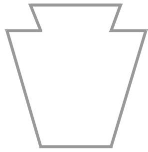

Pennsylvania Department of Public Welfare
Office of Developmental Programs

Informational Memo

Admissions to State Operated Intermediate Care Facilities for Persons with Intellectual Disability

ODP Communication Number: Info Memo 045-12

The mission of the Office of Developmental Programs is to support Pennsylvanians with developmental disabilities to achieve greater independence, choice and opportunity in their lives.

AUDIENCE: All Stakeholders

PURPOSE: The purpose of this Informational Memo is to discuss and consider options to prevent or deter admissions to State Operated Intermediate Care Facilities for Persons with Intellectual Disability (ICFs/ID) effective July 1, 2012.

BACKGROUND: State run institutions for people with intellectual disability have existed in Pennsylvania for over 100 years. While once thought to be state of the art and a standard of care, the option of institutional living has since been replaced with a wide array of inclusive opportunities. In the mid-1960s, there were 13,600 people residing in state run institutions. In 1976, Pennsylvania operated 13 State Institutions. As the community system began to expand, practices evolved and alternatives were offered to self-advocates and their families. Given the robust system of community supports for people with intellectual disability that developed in Pennsylvania, the population of people residing in state institutions declined. As a result, the need for state centers began to lessen. This trend exists not only in Pennsylvania, but in every state throughout the country.

The Pennsylvania Office of Developmental Programs (ODP) currently operates five State Operated Intermediate Care Facilities for Persons with Intellectual Disability (ICFs/ID). Today, a total of 1,125 people reside in these facilities. Admissions dramatically declined over the years and system stakeholders no longer consider state-run institutions a desirable option. Additionally, recent federal legislation mandates least restrictive environment options and delivery of service in a more normalized, inclusive setting.

Although relatively low in numbers, admissions to state run facilities has seen an increase over the past few years. In most instances, these admissions occurred due to unmet needs presented by an individual's behavioral challenges and/or complicated by a co-existing mental illness. In all cases, providers and/or other support structures were challenged and unable to sustain a desired quality of life for the individual in the community.

In January 2012, ODP in Partnership with the Office of Mental Health and Substance Abuse Services (OMHSAS) began to assess Pennsylvania's over all supports for people who have a dual diagnosis and other behavioral challenges. Our mission as we move forward is to identify system change that will enable Pennsylvania to offer an array of quality and comprehensive community based services to individuals in this population thereby eliminating the need for admission to state centers and state mental health hospitals.

ISSUES STATEMENT

It is estimated that between 10 and 40 percent of people with an intellectual disability also have a diagnosed mental illness. Currently in Pennsylvania, individuals with intellectual and/or developmental disabilities, who may also have a psychiatric diagnosis, often struggle with accessing quality community based services that are coordinated and effective to adequately address their specialized needs. Systems of support are often narrowly focused and tend to be limited and incomplete in assessment, treatment and support strategies. Often times these service inadequacies promote lingering and exacerbated symptomatology which:

- Severely and negatively impacts the person's quality of life
- Increases the need for additional resource allocation in the form of enhanced staff and funding
- Exposes the person to the use of restrictive measures and actions
- Increases provider and support staff frustration, burn-out and turnover
- Increases possibility of injury to the individual and those who support the person requires "first responder" services that are limited which may otherwise be used for other emergency needs
- Leads to unnecessary admissions to state centers, hospitals and mental health hospitals

Nationally, as well as in Pennsylvania, the service system continues to struggle with how to best support this population of individuals. Providers, often lacking the competencies to support someone with a dual diagnosis coupled with a limited awareness of available resources accessible to them, do their best to design and implement treatment and support strategies that may in fact be contraindicated. The problem is compounded by a mental health system that is often unsure and lacking as to how best to adequately diagnosis and treats someone presenting with a dual diagnosis. As a result persons who are under or misdiagnosed may not receive appropriate treatments and supports, thus further complicating efforts towards sustained symptom relief and/or recovery.

