

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

Initial Survey of People with Dual Diagnosis Across the Commonwealth

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

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. In addition, with limited public dollars directed towards supporting people with intellectual disabilities and mental illness, it is essential to identify the most cost-effective and person-centered services possible. With the latest National Core Indicators (NCI) data from 2008-2009 showing 31% of people with intellectual disabilities interviewed had a dual diagnosis and 46% were taking medication for mood disorders, anxiety, behavior problems or psychotic disorders, it may be just the time to take a close look at the cost and quality of the services and supports that are being provided (National Association of State Directors of Developmental Disabilities Services [NASDDDS] and Human Services Research Institute [HSRI], 2009).

In the past, some information about costs has been reported but none really attempted to gather precisely the information about costs of supporting people with dual diagnosis. For example, there is an article entitled *Cost and Cost-effectiveness of Hospital vs. Residential Crisis Care Patients Who Have Serious Mental Illness* (Fenton, et al., 2002), which compared the costs for inpatient treatment to the costs for running a residential crisis care program. "Unit costs and service utilization data were used to estimate episode and 6-month treatment costs from the perspective of government payors. (The) mean acute treatment cost was \$3046 in the residential crisis program, 44% lower than the \$5549 episode costs for the inpatient hospital. (The) total 6-month treatment cost for patients assigned to the 2 programs were \$19,941 and \$25,737 respectively." The authors conclude that the treatment outcomes were not significantly different and that the community option was more cost effective.

In a report created by Lakin, et al. (2007), it is asserted that the prevalence of dual diagnosis is greater within ICF/MR programs and institutions than in the community. NCI data indicate the same prevalence in its 2008-2009 data, but indicate that 86.9% of dually diagnosed individuals took medications for mood, anxiety, or behavioral disorders, 32% without a dual diagnosis took medications, and overall, 49% of people living with funding provided through the Home and Community Based Services Waiver (HCBS) took medications (NASDDDS & HSRI, 2009). In ICFs/MR, interestingly the data was almost exactly the same: 86.8% of the dually diagnosed people, 30.3% of people without a dual diagnosis and 49.4% was the average

between the two groups. The article concludes by stating that, “there continue to be inequities with regard to the life experience of those with co-occurring intellectual disability and mental health needs.” It is further suggested that behavioral health needs should be better accommodated through the Medicaid waiver. “The need for mental health services, including access to appropriately prescribed and monitored medications, suggests that close cross systems collaboration between developmental disabilities and the mental health system is needed in order to successfully support individuals with intellectual disabilities and mental health disabilities in the community service systems. Such collaboration must be built on shared commitment to avoid the segregated setting that will further reduce choices offered to people with intellectual disability and mental health needs.” While no cost data was used as a part of the article described above, the reader will see how well systems are collaborating while moving through the cost data survey.

Methodology

This survey was designed to collect information from several service delivery systems including the Intellectual Disability System (IDS), the Mental Health System (MH) and Behavioral Health Managed Care Organizations (BHMCOs). The data elements were created by a subcommittee of stakeholders including, two Directors of Intellectual Disabilities Services from Pennsylvania Counties, a Director from a BHMCO, two HCQU Directors, and the Director of a Provider Association. In addition, a group from the center of the state known as BHARP (Behavioral Health Association of Rural Pennsylvania) collaborated with the subcommittee because they had already designed a cost survey. A preliminary test survey was collected for 18 people from Philadelphia County and later modified to simplify collection of information and streamline data entry.

The final survey was distributed to fourteen counties across the Commonwealth. All the Counties were volunteers; that is, participation in the survey was strictly voluntary. Because collecting the information required some effort on the part of the counties, the number of surveys submitted by each county, also voluntary, varied from a high of eight surveys to a low of two surveys. The fourteen counties represent a mix of urban, suburban and rural areas. From those counties that volunteered, a total of 47 surveys was received.

Surveys by Participating Counties (N=47)

Allegheny	5
Berks	3
Chester	8
Clarion	2
Columbia-Montour-Snyder-Union (CMSU)	3
Fayette	5
Jefferson-Clearfield	2
Lackawanna-Susquehanna	3
Northumberland	3
Philadelphia	3
Schuylkill	3
Tioga	2
Washington	2
Wayne	3

The information was collected by each county from both the IDS system and the MH system. The surveys were then either sent to the BHMCO or information was collected by PCHC from the BHMCO (in the case of Philadelphia). As it turned out, two of the four BHMCOs operating in Pennsylvania, Community Care Behavioral Health and Community Behavioral Health participated in the survey. At no time, were names used in connection with the dollars spent. Finally, the counties were specifically asked to survey dollars spent on their most expensive people who had dual diagnosis, thus the results are reflective of some of the most costly people to support.

The survey covers demographics and program service specifics (see Attachment A). 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. It must be noted that numbers of responses do not always equal the N of 47 surveys. This is because some items were not answered or there are instances when more than one answer is required, such as specific diagnoses and incident reporting.

