

Assessing the Financial Planning Needs of Americans with Mental Illnesses

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Introduction

“The negative impact of poverty on the lives of mental health consumers cannot be understated. The hunger, homelessness, and lack of adequate physical health care that consumers regularly experience are the prime results of poverty. Inadequate clothing, lack of transportation, poor education, and reduced ability to pay for socialization activities are also major factors in the daily lives of many mental health consumers. Poverty has been shown to have a disproportionate frequency among people with mental illnesses and is also associated with harmful outcomes. Poverty-related needs and subsistence issues have been repeatedly identified by consumers of mental health services as their greatest challenges.”*

Americans with disabling mental health disorders are far more likely to live in poverty than the general population. In addition, people with psychiatric disabilities often face complex financial situations, such as having to choose between receiving disability benefits or pursuing employment. Too often, people with mental illnesses are unable to exercise choice in how their financial resources are allocated in terms of housing, education, leisure pursuits, or other important life activities. Unfortunately, existing financial planning tools are either limited in scope (for example, focusing only on planning for Social Security disability benefits), or aimed at too broad an audience, and not specifically tailored to the issues faced by people with mental health concerns. People with psychiatric disabilities deserve a dedicated resource to use in learning to manage money, and plan their own financial futures.

The University of Illinois at Chicago Center on Mental Health Services Research & Policy (CMHSRP) was funded by the National Endowment for Financial Education (NEFE) to assess the financial planning and education needs of people with psychiatric disabilities. Over the

course of this one-year project, we gathered comprehensive information on the complicated financial situations that people with psychiatric disabilities often face. The results of our research are included in this report, as are a set of recommendations for effective financial planning tools. In addition, CMHSRP has compiled a list of national organizations that we feel are promising resources and dissemination partners. Finally, original sources for all the material included in the report have been copied and attached.

The President's New Freedom Commission on Mental Health recently issued a report (2003) calling for a fundamental transformation of the Nation's approach to mental health care. One of the Commission's stated goals for this transformation is that mental health care should be consumer and family driven. This emphasis on self-determination will be difficult to fulfill as long as consumers are living in poverty with few places to turn for financial planning and education skills. This is an ideal time to develop and disseminate financial planning and money management resources and tools oriented toward mental health consumers, their families, and providers.

*(del Vecchio, Fricks, & Johnson, 2000)

Section A: Characteristics and Prevalence of the Major Diagnoses of Mental Illness

In this section we describe the major diagnoses of mental illness that are used by clinicians as set forth in the American Psychiatric Association's *Diagnostic and Statistical Manual of Mental Disorders, Fourth Edition, 1994* (DSM-IV). It is important to recognize that these diagnoses are not universally accepted. Many mental health consumers and others believe that diagnoses are clinically imposed on people's natural experiences of emotional distress. However, these are terms that are commonly used in mental health services to describe groups of symptoms that can be experienced by mental health consumers, and are the basis for clinical assessments of psychiatric disability.

Mood Disorders are among the most commonly diagnosed forms of mental illness, and are divided into Bipolar Disorders, Depressive (unipolar) Disorders, and mood disorders due to medical conditions or substance abuse. These diagnoses are primarily characterized by a disturbance of mood, accompanied by full or partial manic or depressive syndromes. Bipolar Disorders (Bipolar I Disorder, Bipolar II Disorder, and Cyclothymic Disorder) are identified by the presence of at least one episode of mania during the history of the individual's illness. Mania is a phase characterized by feelings of euphoria, extreme optimism, and inflated self-esteem; common symptoms include restlessness, lack of sleep, rapid speech, racing thoughts, irritability, difficulty concentrating, and increased energy or activity. During manic episodes, people may do things that have severe consequences for their financial futures, such as going on spending sprees, giving away everything they own, taking unnecessary risks (including high risk sex or drug use), or rushing into big decisions. As an example, "Martina" works on a crew that cleans offices every day. When she starts to experience the initial symptoms of mania, she has difficulty completing any one task, though she may have several tasks going at the same time. She also

accuses her coworkers of working too slowly. She begins to speak very quickly about a variety of topics at once, confusing those around her. When in this manic state, she feels that she ought to be supervising the crew because she is the only one who can do it correctly, despite the fact that she is actually not completing any work herself. She overextended her credit in a clothes-buying spree, and then gave away all her purchases.

