

If you believe you or someone you support have these conditions or concerns, please seek the advice of a physician.
Upon completion of this presentation the learner will:

• Have a better understanding of how “Naming It” is important to recovery

• Recognize the need for increased mental health supports for those with an intellectual disability

• Understand the direct supporter’s role in advocacy and support for those with dual diagnosis
Dual diagnosis means that a person has both an intellectual disability and mental health challenge. In Pennsylvania, the criteria for obtaining services means having an IQ below 70 and in addition, the onset must occur before the person’s 22nd birthday.

"Intellectual disability" also means having significant limitations in adaptive functioning in at least several of the following skill areas: communication, social and interpersonal skills, use of community resources, self-direction, functional academic skills, work, health and safety.

Mental health challenge means that someone has a primary mental health diagnosis such as: depression, generalized anxiety disorder, bipolar disorder, schizophrenia, etc. These will be discussed in greater depth in the Intellectual Disability and Psychiatric Disorders training.
The quotes on this slide are examples that came from people with a Dual Diagnosis as they began to understand and gain insight into their mental health challenge. Please take a moment to read them.

- “How could I have stopped it if I never even knew it was there?” – Person with Dual Diagnosis discussing how “Naming It” helped them understand their mental health challenges.

- “Everyone told me I was crazy, but nobody could ever tell me why.” – Person with Dual Diagnosis discussing their happiness about gaining insight into their mental health challenges.
The National Core Indicators (NCI) is a collaborative effort between the National Association of State Directors of Developmental Disabilities Services (NASDDDS) and the Human Services Research Institute (HSRI). The purpose of the program, which began in 1997, is to support NASDDDS member agencies to gather a standard set of performance and outcome measures that can be used to track their own performance over time, to compare results across states, and to establish national benchmarks. The primary aim of NCI is to collect and maintain valid and reliable data about the performance of public developmental disabilities service systems. NCI states and project partners continue to work toward a broader vision of utilizing NCI data not only to improve practice at the state level but also to add knowledge to the field, to influence state and national policy, and to inform strategic planning initiatives for NASDDDS.

Of the 1,197 respondents to the NCI survey in the state of Pennsylvania, 41% of respondents reported that they have a current diagnosis of mental illness.

If these statistics in the state of Pennsylvania hold true, there is an obviously significant need for mental health services and supports for the dually diagnosed population which needs to be addressed.
Currently, 21 states have opted to participate in the National Core Indicators Survey. From those combined 21 states, 12,609 peoples were surveyed. Approximately 32% of peoples surveyed reported having a psychiatric diagnosis. This means that almost one third of the client population surveyed has a Dual Diagnosis. From this data, we can clearly see a significant need to address Dual Diagnosis specific concerns and Dual Diagnosis specific training.
Ongoing difficulties persist in locating mental health services and supports for people with an intellectual disability.

Despite a growing need, there remains a high demand and short supply of mental health services and supports of people who are experienced enough to support people with a Dual Diagnosis.
Through this Dual Diagnosis Curriculum series and trainings, many myths will be disproved.

Some common myths still exist regarding people with intellectual disabilities and mental health challenges.

One myth is that an intellectual disability is the direct causation of mental health challenges. In other words - that people with an intellectual disability have mental health challenges because they do not have “normal” brains.

FACT - There are many people who experience mental health challenges but do NOT have an intellectual disability.
It is a myth that people with an intellectual disability are immune to mental health challenges. This myth is stating that people with an intellectual disability do not have the intellectual capacity to have a mental health challenge.

The fact is that mental health challenges can affect anyone, regardless of age, race, IQ, socioeconomic status, physical health, etc.
Another myth is that the separation of intellectual disability and mental health services due to state and federal regulations should continue.

The fact is that the best outcomes for a person with a Dual Diagnosis are when the ID and MH services work together to find solutions to navigate state and federal regulations.
Another common myth is that people with an intellectual disability cannot recover from mental health challenges.

The fact is that with proper supports, treatments and therapies, adapted to the needs of the person, most people can recover from mental health challenges.
Sometimes, in trying to identify needed changes, we assist people in “Naming” issues relating to their diagnosis, but we need to be cautious so that we don’t also call everything challenging behavior. This thinking gets too broad; remember that many behaviors occur for a good reason. Behaviors are a way to communicate.

We want to be careful not to create behavior plans in an attempt to simply reduce disruptive behavior without truly understanding reasons for the behavior. We need to be sure to include the person in decision making because they are the ones most affected by the planning!