Results

Age and Gender

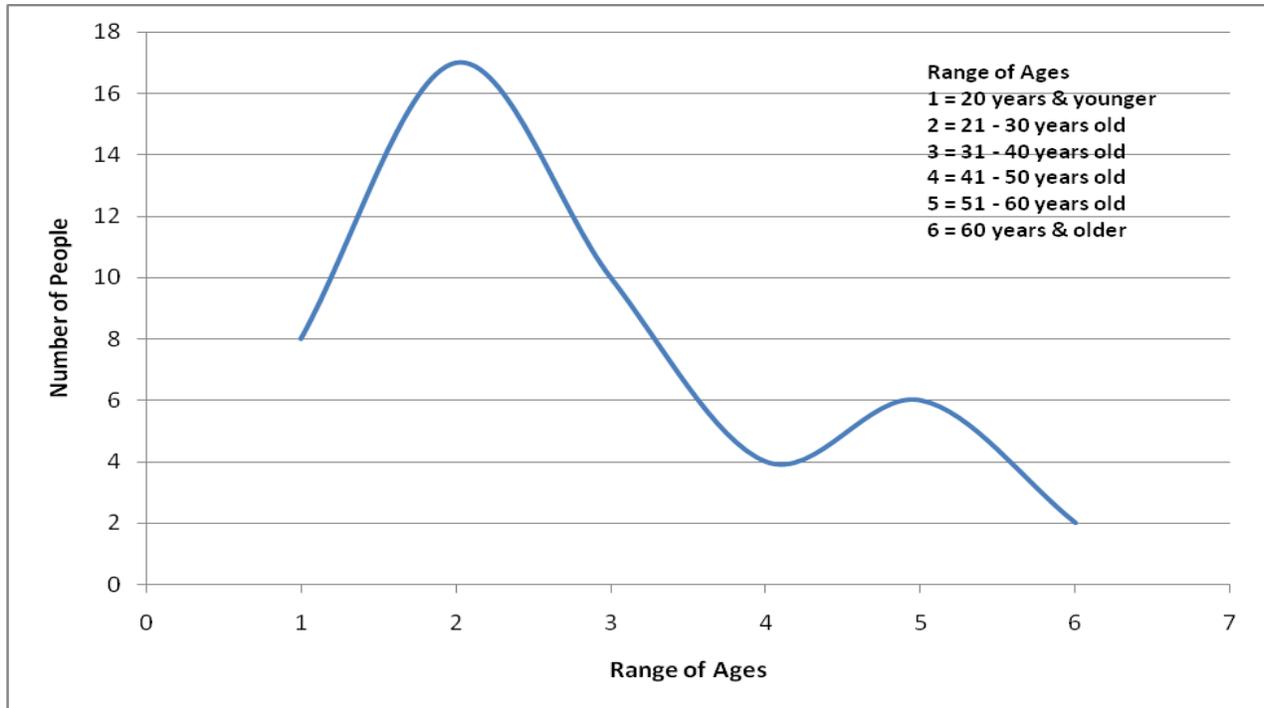
It is clear that the system is seeing and serving a younger population than when the community service system started. In earlier years, the community system primarily supported people who were moving from institutional placements; now the system is seeing young people who may have aged out of Residential Treatment Facilities (RTF) or who may have lived at home with family. The information collected about age as part of this survey indicates that the group is relatively young.

Age Range – 14 to 67 years old

Average Age – 33.7 years old

Age Range	# of Individuals	Percentage
20 years & younger	8	17%
21 – 30 years old	17	36%
31 – 40 years old	10	21%
41 – 50 years old	4	9%
51 – 60 years old	6	13%
60 years & older	2	4%

The following chart clearly displays that a majority of the people (74%) are 40 years old or younger.



When you add age information to gender and diagnosis data, the picture is even clearer.

Gender

	# of Individuals	Percentage
Male	28	60%
Female	19	40%

Intellectual Disabilities (ID) Diagnosis

Diagnosis	# of Individuals	Percentage
Mild	30	64%
Moderate	13	28%
Severe	1	2%
Profound	1	2%
Severity Not Specified	2	4%

Of the most costly people included in this survey, the majority are males between the ages of twenty-one and forty with a clear majority who have only a mild intellectual disability. One puzzling finding was that eight individuals were included who were younger than twenty and

some of those children had childhood diagnoses including *Conduct Disorder-Childhood Onset Type* and *Childhood Disintegrative Disorder*.

Mental Health Diagnoses: Number and Type

The number of diagnoses that were reported shows that the majority of people had between and 1 and 3 diagnoses each. Only a few people had as many as 4-6 diagnoses and one person had eight. For those few people one might wonder if there is ongoing difficulty in settling on a diagnosis which could mean that it would be difficult to determine the best treatment plan.

Range – 1 to 8 Diagnoses

Average Number – 2.4 Diagnoses

Number of Diagnoses	# of Individuals	Percentage
1 Diagnosis	14	30%
2 Diagnoses	16	34%
3 Diagnoses	10	21%
4 Diagnoses	4	9%
5 Diagnoses	1	2%
6 Diagnoses	1	2%
8 Diagnoses	1	2%

However, the more interesting information is the type of diagnosis. The top two diagnoses were Bipolar and Mood Disorder. Together they comprise 56% of the individuals.