Major Depressive Disorder may begin at any age, and is characterized by almost continuous depressed mood for at least two weeks at a time. People with major depression experience: diminished pleasure in all activities; significant weight loss or gain; difficulty sleeping (insomnia) or difficulty getting out of bed (hypersomnia); recurrent thoughts of suicide; feelings of worthlessness or excessive guilt; inability to concentrate; and excessive unproductive nervous activity such as repetitive hand-wringing, pacing, or complaining. For example, when “Kevin” is experiencing major depression, he may spend days at time in bed, not showing up for work, school, or personal appointments. When he does get out of bed, he may move very slowly, and may not attend to personal hygiene or appearance due to severe lack of energy. He has an extremely hard time interacting with other people, and when he does, he tends to show no emotion, to be “dead-pan” with what is known as “flat affect.” Often, he won’t speak to people at all, or interact with others in any way. Such extreme apathy or despondence can lead to a disregard for spending habits or bill paying.

Dysthymic Disorder is characterized by at least two years of depressed mood for more days than not, accompanied by additional depressive symptoms that do not meet criteria for a Major Depressive Disorder.

Anxiety Disorders are the most commonly diagnosed form of mental illness and often occur in conjunction with mood disorders. The major forms of anxiety disorders include:

Generalized Anxiety Disorder; Obsessive-Compulsive Disorder; Panic Disorder; Post Traumatic Stress Disorder; Social Anxiety Disorder; and a number of specific phobias. The following is a description of these categories provided by the Anxiety Disorders Association of American (ADAA): *Generalized Anxiety Disorder (GAD)* is characterized by excessive, unrealistic worry that lasts six months or more; in adults, the anxiety may focus on issues such as health, money, or career. In addition to chronic worry, GAD symptoms include trembling, muscular aches, insomnia, abdominal upsets, dizziness, and irritability. In *Obsessive-Compulsive Disorder (OCD)*, individuals are plagued by persistent, recurring thoughts (obsessions) that reflect exaggerated anxiety or fears; typical obsessions include worry about being contaminated or fears of behaving improperly or acting violently. The obsessions may lead an individual to perform a ritual or routine (compulsions) such as continual hand washing, repeating phrases, or hoarding, in order to relieve the anxiety caused by the obsession. People with *Panic Disorder* suffer severe attacks of panic-which may make them feel as if they are having a heart attack or are losing control-for no apparent reason. Symptoms include heart palpitations, chest pain or discomfort, sweating, trembling, tingling sensations, feeling of choking, fear of dying, fear of losing control, and feelings of unreality. Panic disorder often occurs with agoraphobia, in which people are afraid of having a panic attack in a place from which escape would be difficult, so they avoid these places. *Post-Traumatic Stress Disorder (PTSD)* can follow an exposure to a traumatic event such as a sexual or physical assault, witnessing a death, the unexpected death of a loved one, or natural disaster. There are three main symptoms associated with PTSD: "reliving" of the traumatic event (such as flashbacks and nightmares); avoidance behaviors (such as avoiding places related to the trauma) and emotional numbing (detachment from others); and physiological arousal such as difficulty sleeping, irritability or poor concentration. *Social*

Anxiety Disorder (Social Phobia) is characterized by extreme anxiety about being judged by others or behaving in a way that might cause embarrassment or ridicule. This intense anxiety may lead to avoidance behavior. Physical symptoms associated with this disorder include heart palpitations, faintness, blushing and profuse sweating. People with *specific phobias* suffer from an intense fear reaction to a specific object or situation (such as spiders, dogs, or heights); the level of fear is usually inappropriate to the situation, and is recognized by the sufferer as being irrational. This inordinate fear can lead to the avoidance of common, everyday situations.

