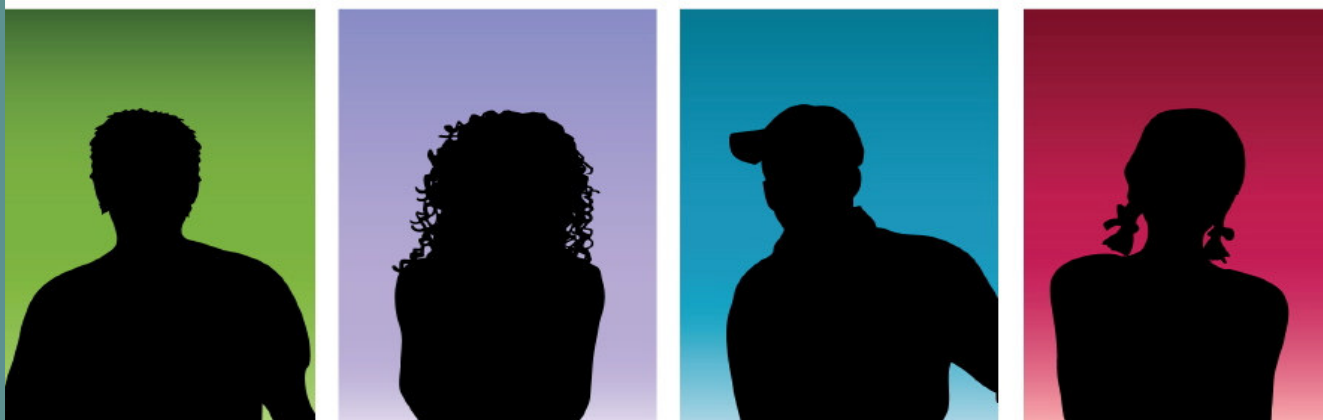


# The Cost of Serving Individuals with Developmental Disabilities and Mental Health Challenges



## EXECUTIVE SUMMARY



# **The Cost of Supporting a Person with Intellectual Disabilities and Serious and Persistent Mental Illness: Results of a Pennsylvania Survey**

## **Executive Summary**

Philadelphia Coordinated Health Care, the Southeastern Pennsylvania Health Care Quality Unit (HCQU), has been the lead of the coalition of Pennsylvania's eight HCQUs, on a grant funded by the Pennsylvania Developmental Disabilities Council. The grant was designed to look at services and supports provided by Pennsylvania for people who have intellectual disabilities as well as mental illness.

As part of the second year of grant activities, a survey was designed to look at costs associated with supporting people with intellectual disabilities as well as serious and persistent mental illness (dual diagnosis for the purposes of this report). The survey was conceptualized as a first look across several systems to illuminate what it really costs both the intellectual disability system and the mental health system to support a person with a dual diagnosis. While we know that the survey will not satisfy strict statisticians, it will help to point out where the various systems should be working more closely with each other and may help to direct further, more robust, research.

The final survey was distributed to fourteen counties across the Commonwealth that represent a mix of urban, suburban and rural areas. From the counties that volunteered, a total of 47 surveys was received.

The survey covers demographics and program service specifics. There were some surprising and some not so surprising results from this exercise. In many ways, collecting this information points out how complicated it is to build a system of supports for each person when several systems are doing the work.

## **Conclusion and Recommendations**

A significant amount of funding has been made available to provide supports to some very challenging people who are coping with intellectual disabilities as well as mental illness across the Commonwealth. This initial snapshot of services and associated costs raises many questions yet appears to offer some evidence of how people with dual diagnosis are being supported by the Intellectual Disability System (IDS), the Mental Health System (MH) and the Behavioral Health Managed Care Organizations (BHMCOs). For example, the data collected indicate a younger and less intellectually compromised population than the traditional program models have been serving. It is possible that service delivery models need to be more closely examined and modified to serve a population with different needs. With roughly half of the individuals served by the IDS system taking psychotropic medications, this is a problem that needs to be addressed across systems (National Association of State Directors of Developmental Disabilities Services and Human Services Research Institute, 2009).

The people surveyed seem to be primarily diagnosed with mood disorders at about twice the rate of the general population. These data should be more closely studied to verify accuracy across the IDS system. Accuracy of diagnosis is a continual problem for people with

dual diagnosis (Focus Groups & Literature Review). If the data are any indication, the related systems of service delivery need to work together closely to support people with dual diagnosis. Accurate treatment may really improve outcomes and perhaps address some of the additional costs around increased staffing. Even though by definition all the people in the survey had dual diagnosis, the costs are primarily borne by the IDS system, and primarily the result of staffing patterns. From the lack of data related to medication management and outpatient services provided by MH or BHMCOs, it would appear that these individuals are not receiving the type of supports that might be necessary to assist in their recovery and management of the symptoms of mental illness. From the data on the use of Behavioral Support Services, it is curious that providers are not even using these services to address the target symptoms of mental illness. A question must be raised about the non-residential support services: are services from MH and BHMCOs, as well as the waiver service of Behavioral Support, not available? Is this an access issue or is this a lack of knowledge about support services? Do the data speak to the need for capacity building in all systems?

It is clear from the raw survey data, that further study should be undertaken to ensure that all costs are included. In addition, a quality of life review should accompany the accounting of costs. While total cost is important, it is difficult to determine which supports are necessary and contributing to the quality of each individual's life. The lack of data relative to day activities for the 47 individuals represented by this survey is a finding that should be further explored. If the people in these surveys are not engaged in some meaningful way it is hard to believe supports are contributing to a healthy life in the community.

The data related to incident reporting is also disturbing. The question of under reporting must be explored. The relationship between heavy staff coverage and lack of incident reporting should be considered. The use of restraints must be addressed especially in light of the lack of alternative supports such as outpatient therapy, medication management, Certified Peer Specialist (CPS) support or Behavioral Specialist support.

The intent of this survey was to get a first look at what it costs to support a person who has intellectual disabilities as well as mental illness. Many people within the IDS system have hypothesized that these are the most costly people to support. This survey would seem to corroborate that conclusion. However, the difficulties experienced in data collection both from the IDS system but also across systems would require caution in interpretation of the results. In general, the results raise a number of questions that would greatly aid the service delivery systems in providing better supports for people with dual diagnosis. It would seem to be a good recommendation to create ways to assess the strategies that are being used, especially in relation to the cost and quality of life of the people who are being supported.

## **Reference**

National Association of State Directors of Developmental Disabilities Services and the Human Services Research Institute (2009). *National Core Indicators Annual Summary Report 2008-2009*, Alexandria, VA & Cambridge, MA.