Many times, adding staff to control disruptive behavior isn’t really the answer either – it is a temporary fix. It doesn’t get to the root of the behavior, and adds additional dynamics to the situation instead of making it clearer.

We must be vigilant so that we are “Naming” the correct issues.
Regarding putting a name on intellectual disability or mental health challenge, we as a supportive field have made good progress in the area of promoting respect for the people we support. We have spent over 30 years of eliminating labels such as “moron”, “idiot”, “stupid” and “crazy”.

Because of that awareness, Naming It can almost feel like we are continuing in the vein of adding more labels by giving things specific names. So some people may be a little resistant given the history of “Names”. We are reluctant to add additional labels to any already stigmatized population.

Although “Naming It” seems to help clarify things, it presents some other challenges as well...

Sometimes there is a lack of understanding and we do not truly name mental health challenges or understand how Dual Diagnosis truly impacts the lives of those we serve.

We sometimes miss opportunities to educate the person and others about diagnosis and naming things to make it clearer.

We can sometimes make decisions without really asking for the input of the people we are supporting, and this takes us away from the purpose of our goal to provide a respectful and therapeutic environment.
Rosa is a 9 year old girl who is diagnosed with Down Syndrome, and she and her family did not like her being called “mentally retarded”. She and her family championed for the elimination of the term “mentally retarded” in legal and governmental documentation. They demonstrated the negative emotional impact of the term “mentally retarded”. Rosa’s Law was enacted in October of 2010 and was passed unanimously through the Senate and House of Representatives. This law removes the terms "mental retardation" and "mentally retarded" from federal health, education and labor policy and replaces them with people first language “individual with an intellectual disability” and “intellectual disability.”

Take a moment to read the quote from Rosa’s brother on the slide.

“What you call people is how you treat them. What you call my sister is how you will treat her. If you believe she’s ‘retarded’ it invites taunting and stigma. It invites bullying and it also invites the slammed doors of being treated with respect and dignity.”

– Rosa Marcellino’s 14-year-old brother
There is a video listed in the reference section of this presentation titled: The “R Word” Documentary.

It would be helpful to watch this video, as it further emphasizes the impact of the words that we use.
When we use the term "Naming It" we are referring to ensuring that the person and the team are aware of and understand the impacts of having both a mental health challenge and an intellectual disability.

By "Naming It", we can help to ensure that the treatments and supports are better able to match the needs of the person.
“Naming It” assists the person and the team in understanding the complex issues that a person may be struggling with and is the foundation for educating and supporting the person and the person’s supporters.

Example: If a person is diagnosed with diabetes. What would that tell us? How would it change the way we provide some of the person’s supports?

- Someone with a Dual Diagnosis may have:
  - Intellectual/Developmental Disability
  - Neurodevelopmental Disorder
  - Undiagnosed conditions
“Naming It” acknowledges both the intellectual disability as well as the specific known mental health challenge. This can help the team to provide an integrated treatment or services that focus on the unique needs of the person.

Once named, there may be treatment and there is hope for recovery.

Another purpose of “Naming It” is for the people THEMSELVES to acknowledge their own struggle and recovery process regarding having a mental health challenge and an intellectual disability.
“Naming It” can help the person:

Understand the symptoms of their mental health challenge, intellectual disability and other medical challenges. Be provided with education assistance and resources to reduce the negative impact of their challenges. Provide hope that they are not alone and that there are ways to make these challenges impact their everyday life less.
“Naming It” is also about:

- Opportunity to learn about mental health challenges and intellectual disability

- Reducing the impact of Dual Diagnosis on an *Everyday Life*

“Naming It” is also about a person having the opportunity to learn about his or her own mental health challenge and intellectual disability. Also, it can help people reduce the impact of Dual Diagnosis on their *Everyday Life* by providing supports and services that acknowledge and accommodate for the specific needs of the Dual Diagnosis.
Support professionals are NOT just recognizing the mental health challenges of people … they are recognizing:

- The intellectual disability **AND** mental health challenges of people
- How **ALL** of these diagnoses impact the persons’ quality of life
- The need to adapt supports specific to improving that quality of life

Support professionals can also adapt their supports to the specific needs of the person so that their quality of life can improve.