According to the DSM-IV, both *Panic Attacks* (sudden onset of intense terror and fear) and *Agoraphobia* (fear of unfamiliar places or situations) can occur in the context of any of these Anxiety Disorders. People who live with severe anxiety disorders often feel unable to leave the house or engage in activities such as money management due to feelings of extreme apprehension or exhaustion.

Schizophrenia Spectrum Disorders, have psychotic symptoms as the defining feature, and include: schizophrenia; schizophreniform disorder (schizophrenia of shorter duration); schizoaffective disorder (psychotic symptoms co-occur with mood disturbance); and psychotic disorders due to medical conditions or substance abuse. A variety of definitions have been applied to the meaning of “psychotic” over the years, and debate continues to this day. In general, psychosis is used to refer to symptoms that seem to detach a person from reality, such as delusions, prominent hallucinations, disorganized speech, and disorganized or catatonic behavior. Schizophrenia has an earlier onset than most other psychiatric disorders, usually becoming apparent in an individual by their late teen years or early 20’s. Schizophrenia disturbance lasts for at least six months with at least one month of active-phase psychotic

symptoms. While schizophrenia is one of the least understood of mental illnesses, it is also one of the most challenging to live with.

There are five major types of schizophrenia. Features of *paranoid type* schizophrenia include: preoccupation with delusions or auditory hallucinations that are either persecutory or grandiose, or both, unfocused anxiety, anger, argumentativeness, and occasionally, dangerous behavior. As an example, “Earl” has been working in an office for two years. When he starts to experience symptoms of paranoid schizophrenia, he believes that his co-workers and supervisor are giving him all of the unpleasant tasks in the office. He believes that they do this in order to make him look bad and he feels as if they are “ganging up” on him. Earl then starts to feel like everyone is watching his every move and reading all of his mail. When this happens, he becomes very angry and starts arguments with office mates. He thinks that bills are threatening messages from enemies, and he destroys them. He won’t answer the phone at home.

Schizophrenia of a *catatonic type* is distinguished by marked mental and physical disturbance, usually in the form of mental excitement or stupor and physical rigidity or bizarre postures or activities, prominent grimacing, or repetitive imitation of words or movements. Alternation between excitement and stupor is common, as is an apparent inability to speak. For example, “Jeanne” has been working in the kitchen of a large cafeteria. When she started to experience symptoms, her left arm “froze up” and she was not able to prepare food or wash dishes for at least an hour, causing coworkers to become angry at her lack of assistance. Within several days, Jeanne began to stand completely still in the middle of the kitchen, with her hands rigid against her sides. She was unable to continue working, and stood that way until someone called for professional assistance.

Disorganized, or hebephrenic, schizophrenia typically has an early onset and displays a chronic course without significant remissions. The essential features of this type are incoherence, marked loosening of associations, grossly disorganized behavior, and inappropriate affect including irrelevant silliness and laughter. Social impairment and oddities of behavior are common, as are fragmentary delusions and hallucinations without a coherent theme. As an example, “Phil” has difficulty interacting with coworkers and supervisors because he often discusses current events he has seen on the news as if they are happening to people in the office. He usually speaks much too loudly, almost yelling, and walks around and around someone’s desk when he is telling a story. Phil regularly forgets to go to work, especially when he is caught up in watching the news, which causes his coworkers to feel over-burdened and resentful.

When diagnosed as having schizophrenia of an *undifferentiated* nature, the individual meets the usual criteria for schizophrenia (delusions, hallucinations, thought disorder, and bizarre behavior) but does not clearly fit into any one subtype because of a mixed symptom picture. For example, “Norma” works as a bagger in a grocery store. When she experiences symptoms, she had difficulty determining what is real and what is delusional. She quickly fluctuates back and forth between her present situation and her hallucinations. Norma also starts to believe that the items customers purchase have some special significance in her own life. This belief causes her to start unusual, inappropriate conversations with customers about the ways in which their purchases are affecting her life.

Finally, schizophrenia of the *residual type* is characterized by common signs of schizophrenia, such as emotional blunting, social withdrawal, eccentric behavior, illogical thinking, and mild loosening of associations, without prominent psychotic symptoms (i.e., loss of contact with reality, usually involving delusions or hallucinations). As an example, “Bill” has

been refusing to go into work for the past week. When Bill starts experiencing symptoms he will not leave his apartment. He becomes reluctant to have regular contact with people and believes that his supervisor regrets having hired him.

