Increasing Our Capacity to Support People with Intellectual Disabilities and Mental Illness The Pennsylvania Experience

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Commonwealth of Pennsylvania

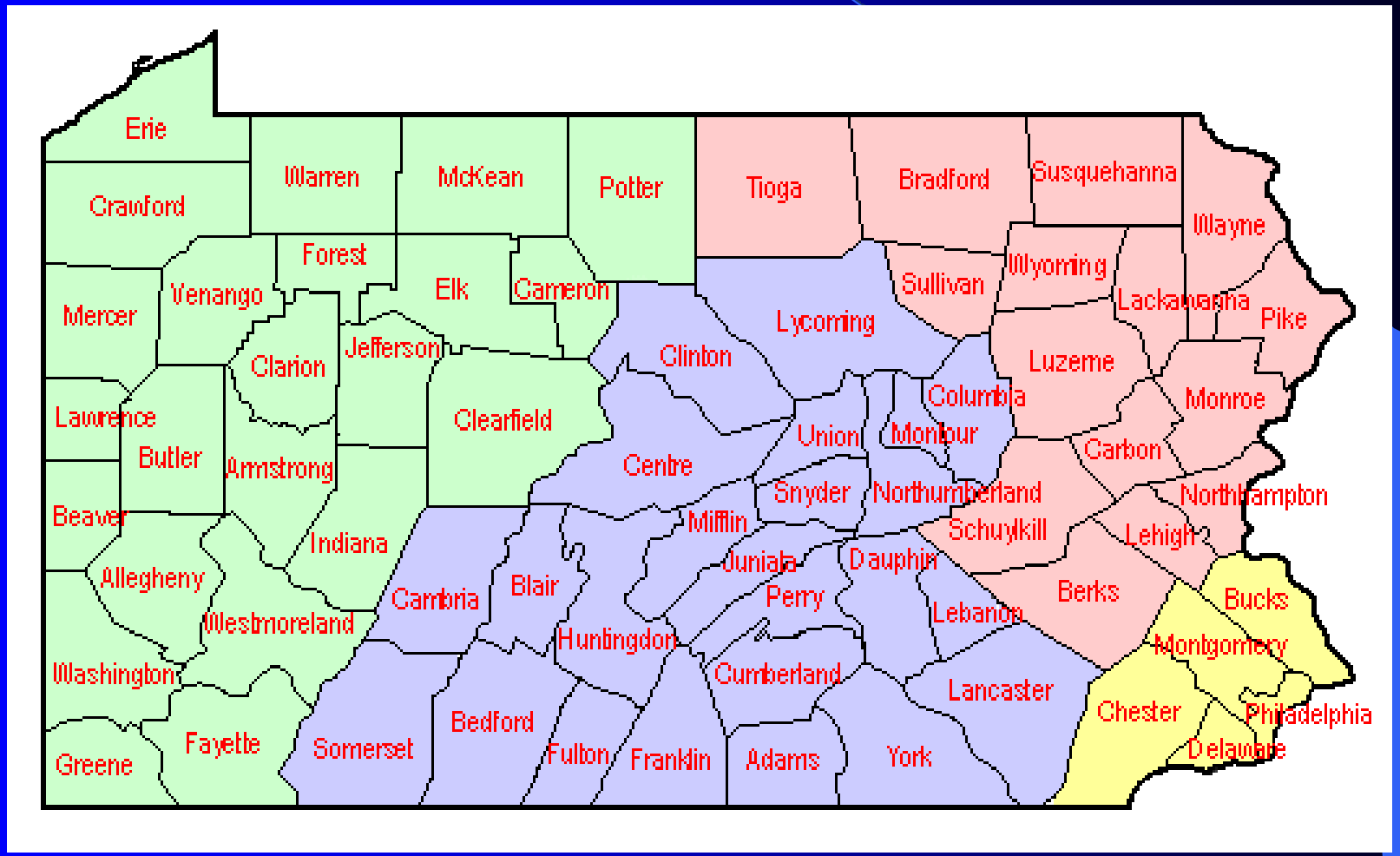
Department of Public Welfare

- Office of Mental Retardation (OMR)
- Office of Mental Health & Substance Abuse Services (OMHSAS)

Dual Diagnosis

People with Mental Retardation and a Mental Disorder (as defined by current edition of the Diagnostic and Statistical Manual for Mental Disorders - DSM)

The Mental Retardation system in Pennsylvania is state-funded and county administered.