Other complicating factors that challenge efforts to provide quality supports and treatments include:

- Non-integrated service, support and treatment plans
- Sporadic expertise in the areas of assessment, diagnosis, and support and treatment plan design
- Varying degrees of expertise of support staff as to how and what to communicate to clinicians – collecting and providing accurate and meaningful information
- Unavailability of technical assistance services designed to intervene when needed and prior to crisis

ODP/OMHSAS Partnership Expectations include enhancements that are:

- Proactive and responsive to individual's needs
- Cognizant of the need to increase stakeholder competencies
- Inclusive of stakeholder input
- Creative and consistent with current and future promising practices
- Considerate of efficient utilization of existing and future resource availability and management
- Structured to allow for the blending of services among DPW Offices and system resources
- Accessible and available to consumers throughout Pennsylvania
- Sustainable and maintained as a priority focus area
- Measurable and inclusive of sound quality management practices

ODP/OMHSAS Partnership Objectives include:

- To develop competencies among and throughout ODP's and OMHSAS's partners to better address the needs of people who experience behavioral challenges, mental illness and/or have other specialized needs
- To expand the community system's capacity to serve additional self-advocates with specialized needs
- To embed at every level of ODP's/OMHSAS's community service/support system, the ODP values base to ensure unwavering commitment to support people in the most integrated and least restrictive community setting
- To identify and incorporate creative service options that may enhance ODP's/OMHSAS's service delivery system
- To create a system of support and partnership throughout and among ODP and OMHSAS stakeholders
- To proactively identify and address system issues that ultimately will create opportunities for creative solutions, strategies and options

Objectives through Partnerships

Much effort has been taken to meet with diverse and representative groups of system stakeholders from across the State. These include provider organizations, advocacy organizations, counties, self-advocates, families and other professional entities.

The intent of these meetings was to better understand stakeholder issues, gather ideas and solicit support. In every instance groups demonstrated a high level of interest and willingness to partner with DPW in further enhancing services for people with a Dual Diagnosis. The "Issue Statement" located on page 3 of this document summarizes the issues and system deficits that were mentioned/discussed during these stakeholder meetings.

Services to support individuals with a dual diagnosis can be costly and resource depleting. Many of these individuals require enhanced staff requirements necessary for the safety of the person and others. Additionally, costly in-patient and emergency services often accompany deficits to proper assessment, diagnosis and treatment services. Efforts to develop an infrastructure that is responsive to stakeholder needs will help to lessen the service and support demands by better equipping those who support individuals with complex and challenging needs with the tools they need.

As a result, this ODP/OMHSAS Partnership Project will focus on three main areas which include:

1. Competency Development to enhance the skills and knowledge of all community system partners
2. Community Capacity Expansion to serve additional self-advocates with Specialized needs
3. Cost Effective Service Alternatives/Options that offer blended (ID and MH services

Competency Development

In order to enhance and strengthen competency throughout the system, specifically designed curricula are being developed to address the training needs necessary to support individuals with a dual diagnosis. The need to strengthen competency exists more profoundly within the provider and clinical communities. Measures to incentivize the training opportunities, such as revising the Procedure Codes to allow for higher rates for trained provider staff, will be identified and incorporated into the process. Specific to providers, training curricula will be "graduated" in nature beginning with a foundational emphasis on understanding mental disorders in persons with Intellectual Disabilities. Other topic areas will include; communicating with clinicians and mental health professionals in terms of providing accurate, meaningful and reliable information necessary for accurate diagnosis, positive behavioral practices, ODP/OMHSAS mission and value platform and Person Centered Planning.

Other curricula will target the training and education needs of licensed/certified professionals such as Physicians, Mental Health Professionals, Nurses, Occupational/Physical Therapists, Licensed Social Workers, and Behavioral Specialists. These trainings will be offered to agencies such as hospitals, mental health facilities, and practitioner offices.

Lastly curricula specific to Judicial System staff (Judges, Magistrates, Public Defenders and District Attorneys), First Responders (Police, Ambulance Personnel) and Criminal Justice System staff will be identified and offered.