Diagnosis Type	Frequency	Percentage
Bipolar Disorder	14	30%
Mood Disorder NOS	12	26%
Intermittent Explosive Disorder	11	23%
Depression	9	19%
Impulse Control Disorder	8	17%
Anxiety Disorder	7	15%
PDD/Autism	7	15%
Attention Deficit Disorder	6	13%
Post Traumatic Stress Disorder	4	9%
Psychotic Disorder NOS	4	9%
Schizoaffective Disorder	4	9%

Statistics from the National Institute of Mental Health (NIMH) indicate that in the general population Bipolar Disorder accounts for 6% and Mood Disorder accounts for 20% of the diagnoses (NIMH, n.d.). Thus, we see diagnoses of Mood Disorders at more than double the rate of the general population. In addition, 19% of the diagnoses were that of Depression, which is usually designated as Major Depressive Disorder and is categorized under Mood Disorders in the DSM-IV. In the general population, this occurs at a rate of about 9.5% in any given year. So, combining all the Mood Disorders gives us nearly 75% of all the diagnoses.

In contrast, Schizophrenia, the one-time most popular diagnosis, was only noted for three people or 6% of the individuals surveyed. NIMH reports that the national prevalence for Schizophrenia is 1% (NIMH, n.d.). Rates for diagnoses in this study clearly warrant further review to confirm prevalence and accuracy.

Another interesting finding is the prevalence of the diagnosis of Post Traumatic Stress Disorder (PTSD) revealed in the data. The survey shows 9% of the individuals in the survey had a diagnosis of PTSD. In a survey conducted between 2001 and 2003 in the general population, the prevalence of PTSD among American adults was reported at a rate of 6.8%. In an earlier related survey the prevalence was reported at 7.8% (National Center of PTSD, n.d.). It has long been suspected that PTSD is more commonly found in the IDS population (Focht-New, et al. 2008).

Several Diagnoses were reported only once such as Organic Brain Disorder, Somatization Disorder, Sleep Disorder and PICA.

Physical Health Diagnoses: Number and Type

Range – 0 to 8 Physical Health Diagnoses

Average Number of Physical Health Diagnoses – 3 (2.97) diagnoses

# of Diagnoses	# of Individuals	Percentage
0	8	17%
1	10	21%
2	4	9%
3	5	11%
4	7	15%
5	7	15%

Most Frequent Physical Health Diagnoses	Frequency	Percentage
Seizure Disorder	12	26%
GERD	10	21%
Hyperlipidemia	10	21%
Allergies	6	13%
Asthma	6	13%
Constipation, Chronic	6	13%
Hypertension	6	13%
Cerebral Palsy	5	11%

Most people had between zero and five physical health diagnoses. Given the average age of this group for whom surveys were completed, this is not unexpected. The most frequently seen diagnosis was seizure disorder, with 26% of the sample of people having this diagnosis. From the Vanderbilt Kennedy Center Research on Seizure Disorders, the prevalence of seizure disorders among children with intellectual disabilities 16% (7). Why the prevalence

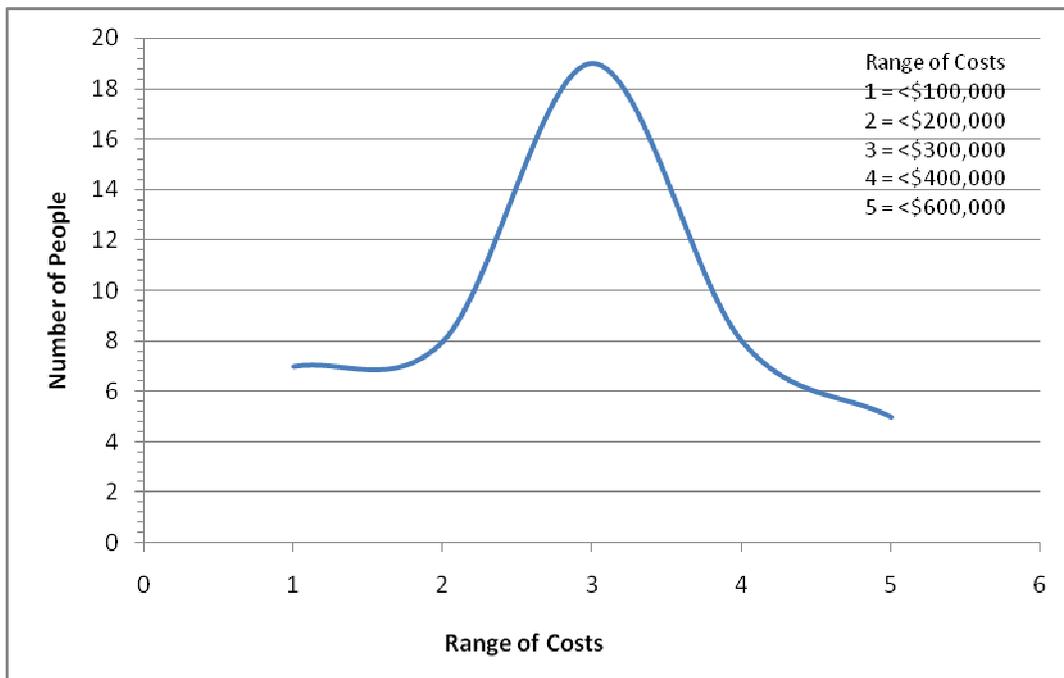
in this group is higher is unknown, however this may be contributing to difficulties in their lives and in providing supports. The second most frequent diagnoses were Gastroesophageal Reflux Disorder (GERD) and Hyperlipidemia, each affecting 21% of surveyed individuals. According to a study conducted in 2001 by the American Gastroenterological Association about one third of the population has a diagnosis of GERD (8). That the frequency is slightly lower in the study population may be due to age factors, may be an artifact of lack of reporting of symptoms by the individuals, or may be of no significance.