The Early Years

Positive Approaches

- History
- Building Momentum

Dual Diagnosis Initiative

- Dual Diagnosis Forum
- Positive Approaches Journal
- Training
  - Clinical Institutes
  - Biographical Timeline Process
  - Unmasking Mood Disorder
  - Person Centered Approaches
  - Understanding the Impact of Trauma
  - Autism
- County Surveys & Findings

Prevalence

Mental Retardation

- 1 - 3 % of general pop have mental retardation (JAACAP, 12/99)
- Effects 6.2 to 7.5 million Americans (*based on 1990 census)*
- There are 77,000 people receiving service from PA's mental retardation program of that 15,000 people live in licensed community residences

Prevalence

Mental Illness

- 1 in 5 Americans have a diagnosable mental illness in a given year *(NIMH 2001)*
- Of American Adults, 5.4 % have a serious mental illness. *(Kessler 98)*
- Of the 1,012,582 total hospital admissions in the U.S. in 1998, 25.8% were psychiatric admissions (Center for Mental Health Services 98)

Mental Retardation & Mental Illness

- Mental disorders in persons with MR are often under diagnosed…

  Clinicians focus on disruptive behaviors neglecting to evaluate the global picture.

  Tendency to write off symptoms as expression of MR and not mental disorders. *(Reiss et al.1982)*

- The only behavior that can be directly attributed directly to mental retardation is slow learning of new academic skills *(Ryan 1993)*

Mental disorder occur more commonly in persons with MR than in the general population. *(JACAP 12/99)*

- 20 – 35% of all people with mental retardation have a psychiatric disorder. *(NADD-Fletcher)*

Mental Retardation & Mental Illness in PA

- Based on the number of people receiving services there are between 15,000 – 27,000 people with a dual diagnosis
- 51% of a sample group of 584 people with mental retardation in PA had seen a psychiatrist in the past year. *(PA Healthy Futures Report 1999)*
- 43% of people living in public and private ICF/MR in PA receive psychotropic medication
- Smaller numbers have severe mental illness and mental retardation
- Need more specific data on this population

What are the Obstacles to Proper Support/ Treatment ?

- Symptoms of mental illness are often misinterpreted as an attribute of mental retardation *"they behave that way because they are retarded…" or "..they're a bad actor"*
- Many people can't tell us their subjective experience
- Some cannot participate in the most common "talking models" of treatment
- Caregivers do not recognize and so may not report signs / symptoms of MI
- Clinicians are are generally not aware to look for signs of MI and do not include caregivers in the interview process

What are the Obstacles to Proper Support/ Treatment ?

- Short supply of people in both systems who know how to treat & support
- The two systems - language & philosophy
- Personal and medical histories are often incomplete and not integrated into a holistic summary
- There can be a number of complexities in doing the assessment

Central nervous involvement

Developmental disability

The impact of trauma

Multiple chronic medical conditions

Co-morbid mental health issues

Why is a Focus on People with a Dual Diagnosis Critical ?

Psychiatric disorders in this population are sometimes: untreated, under-treated, incorrectly treated, and as a result:

- Functioning is being limited as well as quality of life
- May be inappropriately medicated and/or restrained
- May be at risk of injury and death
- Have been stigmatized by the media
- People & Families loose hope
- People fall through the cracks and may end up in inappropriate environments, including jail

Interdepartmental Approach to Treat & Support People with Mental Retardation & Mental Illness

- Office of Mental Health & Substance Abuse Services & Office of Mental Retardation Dual Diagnosis System Design Work Group.
- The OMHSAS & OMR creates a vision document for a system design for people with mental retardation & mental illness.

Goals of the system design for people with mental retardation and mental illness.

- Increase general awareness of the needs of people who have a Dual Diagnosis.
- Ensure that Dual Diagnosis specific treatment and support are available in each county.
- Design & imbed policies and processes into the OMR and OMHSAS service system structure.
- Develop cost effective quality supports and treatments that are fiscally responsible and enable people to have an *Every Day Life*.

Designing Supports

- Supports will be designed using the core principles of Positive Approaches & Community Support Program
- The effects of a person's Biological, Psychological and Social environment will be explored before more intrusive interventions are considered.
- When at all possible, when supports are required, the person will be supported in their home.

Ruling Dual Diagnosis In or Out

Need to examine the challenging behavior

May be the result of multiple influences

- Medical condition
- Response to medication
- Form of communication
- Reaction to physical or social environment
- Unmet needs
- Behavioral expression or sign of a mental health symptom
- Other influences
- Or a combination of the above

Requires further analysis and assessment

Create an Assessment Tool

A Comprehensive Dual Diagnosis Assessment includes:

- Presenting problems/concerns/signs/symptoms
- Current medical status
- Life time medical history
- Life time mental health history
- Review of assessments/evaluations
- Environmental supports and stressors
- Influences of family and care-giving

Information is gathered from the person, family and the caregivers.