Some individuals with mental illness have either a primary or secondary diagnosis of one of the many types of Personality Disorders. Diagnostic criteria refer to behaviors or traits that are characteristic of the person's recent and long-term functioning. The behaviors cause either significant impairment in social or occupational functioning or subjective distress. There are ten types of personality disorders, including: Paranoid, Schizoid, Schizotypal, Borderline, Histrionic, Narcissistic, Antisocial, Avoidant, Dependent, and Obsessive-Compulsive.

The essential feature of a *Paranoid Personality Disorder* is a pervasive and unwarranted tendency, present in a variety of contexts, to interpret the actions of others as deliberately demeaning or threatening. Persons with this disorder feel exploited or harmed by others. Frequently they will question the trustworthiness of others, harbor jealousy, are easily slighted and quick to react with anger, and are reluctant to confide in others, fearing the information may be used against them. Persons diagnosed with *Schizoid Personality Disorder* have a pervasive pattern of indifference to forming social relationships and a restricted range of emotional experience and expression. They prefer to be "loners." They almost always choose solitary activities and are indifferent to praise and criticism. Individuals with *Schizotypal Personality Disorder* exhibit a pervasive pattern of peculiarities of ideation, appearance, and behavior, as well as deficits in interpersonal relatedness. Characteristics may include excessive social anxiety, magical thinking, unusual perceptual experiences, odd speech, or suspiciousness. The essential feature of *Borderline Personality Disorder* is a pervasive pattern of instability of self-image, interpersonal relationships, and mood, as well as a marked, persistent identity

disturbance. People diagnosed with this disorder often appear to be uncertain about major life issues, such as jobs/career, goals, friends, and values. Instability of mood is also common, and in severe cases, so are recurrent suicidal threats and gestures. Frequent displays of temper, anger, and recurrent fights may be present as well. A *Histrionic Personality Disorder* is characterized by excessive emotionality and attention seeking. Persons seek and demand reassurance, approval, or praise, and are uncomfortable when they are not the center of attention. They display rapidly shifting and shallow expression of emotions. Their behavior is overly reactive and intensely expressed. There is a tendency to be very self-centered with little tolerance for the frustration of delayed gratification. Individuals diagnosed with *Narcissistic Personality Disorder* will display a pattern of grandiosity, hypersensitivity to the evaluation of others, and lack of empathy. Persons will display an exaggerated sense of self-importance and exaggerate their accomplishments and talents. Self-esteem is almost invariably very fragile and feelings are masked with an aura of cool indifference. Persons with *Antisocial Personality Disorders* show a pattern of irresponsible and antisocial behavior. They must be at least 18 years old, and have a history of conduct disorder before the age of 15. Lying, stealing, truancy, vandalism, and fights are typical childhood signs. The pattern continues in adulthood and may include failure to honor financial obligations, to function as a responsible parent, or to sustain consistent work behavior. These persons fail to conform to social norms and repeatedly perform acts that are grounds for arrest. They tend to be irritable and aggressive. Generally, they have no remorse about the effects of their behaviors on others. Individuals diagnosed with *Avoidant Personality Disorder* show social discomfort, fear of negative evaluation, and timidity. They are easily hurt by criticism and devastated by the slightest hint of disapproval. These persons are generally unwilling to enter into relationships unless they feel a guarantee of uncritical acceptance. Dependent and

submissive behavior is the essential feature of a *Dependent Personality Disorder*. Persons with this disorder are unable to make decisions without excessive advice and reassurance. This tends to lead to difficulty in initiating projects or doing things on one's own. People with this disorder are easily hurt by criticism and disapproval and tend to subordinate themselves to others, agreeing with people even when they believe them to be wrong. Finally, an *Obsessive-Compulsive Disorder* (commonly referred to as OCD) is characterized by perfectionism and inflexibility. Persons with this disorder show a preoccupation with rules and details, and this interferes with their ability to take a broad view. Work and productivity are prized and decision-making is avoided. Persons with OCD are extremely conscientious, moralistic, and judgmental of self and others.