FY 09-10 Funding

Total Funding – IDS/MH/BHMC0

Range	Average	Median	Total
\$654 to \$570,667	\$239,325	\$229,048	\$11,248,282

The cost data collected as part of this survey indicate that a total of \$11,248,282 was spent for the 47 people during FY 09-10. It is interesting to note the wide range of funds spent, from a low of \$654 to a high of \$570,667. The average dollars spent to support an individual with intellectual disabilities and mental illness was \$239,325 for the year. The very low numbers could represent partial year funding, the type of living arrangement or use of supports coordination services only.



On the chart above, the distribution of the funding across the survey participants is displayed. For a few people (7 or 15%), annual costs were less than \$100,000. A similar number of

people (5 or 11%), had costs that exceeded \$400,000. Many of the people surveyed (19 or 40%) received services costing between \$200,000 and \$300,000. A complete list of total costs by survey participant can be reviewed in Attachment B.

IDS Funding

Range	Average	Median	Total	Percentage
\$654 to \$409,923	\$225,149	\$220,237	\$10,356,838	92%

A total of \$10,356,838 in IDS funding was spent in supporting this group of people who cope with dual diagnosis. This represents 46 of the 47 people (98%) for whom surveys were completed. The average cost per person was \$225,149. When the funding information is combined with the staffing information it appears as if much of the cost is related to additional staffing.

Staffing in IDS-Funded Homes

<i>Number of Individuals/ Size of Home</i>	# of Individuals with 1:1 Staffing	# of Individuals with 2:1 Staffing	# of Individuals with 3:1 Staffing
30 individuals live in one-person homes	21	9	---
5 individuals live in two-person homes	2	2	1
6 individuals live in three-person homes	4	2	---
2 individuals live in four-eight person homes	2	---	---

Forty-three of the 47 people (91%), for whom surveys were completed, had **1 to 1**, **2 to 1** or **3 to 1** staffing in their homes. The survey participants were selected to be the most costly, however the question must be raised, are we supporting people in the community in the most cost effective way?

Thirty of the 47 people (64%) who were represented in the surveys were living in one-person homes. For those 30 individuals, 21 had one to one staffing and 9 had two to one staffing. Five people lived in two-person homes with two having one to one staffing, 2 having two to one staffing and one person having three to one staffing. Six people lived in three-person homes with 4 having one to one staffing and 2 having two to one staffing. Finally, two people lived in four to eight person homes (ICF/MR, RTF, and State MH Center). Both of those individuals required one to one staffing. The lack of full reporting on this question could reflect a number of issues including: difficulty in determining staffing from ISPs; changes in staffing when the individual moved from one setting to another; or, no formal staffing in a family living situation. However, what is clear is that 29 of the 47 people represented in the survey have one to one staffing, 13 people have two to one staffing and 1 person has three staff people with him/her for support. The question for the system might be, is it safe to assume that each of the people represented through this survey is living a full and active life in their community? A number of other questions also might be asked. How is the decision to move to intense staffing made? For example, are provisions for fading addressed? Have Behavior Support Services been used? What does the behavior support plan data show? Have clinical mental health services been used? Has staff training been implemented? Further study would be

important to determine the quality of the programmatic supports both to the person and from a cost benefit standpoint.

MH Base Funding

Range	Average	Median	Total	Percentage
\$92 to \$10,258	\$5,214	\$5,036	\$46,925	<1%

A total of 9 of the 47 surveys (19%) indicated MH Base funding was used. Of these nine individuals, six were receiving administrative case management, 4 used outpatient mental health services, one had intensive case management, one person used medication management, and one used partial hospitalization. "Other" responses included emergency services, service coordination, certified peer specialist (CPS), transportation to social rehab, prevocational and social rehabilitation, and prevocational services. The use of a CPS was a nice finding as this could be a potential support to many of the dually diagnosed individuals who were the focus of this survey.

BHMCO Funding

Range	Average	Median	Total	Percentage
\$63 to \$229,510	\$44,448	\$5,314	\$844,519	8%

Nineteen of the 47 people (40%) who were identified through the survey used BHMCO services. The services used included medication management (18 people), inpatient hospitalization (9 people), outpatient mental health (7 people), intensive case management (4 people), resource coordination (2 people), and partial hospitalization (1 person). It is curious that so few of this select group of individuals, all of whom struggle with mental illness and most of whom have extra staffing, are using so few services provided by the BHMCOs. One hypothesis could be that some individuals are dually eligible for Medical Assistance and Medicare so they are getting their mental health care under the Medicare umbrella. Another hypothesis is that some IDS funded agencies are using agency funds to hire psychiatrists to perform medication reviews. Further detail would be required to determine and refine these results.