There is so much about people that we can’t just focus on the intellectual disability or the mental health challenges, “Naming It” is about identifying, understanding and recovering from all the challenges (medical, intellectual and psychiatric).
The image on this slide provides a snapshot of Pennsylvania's goal for their system of supports. People really DO want *Everyday Lives*, and people with intellectual disability and mental health challenges are no different in that desire. The concepts of Everyday Lives includes:
• Choice and Control
• Quality
• Stability and Safety
• Individuality
• Relationships
• Freedom
• Success
• Contributing to the Community
• Accountability
• Mentoring
• Collaboration
• Community Integration

In addition, to the concepts of Everyday Lives, the recovery process promotes:
Hope, Secure Base, Self, Supportive relationships, Empowerment and Inclusion, Coping Strategies, Meaning
“Naming It” helps to advocate for the correct services, such as finding a therapist who is trained and skilled in supporting people with a Dual Diagnosis and who is also able to customize therapies to meet the specific needs of the person.

Supports need to be obtained from the appropriate resources to match the expressed needs by the person themselves.

Treatment should be tailored to the person as a whole, and not just to one diagnosis or another but the person as a whole.

Assistance should be obtained from a variety of resources so they can partner together for a positive outcome for the person.

A final outcome seeks to help those coping with an intellectual disability and mental health challenges to cope well and to sustain positive coping strategies over the long term course of their recovery.
“Naming It” is a process by which support professionals seek to understand the struggle of those being supported.

Here is a story about supporting a person whose mother passed away.

Staff were supporting a young man who screams and talks loudly. The staff believe he is unhappy and angry with them and so they check on him to make certain he is safe and basically leave him to himself. He is seen by a psychiatrist who diagnoses him with schizophrenia. The psychiatrist and therapist suggest that staff attempt to keep him distracted during auditory hallucinations and, besides medication, suggest the use of an iPod headset to listen to music. Once the staff understands that he is having auditory hallucinations, they can empathize and understand that he is having symptoms of his mental health challenge and not a reaction of being angry or upset at the staff. They will be able to support his needs more appropriately.

Naming it helps us to gain respect and admiration for what some person has overcome. This new perspective can help us to approach people in a way that promotes greater empathy and respect for them.
For the direct supporters, “Naming It” helps to better understand and support the person. It promotes the process for a more appropriate request for help from the mental health system.

The process helps to better match proper treatment modalities within the systems that exist. This leads to better treatment from the mental health and intellectual disability systems. Throughout this process, something else develops – there is better insight about the unique struggles of those who we support.
Part of increasing understanding about a diagnosis means applying the education we receive with specific situations, and being able to “connect the dots” so people with disabilities are supported in the best way possible especially during times of possible misunderstanding.
On the road to recovery, there are several things that need to happen. First, there needs to be a conscious effort to adopt recovery strategies that purposely gives control and responsibility back to the person who is most affected – the person!

The next step is the necessity to explore a variety of services from both the intellectual disability and mental health systems; thoughtful and targeted in terms of the goals and outcomes for recovery.
By “Naming It”, we are acknowledging the need for mental health services and supports to adequately address the mental health aspects of the Dually Diagnosed person.

We are here to help those who have a mental health challenge and intellectual disability take back control of their lives by helping those we serve to speak for themselves.
One avenue that helps us as support professionals is to better understand some of the biopsychosocial information about the people we support. This is part of a bigger picture called the biopsychosocial model.

In simpler terms, it paints a big picture view, while also moving us closer to an understanding of the people themselves. It reinforces the person-centered thinking mindset which emphasizes the need to get to know the people we support and to learn everything we can about them.

We need to understand their medical concerns and how that impacts their lives. Think about how much our own daily health, illnesses and bodily injuries affect us and how we must adjust to them. We need to understand how the person’s disability may impact their life, on a daily and regular basis. This is sometimes a permanent condition, and it affects everything they do.

We should seek to understand the history of the person and how it has impacted his/her life. It helps us understand by knowing where they came from and what their family was like. It shows us a timeline of what things have happened in the course of their lives – it all has an effect, both positive and negative.

We also must recognize how what occurs around us can change our attitudes and behaviors, and this happens too for the people we support. We are all affected by our environments and circumstances, and we make choices based on our understanding of what has occurred in our lives. This can change attitudes and behaviors - some of those may be easy to understand and others not as clear.
It is important to educate yourself about the impact of mental health challenges, especially if your life has never been impacted by it, through other family members or significant people in your life. More knowledge leads to greater understanding and effective interactions with those you support.

You also need to know and learn what a person’s diagnosis means to him or her; it may be different than you were thinking it might be. Hear it from their own perspective - what is it like for them.

Lastly, when you try to name the process and what a person is dealing with in specific terms, think about how this affects your role as a support professional. Ask yourself and then take action about how YOU can impact their lives in a positive way.
Congratulations, you have successfully completed the “Naming it”: Mental Health Challenges and People with an Intellectual Disability Training.
Thank you for your participation in this presentation