Prevalence of Mental Illness in the United States. Mental illness affects people of all racial and ethnic backgrounds, economic levels, educational levels, and national origins. Mental disorders are currently one of the leading causes of disability worldwide (Mental Health: A Report of the Surgeon General). The onset of mental illness is usually during young adulthood, but can occur or reoccur at any time. Currently, the best estimate of prevalence is that about 19%-20% of the adult U.S. population is affected by mental disorders in any given year (almost 40 million adults). Most common are Anxiety Disorders (~16% of the population), followed by Mood Disorders (~7% of the population, mostly Major or Unipolar Depression). Only a little over 1% are diagnosed with schizophrenia, and 2% with Antisocial Personality Disorder (current estimates for other Personality Disorders are not available). An additional 3% of the adult population has co-occurring mental and addictive disorders, and 6% have addictive disorders alone. It is estimated that 9% of U.S. adults have a diagnosable mental disorder resulting in some level of functional impairment, and 5% experience "serious mental illness" interfering with

social functioning (about 11 million adults). Finally, an estimated 8.1 million civilian, non-institutionalized adults are disabled by their psychiatric disorder and unable to work (LeBlanc, Kang, Mullan & LaPlante, 2003).

Disparities and Vulnerable Groups. According to the former Surgeon General David Satcher, race/ethnic, gender, and age disparities in access to and utilization of mental health services are even more extreme than in other areas of health and medicine (U.S. Department of Health & Human Services, 1999). On the other hand, although there are associations between demographic characteristics and particular diagnoses (e.g., women are more likely to be diagnosed with mood disorders than men, and schizophrenia almost always manifests in young adults), mental illness affects men and women of all ages and race/ethnicities. Even though the prevalence of mental disorders is estimated to be higher among African Americans than among Caucasians/whites, this difference has been shown to be attributable to disparities in socioeconomic status (i.e., higher proportions of African Americans living at a lower socioeconomic statuses). Given the strong association between mental illness and poverty, all people with severe mental illnesses are a vulnerable group, often underserved and economically marginalized. According to Satcher, “A key disparity often hinges on a person’s financial status; formidable financial barriers block off needed mental health care from too many people regardless of whether one has health insurance with inadequate mental health benefits, or is one of the 44 million Americans who lack any insurance.” As a result, fewer than one in four people with severe mental illness in the United States receive the treatment that they need (Wang et al., 2002). Not surprisingly, people with mental illness who are also members of race/ethnic minorities or other discriminated-against groups may be at a compounded social disadvantage.

Mental Health Symptoms and Medication Side Effects. Regardless of diagnosis, mental health symptoms are often characterized into two types: positive (e.g., delusions, hallucinations, disorganized thinking, and agitation) and negative (lack of drive or initiative, social withdrawal, apathy and emotional unresponsiveness). Either type of symptom can interfere with the kind of organization and impetus that is necessary to engage in sensible money management or financial planning. Symptoms can often be controlled by psychopharmacologic medications, but sometimes the side effects of these medications are just as impairing as the original symptoms. For example, antipsychotic medications (for Schizophrenia Spectrum Disorders) can result in sedation, drowsiness, memory problems, confusion, restlessness, tremors, and weight gain. Mood stabilizers (for Bipolar Disorders) can result in feeling dazed or tired, muscle weakness, tremors, gastrointestinal distress, and weight gain. Antidepressants can result in sleepiness, restlessness, tremors, memory loss, headaches, muscle aches, and weight gain. Similarly, anti-anxiety agents can result in drowsiness, dizziness, fatigue, lack of coordination, confusion, and irritability.