Funding Summary

In summary, ninety-two percent (92%) of the total funding (i.e., IDS/MH/BHMCO) received by the people reviewed as part of this study, came from the IDS system, while local MH funding covered less than 1% and BHMCO funding covered about 8%. To put this in a little clearer perspective, 46 of the 47 people in the survey were supported through IDS funding; 9 people additionally had local MH funding; and 19 people used BHMCO funding for at least part of their care. The one individual who did not use IDS funding spent the entire year in an extended acute hospital setting.

The results of this survey may indicate that the IDS system has moved from using services from the MH/BHMCO systems to managing most of the care for people who have intellectual disabilities and mental illness within their own system. This could be seen as

evidence of the long standing divide between the MH and IDS systems, which includes the traditional barriers that were so eloquently clarified during the focus groups that were conducted in the first year of the grant (*"Dual Diagnosis Services and Supports," 2009*), funded by the Pennsylvania Developmental Disabilities Council. Certainly, it would be interesting to look at costs on a broader scale to see if these results could be verified.

IDS Waiver and Base Funded Services

ID Waiver Services

Waiver Service	# Receiving Service	Percentage
Supports Coordination	43	91%
Licensed Residential Habilitation	27	57%
Behavior Support Services	24	51%
Home & Community Habilitation	12	26%
Supplemental Habilitation	7	15%
Residential Enhanced Staffing	6	13%
Vocational Facility	5	11%
Adult Training Facility	3	6%
Respite (In-Home)	3	6%
Respite (Out of Home, Lic.)	2	4%
Respite (Out of Home, Un-Lic.)	1	2%
Companion Services	1	2%
Home Accessibility Adapt.	1	2%
Individual Behavior Therapy	1	2%
Speech Language Pathology	1	2%
Transitional Work Services	1	2%
Older Adult Day Services	1	2%
Supported Employment	1	2%
Other ***2	17	36%

*****2** Responses included 6 Community Homes (licensing status not indicated), 2 Lifesharing Homes (licensing status not indicated), 2 Children's Residential Homes, 1 ICF/MR, 1 Community Living Arrangement, 4 Community Homes Licensed, and 1 Transportation.

ID Base Funded Services

Base Service	# Receiving Service	Percentage
Family Aide	1	2%
Recreation Leisure Activities	1	2%
Other ***3	1	2%

*****3** Response was "Not funded – helmet".

So, what supports did the surveyed individuals receive for their money? In the IDS service system, 91% of people received supports coordination, 57% of people were supported

in a licensed residential setting, and, 51% used IDS-funded behavior support services. Thirteen percent (6 people) were reported to have residential enhanced staffing. There were “other” responses which were interesting including: 6 surveys indicating the individual lived in a “community home” (licensing status not indicated), 2 people lived in Lifesharing settings, 2 people lived in children’s residential homes, 1 person lived in an ICF/MR, 1 person lived in a community living arrangement, and 4 people lived in licensed community homes.

What was confusing about this particular data was that only 23% of individuals reportedly attend a day activity. Surveys for five people (11%) reported the use of a vocational facility; for three people (6%) attendance at an adult day training facility was noted. For three people (6%), an older adult day service, a supported employment program, or a transitional work service are reported. Are these data an artifact of poor reporting? Or are these individuals difficult to serve in traditional work arrangements that are provided by the IDS system? Are people creating their own tailored program of day activities when they have a 1 to 1, or greater, staff ratio? If the data are accurate, it is definitely an area where the IDS system could explore more options for daily activity.

Very few surveys indicated IDS base funding. The three times it was noted were for a family aide, recreation/leisure activities and something labeled “not funded-helmet”. What must be noted is that after much discussion with the subcommittee, comparison with the BHARP survey and the pilot in Philadelphia, it is very hard to get a potential list of services to meet all the ways services are described in Individual Support Plans (ISPs) and other documents. It appears that the IDS funding system is very complicated with many choices but it also appears that people completing the survey were not always clear on which type of service a person was receiving.

Housing

Type of Living Situation	# Living in Setting Type	Percentage
MR Community Group Home	39	83%
Inpatient (Mental Health)	8	17%
Family Living Home	6	13%
Inpatient (Physical Health)	5	11%
Respite (Mental Retardation Funded)	2	4%
Community Rehabilitative Residence	1	2%
Respite (Mental Health Funded)	1	2%
State Hospital	1	2%
Independent Living	1	2%
RTF (Accredited)	1	2%
Other ***6	1	2%

***6 The *Other* response noted was MH State Center (not clear if this was a state center or state hospital).

When the type of housing for each person was queried, 66 responses were noted. Individuals may have spent parts of the year in several different settings, such as inpatient mental health services, respite services, or/and a community residential home. The clear majority of people, 83% or 39 people, lived in IDS-supported community group homes. Thirteen people spent at least some of their time in an inpatient setting (eight in a mental health inpatient setting and

five in a physical health inpatient setting). Six people resided in family living homes. Two people were living in MH-funded homes, one in a community rehabilitation residence and one in respite for at least part of the year. One person was in an RTF. The one “other” response was “MH State Center” and it was unclear if this was a state center or a state hospital. Despite difficulties with data collection, it might have been helpful to ask how many settings each person experienced over the year and how long they stayed in each setting. The number of settings people lived in may relate to mental health instability or to system related factors such as housing decisions not dictated by the individual. A quality of life review would be helpful to determine how changes in residential arrangements affect each person surveyed.