Trainings specific to provider staff will be competency-based and will include learning expectations with certification options available. Detailed training "roll out" plans will also be developed which will include entities responsible for training and expectations associated with tracking and monitoring training audience.

In addition, a "Standard of Care" will be established for the purpose of infusing consistencies in how individuals receive clinical assessment and treatments.

Community Capacity Expansion

The willingness to serve additional people who have a dual diagnosis is compromised by a number of factors which include: Lack of trained staff; heavy resource (funding, enhanced staffing) needs; lack of skilled community resources. As a consequence of efforts to enhance the skills and abilities of system stakeholders, providers will be able to offer enhanced quality services that are more comprehensive and efficient.

In meeting with the various stakeholder groups, attendees were asked to think about the future improvements and the impact that these will have on system responsiveness. Providers voiced optimism toward the future given the ideas, direction and commitment that were communicated.

Service Alternatives/Options

Currently, community options that offer blended Intellectual Disability and Behavioral Health Services in one setting are limited and rare. More often than not, individuals who experience behavioral crisis are taken to a hospital emergency room or psychiatric facility that is often ill equipped to treat them. To better address the need for "specialized" settings, stakeholders are being challenged to identify creative and blended service option ideas. Creating programs equipped to provide blended services is one way of offering providers opportunities to deliver the most comprehensive specialized services and supports to individuals who are dual diagnosed. Pilot program opportunities that are essential to system change will then be considered.

Blended service options can then be utilized to provide more specialized services to people in need. They can also offer crisis respite (in and out of home), in-home assistance teams, discharge follow-up, training, education.

As a supplement to such services, Mobile Clinical Teams will be made available for the purpose of offering clinical technical assistance to individuals, their families and their support staff. These teams will be made up of “specialists” and other highly trained staff who are well versed in proven behavioral assessment techniques, developing comprehensive behavioral support planning, and other support strategies.

ADDITIONAL ACTIONS TO PROMOTE/ENHANCE SUCCESS:

- **Development of a Dual Diagnosis Catalog** – a collection of resources in the area of Dual Diagnosis available statewide
- **Development of a Risk Assessment Tool** – to better predict individuals/ providers who may be in need of assistance and/or direction
- **Implementation of Weekly Diversion Calls** – to coordinate efforts necessary to divert admissions to state centers and hospitals
- **Quality Management Performance Measures** – to track progress and the impact of changes

Our Work and its Impact on State Center Admissions

Every decision to admit someone to a state center is taken very seriously. A move such as this involves the relocation of someone to an unfamiliar location with people who, in many cases, have never met the person. Attempts are made to learn as much as possible in as little time as possible but given the situation that often accompanies an admission, timeframes are tight.

The intent of the effort to improve services to people with a dual diagnosis is to not only impact this population of individuals, but to influence change and improve services to a much broader group. The ability to identify and access available community resources in a timely manner prior to someone experiencing a crisis is paramount to success. Additionally, our attention to the process of how we plan with and for people, utilizing sound and proven person centered principles, must be the foundation that supports the needs and desires of each person. This plan must ensure that attention is given to the fulfillment of each person’s human needs and desires of each person. This plan must ensure that attention is given to the fulfillment of each person’s human needs to feel included, needed, cared about and part of a life that has meaning and purpose. Absent the fulfillment of these needs, the expression of symptoms associated with a mental illness or other behavioral challenges may emerge.

Application: The Pennsylvania Office of Developmental Programs is committed to partnering with all system stakeholders in their efforts to ensure that all Pennsylvania citizens with Intellectual/Developmental Disability live an Everyday Life in their communities. Our efforts to divert admissions must continue with a renewed commitment to ensuring that any and all available alternative resources have been considered.

So that we can all identify with a comprehensive effort to divert admissions, we will include, as part of our Balanced Scorecard, a goal of “0” admissions to state centers for a 12 month period starting July 1, 2012.

Our combined efforts to achieve this very meaningful outcome will involve a strong and unified dedication on the part of all system stakeholders along with a willingness to stay committed to each person – especially in times of behavioral challenges.