Mental Illness & Education. Since the major mental disorders have an average age of onset in the late teens and early twenties, interrupted educations characterize many individuals with this disability. Only 38% of special education students diagnosed with severe emotional disturbance (SED) graduate from high school, while another 6% receive a certificate such as a General Equivalency Degree. The remaining 56% do not complete their schooling (Kaye, 2001). The National Longitudinal Transition Study (NLTS), a survey of young people exiting special education programs across 303 nationally representative school districts (Wagner, 1993), found that youth classified as emotionally disturbed had the highest percentage of high school noncompletion and failing grades. One to two years after exiting high school, only 18% were

employed full time, while another 21% worked part time. The NLTS also found that this group had post-high school work experiences characterized by greater instability than all other disability groups (Wagner, 1993).

Perhaps not surprisingly, by the time they reach adulthood, reading comprehension and mathematics computation levels of adult psychiatric rehabilitation populations are well below age-appropriate levels (Cook, Wessell & Dincin, 1986; Cook & Solomon, 1993). Less than 6% of all participants entering the 8-state Employment Intervention Demonstration Program (EIDP) study of supported employment interventions had a college degree (Cook et al., 2002). These gaps in education are critically important because the growth rate of occupations is fastest among those requiring an Associate's Degree (A.A.) or more advanced education. Seventy percent of the 30 fastest growing occupations and a third of the 30 occupations with the largest anticipated numerical increase require a community college or university degree or some post-secondary training (Hecker, 2001). Lack of education also impedes individuals' ability to read and comprehend financial education and planning materials. Those at low literacy levels may require products developed for those with less than an 8th grade education.

Summary. Although there are a variety of diagnoses associated with severe mental illness, there are a number of similarities in terms of symptoms and medication side effects that can interfere with money management regardless of diagnosis. At varying times, most people with mental illnesses are likely to experience considerable tiredness, some cognitive confusion and trouble remembering things, and difficulty interacting with other people. People with psychotic or manic disorders may at times be delusional and therefore unable to manage money, and people with mood or anxiety disorders may be unable to bring themselves to manage money out of overwhelming disinterest or fear. The likelihood of interrupted or low-levels of education

must also be taken into account when developing any training or education materials for people living with mental illnesses. Although all people with mental illnesses should be considered to be a socially vulnerable group, minorities, women, and older adults with mental illnesses may be at a particular risk of poverty.

Section B: Mental Illness & Poverty

In the United States, people who have been diagnosed with a disabling mental disorder are far more likely to live in poverty than the general population (Kessler et al., 1994; Polak & Warner, 1996; Willis et al., 1998). Policy analyses of the relationship between poverty and psychiatric disability have focused heavily on systems issues. A 1998 review of U.S. policies affecting people with psychiatric disabilities by Noble posed the issue in terms of the inadequacies of federal macrosystems in serving people with psychiatric disabilities from a rehabilitation point of view (Vocational Rehabilitation), with an acknowledgement of related systems, including job opportunities (Americans with Disabilities Act), income support programs (Social Security Administration Disability) and health insurance (Medicare & Medicaid). This analysis also noted the tangible and intangible social costs incurred by the impoverishment of such a large population, and the uniquely marginalized position of people with psychiatric disabilities, as being “at the tail-end of the labor queue” (p. 780), both last hired and first fired. In this section, we analyze the disability, income support, employment, health care and education policies that affect the financial lives and well being of people with psychiatric disabilities.

History of Disability Policy in the United States. It is difficult to identify a “disability policy” in the U.S. because the programs involved are largely disparate and were established before there was a concept of disability groups (Berkowitz, 1987). For example, Social Security Disability Insurance (SSDI), legislatively enacted in 1956, was initially available only to commercial and industrial workers over age 50, who could demonstrate they were unable to hold any job, anywhere in the country, because of a permanent physical or mental condition. SSDI, Vocational Rehabilitation and other programs developed piecemeal over the 20th century, as a series of separate programs often working at cross-purposes, with different intentions and

eligibility requirements. According to Berkowitz' analysis, the U.S. has misplaced its priorities simply because the Social Security Administration transfers money more efficiently than Vocational Rehabilitation prepares people to enter the labor force. Instead of making disability anachronistic, the end result of these complex and disparate programs has been to keep people with disabilities from working.