Inpatient MH Hospitalizations

16 Individuals with MH Admissions

Average Length of Stay = 71 days
 Range of Length of Stay = 1 day to 365 days

Data collection here is incomplete; of the sixteen individuals who experienced MH admissions, only nine reported on the length of stay. The data would suggest that the IDS system does not use inpatient hospitalization frequently. It is not clear whether it is because this service is often denied to individuals with intellectual disabilities or if it is because the IDS system has “learned” to cope with exacerbations of mental health symptoms in other ways (e.g., medications, extra staffing). However, the data would also suggest that when inpatient hospitalizations occur, some people stay for exceptionally long periods of time. Data for the 16 people who experienced inpatient hospitalizations is detailed in the following chart.

Individual #	MH Inpatient Hospitalizations	Average Length of Stay
1	1	1 day
2	1	5 days
3	1	7 days
4	1	215 days
5	1	365 days
6	2	3 days
7	2	15 days
8	4	8 days
9	5	25-30 days
10	6	24 days
11	1	Not Reported
12	1	Not Reported
13	2	Not Reported
14	3	Not Reported
15	6	Not Reported
16	7	Not Reported

Other Supports

Type of Support	#
Drug & Alcohol	0
Juvenile Probation	0
Parole	1
CYS	3
Aging	1

A few people had some additional supports from systems other than IDS, MH or BHMCO. One person was noted as on parole, three people were supported by the Children and Youth System (CYS), and one person had additional support from the Aging system. The data would seem to suggest the silo effect at work.

Relevant Incident Information

# Individual-Individual Abuse Incidents	# of People
9 incidents	1
3 incidents	1
2 incidents	1

Suicide Attempt	# of People
1 incident	1

ER Visits Med/Secondary Psych	# of People
13 incidents	1
6 incidents	1
3 incidents	1
2 incidents	5
1 incident	5

# ER Visits Behavioral Incidents	# of People
1 Incident	5
3 Incidents	2
4 Incidents	1
5 Incidents	2

Thirteen individuals experienced incidents in the category, *Emergency Room Visits – Medical/Secondary Psychiatric*, during the survey period. The average number of incidents per person was 2.8 incidents with the range from 1 to 13 incidents. Ten individuals experienced incidents in the category *ER Visits Behavioral*. The average number of incidents for these people was 2.5 with a range from 1 to 5 incidents. In both of the ER categories, it may be

interesting and informative to look at the actual incident reports to determine how many people were successfully supported.

# Law Enforcement Incidents	# of People
1 Incident	5
2 Incidents	3
3 Incidents	2

Again, ten people were involved with law enforcement incidents. The average number of incidents was 1.7 per person and the range was 1 to 3 per person during the survey year.

# Restraints	# of People
1 Restraint	2
3 Restraints	1
21 Restraints	1
28 Restraints	1
30 Restraints	1
38 Restraints	1

Seven people were restrained during the survey time period. The range was 1 restraint to 38 restraints for one individual. For the people with 38, 30, 29 and 21 restraints, it would be interesting to determine what supports were being offered in the residential setting.

Some interesting data can be found in looking at the incident data by individual.

Incident Data by Individual

Individuals	Individual to Individual Abuse	Suicide Attempts	ER Medical - Secondary Psych	ER Behavioral	Law Enforcement	Restraints
1			2	3		
2			2			
3			1			
4						30
5						1
6			1	1		
7				1	3	21
8						3
9			2		1	
10			1			
11			13	1		
12					2	
13					1	
14					1	
15			3	1	2	
16	3		2	1	1	1
17				5		38
18			1			
19		1	6			
20			1	5	3	28
21					2	
22	2		2	3	1	
23	9			4		

The total data on incidents represents 23 individuals, meaning 24 of our most costly individuals with dual diagnosis have no incidents in HCSIS. Does this imply that there is under reporting because these are the most costly people from each of the sampled counties? Or does this imply that the additional staffing provided is, in fact, containing some of the more difficult target symptoms of their mental illness.

Some noteworthy examples of data in which one person had multiple incidents of multiple types are described.

- One person who had 38 restraints also had 5 ER visits for behavioral reasons.
- An individual who had 28 restraints additionally had 3 incidents with law enforcement, 5 visits to the ER for behavioral reasons, and 1 ER visit for a medical reason.
- One individual who had 30 restraints reportedly had no other related incidents.
- In the restraint category, there were two individuals who had 1 restraint and 3 restraints respectively but had no other incidents.
- One individual experienced 1 restraint, 1 incident of law enforcement, 1 ER visit for behavioral reasons and 2 ER visits for medical reasons.
- For a different individual there were 2 incidents of individual to individual abuse, 2 incidents of ER visits for medical reasons, 3 incidents of ER visits for behavioral reasons, and 1 law enforcement incident.
- One person who had 9 incidents of individual to individual abuse also had 4 incidents of ER visits for behavioral reasons.
- The one individual who attempted suicide also had 6 ER visits for medical reasons.
- One person had 2 ER visits for medical reasons and three other people had 1 visit to the ER for medical reasons; none of these people had any other incidents in HCSIS during the survey year.
- Also notable, two people had 2 instances of law enforcement involvement and two others had a single incident of law enforcement involvement but no other relevant incidents reported to HCSIS within the survey period.