Awareness

- Information will be available on Dual Diagnosis
- Providers and staff will be knowledgeable and Dual Diagnosis literate

Intake

The system (OMR & OMHSAS) will identify potential Dual Diagnosis issues

County & State Regional Dual Diagnosis Focus Staff

Define the roles of the focus staff

Big picture people

- Identify people at risk through a risk management process
- Review & expand local resources
- Access regional & state resources
- Collaboration between different offices

Assist counties/providers

Supports Coordinators/Mental Health Staff

Supports Coordinators/Mental Health staff, will have training in services for people with Dual Diagnosis and will be available to:

- Be a resource on services available for people in their home and out of their home
- Ensure the individual support plan integrates appropriate Dual Diagnosis supports and treatment

Crisis Prevention

People will receive the support they need in their home

There will be a focus on crisis prevention:

- Care givers in the MR system will be able to recognize mental illness and be able to report information effectively to the psychiatrist
- Core principles: CSP and Positive Approaches will be used in planning of supports & treatment
- Clinicians will be involved before a crisis
- Expand availability of DD clinicians & therapy
- Expanded Respite opportunities

Crisis Prevention

When out of home services are necessary to support and treat a person with a Dual Diagnosis these options will be offered regionally or locally:

- Small scale crisis stabilization residential program
- Hospital diversion opportunities
- When residential placement is needed there will be providers who are able to serve
- When emergency hospitalization is needed there will be appropriate options available
- Collaboration between offices

Psychiatrist and other Clinicians

- Support the development of training opportunities for psychiatrist and other clinicians on dual diagnosis
- Create relationships with teaching hospitals, Managed Care Organizations and private hospitals to expand clinicians awareness of treatment & supports for dual diagnosis.

The FOCUS Plan-Do-Act Framework

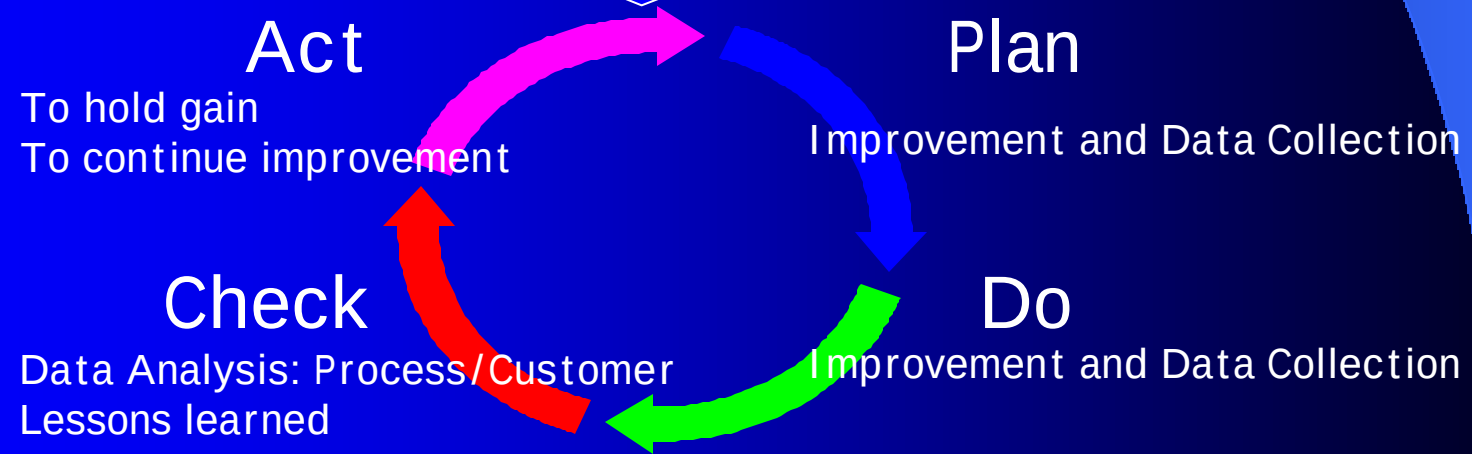
Find a process to improve

Organize team that knows the process

Clarify current knowledge of the process

Understand causes of process variation

Select the process improvement



Making it a Reality

OMR & OMHSAS System Change Workgroup

- Agreement on vision
- Create policy & support change
- Collaborate on and support training
- Standardized assessment tool
- Role of the Regional & State DD Focus Staff
- Improve Data Collection
- Establish clear expectations and outcomes
- Build capacity to support people in crisis
- Collaborate on developing & training clinicians and psychiatrist

Training and Technical Assistance Initiative for PA Counties

Counties design how to use training to build local capacity for people with a dual diagnosis