For some people it is obvious, when reviewing HCSIS data, which the person and their team have been struggling. But for others it seems, at least from the reported data, that all is quiet and working well. It is of concern when you see people with 28, 30 and 38 restraints. It is also concerning when there appear to be patterns of difficulty but only 51% report using Behavioral Support Services. Where are these people receiving support? Are they getting the clinical support they need to cope with their symptoms of mental illness? Are staff getting the training they need to understand mental illness and the symptoms as presented by each person? It is suspected that all factors, that might impact this data and the quality of life for the 47 people, are not represented in this survey.

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 IDS, MH and 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 at least half of the individuals served by the IDS system taking psychotropic medications, this is a problem that needs to be addressed across systems.

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 are 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.

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

Initial Survey of People with Dual Diagnosis Across the Commonwealth

Attachment A

PA Dual Diagnosis Cost Survey

Please identify the three individuals, who are dually diagnosed, from your county or joinder that have the largest service budgets for fiscal year 2009/2010. This would include all mental health and mental retardation funded services, excluding services reimbursed by MA. The total cost for MCO funded services, for each individual, for the same fiscal year will be provided following submission of the survey. A separate questionnaire should be completed for each of the three individuals.

1) Demographic Information:

Medical Assistance ID #

County/Joinder of Registration	County of Residence	Date of Birth	Gender

2) MR Diagnosis:

<input type="checkbox"/> Mild	<input type="checkbox"/> Moderate	<input type="checkbox"/> Severe	<input type="checkbox"/> Profound	<input type="checkbox"/> Severity not specified
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3) MH Diagnoses: List the Axis I and II ICD9 Diagnoses for the last two years (most recent first).

a) ICD9 Diagnosis #	b) ICD9 Diagnosis #	c) ICD9 Diagnosis #
d) ICD9 Diagnosis #	e) ICD9 Diagnosis #	f) ICD9 Diagnosis

4) Funding Information: Provide the total amount for all funding that applies for FY 09/10.

MR Funding:	\$	MH Funding:	\$	MCO Funding:	\$
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5) MR Waiver Services: Check all of the services that were provided for FY 09/10.

<input type="checkbox"/> Home & Community Habilitation	<input type="checkbox"/> Licensed Residential Habilitation	<input type="checkbox"/> Residential Enhanced Staffing
<input type="checkbox"/> Licensed Practical Nurse	<input type="checkbox"/> Registered Nurse	<input type="checkbox"/> Supplemental Habilitation
<input type="checkbox"/> Companion Services	<input type="checkbox"/> Adult Training Facility	<input type="checkbox"/> Older Adult Day Services
<input type="checkbox"/> Vocational Facility	<input type="checkbox"/> Supports Coordination	<input type="checkbox"/> Supported Employment
<input type="checkbox"/> Job Finding/Job Support	<input type="checkbox"/> Transitional Work Services	<input type="checkbox"/> Individual Behavior Therapy
<input type="checkbox"/> Group Behavior Therapy	<input type="checkbox"/> Physical Therapy	<input type="checkbox"/> Occupational Therapy
<input type="checkbox"/> Speech Language Pathology	<input type="checkbox"/> Visual Mobility Therapy	<input type="checkbox"/> Behavior Support Services
<input type="checkbox"/> Respite (In Home)	<input type="checkbox"/> Respite (Out of Home, Licensed)	<input type="checkbox"/> Respite (Out of Home, Unlicensed)
<input type="checkbox"/> Home Accessibility Adapt.	<input type="checkbox"/> Vehicle Accessibility Adapt.	<input type="checkbox"/> Assistive technology (non medical)
<input type="checkbox"/> Assistive Technology (medical)	<input type="checkbox"/> Other	

6) MR Base Funded Services: Check all of the services that were provided for FY 09/10.

<input type="checkbox"/> Respite	<input type="checkbox"/> Support (Medical Environment)	<input type="checkbox"/> Licensed Residential Habilitation
<input type="checkbox"/> Child Residential Services	<input type="checkbox"/> Community Residential Rehab.	<input type="checkbox"/> Community Home
<input type="checkbox"/> Family Aide	<input type="checkbox"/> Special Diet Preparation	<input type="checkbox"/> Recreation Leisure Activities
<input type="checkbox"/> Home Rehabilitation	<input type="checkbox"/> FSS/Individual Payment	<input type="checkbox"/> Other (please list below)

7) MH Base Funded Services: Check all of the services that were provided for FY 09/10.

<input type="checkbox"/> Outpatient Mental Health	<input type="checkbox"/> Partial Hospitalization	<input type="checkbox"/> Intensive Outpatient
<input type="checkbox"/> Acute Partial	<input type="checkbox"/> Administrative Case Management	<input type="checkbox"/> Resource Coordination
<input type="checkbox"/> Intensive Case Management	<input type="checkbox"/> Residential	<input type="checkbox"/> Psychiatric Rehabilitation
<input type="checkbox"/> Medication Management	<input type="checkbox"/> Other (Please list below)	

8) MCO Funded: Check all of the services that were provided for FY 09/10.

<input type="checkbox"/> Inpatient Hospitalization	<input type="checkbox"/> Partial Hospitalization	<input type="checkbox"/> Outpatient Mental Health
<input type="checkbox"/> Acute Partial	<input type="checkbox"/> Intensive Case Management	<input type="checkbox"/> Resource Coordination
<input type="checkbox"/> Psychiatric Rehabilitation	<input type="checkbox"/> Medication Management	<input type="checkbox"/> Other (Please list below)

9) Housing: Check all living situations that apply for FY 09/10.

Type of Living Situation	Average Length of Stay (Days)	Location of Placement
<input type="checkbox"/> Personal Care Boarding Home		_____ Out of County
<input type="checkbox"/> Community Rehabilitative Residence		_____ Out of County
<input type="checkbox"/> Family Living Home		_____ Out of County
<input type="checkbox"/> Long Term Structured Residence		_____ Out of County
<input type="checkbox"/> Respite (Mental Health Funded)		_____ Out of County
<input type="checkbox"/> Respite (Mental Retardation Funded)		_____ Out of County
<input type="checkbox"/> Inpatient (mental health)		_____ Out of County
<input type="checkbox"/> Inpatient (physical health)		_____ Out of County
<input type="checkbox"/> State Hospital		_____ Out of County
<input type="checkbox"/> Incarceration		_____ Out of County
<input type="checkbox"/> MR State Center		_____ Out of County
<input type="checkbox"/> MR Community Group Home		_____ Out of County
<input type="checkbox"/> Independent Living		_____ Out of County
<input type="checkbox"/> RTF (Non-Accredited)		_____ Out of County
<input type="checkbox"/> RTF (Accredited)		_____ Out of County
<input type="checkbox"/> Therapeutic Foster Care		_____ Out of County
<input type="checkbox"/> Juvenile Detention Center		_____ Out of County
<input type="checkbox"/> Other (specify):		_____ Out of County

9a) MR Community Group Home: Check all that apply if this placement was selected for Question 9.

Number of Individuals in Home	Staffing Ratio
<input type="checkbox"/> 1 Individual Home	___ 1:1 ___ 2:1 ___ 3:1 ___ 4:1 ___ 5:1
<input type="checkbox"/> 2 Individual Home	___ 1:1 ___ 2:1 ___ 3:1 ___ 4:1 ___ 5:1
<input type="checkbox"/> 3 Individual Home	___ 1:1 ___ 2:1 ___ 3:1 ___ 4:1 ___ 5:1
<input type="checkbox"/> 4-8 Individual Home	___ 1:1 ___ 2:1 ___ 3:1 ___ 4:1 ___ 5:1

9b) Inpatient Hospitalizations: If mental health hospitalizations were selected indicate the number for each category below.

Number of Admissions:		Average Length of Stay:	
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10) Medical Conditions: List all medical conditions (indicate if they required hospitalization for 09/10).

Medical Condition	ICD9 Diagnosis	Hospitalization Required
		___ yes ___ no ___ n/a
		___ yes ___ no ___ n/a
		___ yes ___ no ___ n/a
		___ yes ___ no ___ n/a
		___ yes ___ no ___ n/a

11) Other Supports: Check each category that provided additional supports for FY 09/10.

<input type="checkbox"/> Drug & Alcohol	<input type="checkbox"/> Juvenile Probation	<input type="checkbox"/> Parole	<input type="checkbox"/> CYS	<input type="checkbox"/> Aging	<input type="checkbox"/> n/a
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12) Relevant Incident Information: Indicate the number of incidents for each category (N/A for no contacts).

Individual to individual abuse	Suicide attempts

ER Visits Medical/Secondary Psych	ER Visits Behavioral	Law Enforcement	Restraints

13) Positive Practices Resource Team: Check all that apply.

<input type="checkbox"/> Referral Made	<input type="checkbox"/> Referral Fulfilled	<input type="checkbox"/> Plan Developed	<input type="checkbox"/> Plan Utilized	<input type="checkbox"/> n/a
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14) Clinical Review: *Check all that apply.*

<input type="checkbox"/> Referral Made	<input type="checkbox"/> Referral Fulfilled	<input type="checkbox"/> Plan Developed	<input type="checkbox"/> Plan Utilized	<input type="checkbox"/> n/a
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15) Contact Information:

Completed By	Position	Date

Phone (with area code)	Email Address

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Developmental Disabilities and Mental Health Challenges

Initial Survey of People with Dual Diagnosis Across the Commonwealth

Attachment B

ID/MH/MCO Funding

	\$654
	\$3,776
	\$14,332
	\$36,943
	\$71,949
	\$76,508
	\$84,465
	\$147,454
	\$161,790
	\$163,176
	\$164,381
	\$167,726
	\$169,186
	\$179,313
	\$193,812
	\$205,997
	\$211,481
	\$214,623
	\$220,665
	\$221,249
	\$223,424
	\$225,122
	\$228,451
	\$229,048
	\$229,510
	\$232,833
	\$233,888
	\$236,108
	\$247,448
	\$252,317
	\$266,149
	\$270,139
	\$290,739
	\$296,146
	\$305,933
	\$306,128
	\$306,967
	\$318,338
	\$367,610
	\$374,956
	\$386,274
	\$399,561
	\$401,019
	\$403,521
	\$433,603
	\$502,902
	\$570,667
Total	\$11,248,282