Other researchers have articulated how U.S. disability policy reinforces the social and economic marginalization of people with disabilities (Scotch, 1999). Scotch notes that a persistent theme in U.S. disability policy is "its cultural constructs of worthiness and morality, both in its broad conception and in concrete criteria of eligibility" designed for the "deserving poor." In this context, people with psychiatric disabilities are particularly likely to be considered as malingerers, representing a lack of self-control or poor character. In order to benefit from governmental supports, people with mental illnesses must prove themselves to be medically ill and dependent on assistance, and in the process they become segregated from mainstream society. This requirement of incapacity is an underlying social construction of disability that serves to marginalize and impoverish individuals who already constitute a vulnerable population. For example, the currently accepted standard of gainful employment is that an individual should work at least 37.5 hours a week (considered full-time), year-round. Although historically this is an arbitrary demarcation, it now essentially serves to enforce unemployment and poverty among people with mental illnesses who typically cannot work that many hours because of symptom- or medication-related impairments.

Employment for Mental Health Service Consumers: The Problems

Many individuals with serious mental disorders experience symptoms and/or medication side-effects that are disabling and impair their ability to work. As a result, most working-age

individuals with severe mental illnesses are out of the labor force, unemployed, or underemployed. People who are not working are considered to be either “out of the labor force,” if they are not seeking employment due to retirement, disability, or some other reason, or “in the labor force but unemployed,” if they are seeking employment. Studies have shown how labor force participation among people with disabilities is closely tied to overall labor market dynamics (Yelin & Katz, 1994). For example, long-term labor market trends, from 1970 through 1992, in which there was a decline in male labor force participation and an increase in female labor force participation, were mirrored in proportional labor market participation rates among men and women with disabilities. However, in the short-term, while people with disabilities experienced proportionally larger gains during periods of market expansion, they also evidenced greater losses during times of market contraction than did people without disabilities (Yelin & Katz, 1994).

Almost two-thirds (61%) of working age adults with mental health disabilities are out of the labor force (defined as not having a job and not having looked for work in the past 2 weeks), compared to only 20% of their counterparts in the general population without psychiatric disabilities (National Health Interview Survey-Disability Supplement [NHIS-D], 1994-5). Of those American citizens with mental health disabilities who *are* in the workforce, 16% are unemployed, compared to only 4% unemployed in the adult working age population at large (NHIS-D, 1994-5). While over three-quarters (77%) of the general adult working age population are employed, only 33% of working age adults with mental health disabilities are employed and only 17% of those with *severe* mental health conditions are working (NHIS-D, 1994-5). Even a college education does not appear to ameliorate the disadvantageous position of consumers in the

labor market. Among college graduates, 43% of those with mental health disabilities are not working compared to only 13% of those without mental health disabilities (NHIS-D, 1994-5).

Underemployment is also a serious problem for people with severe mental illnesses. Among a large group of mental health consumers receiving intensive employment support services as part of an 8-state national study called the Employment Intervention Demonstration program (EIDP) (Cook et al., 2002), a full 70% of those with college degrees (AA or higher) earned less than \$10/hour (equivalent to an annual salary of \$21,000) at their highest level job, and the majority (54%) were employed only part-time. Underemployment also characterizes the population of individuals with all types of disabilities at large. Yelin's analysis of 1995 Current Population Survey data showed that, among people with some graduate school or higher education, those with disabilities had a labor force participation rate only half that of persons without disabilities (Yelin, 2001). However, as described earlier, a related problem is the fact that many mental health consumers lack the necessary high school and post-secondary education and training required to build careers.

Given these sobering findings, it is equally problematic that most people with disabling mental illnesses receive little or no services to help them obtain or maintain employment. Among a stratified random sample of persons diagnosed with Schizophrenia in two states, only 23% of outpatients were receiving vocational rehabilitation services (Lehman et al., 1998). By federal legislative mandate, the Rehabilitation Services Administration (RSA), an agency of the Department of Education, funds vocational rehabilitation (VR) programs in each state to provide job placement and training services to all eligible persons with disabilities. In fiscal year 1995, 1.3 million adults were clients of state-run VR programs, accounting for 12% of all Americans estimated to have health conditions or impairments that limited their ability to work (U.S. Census

Bureau, 1995). Some 2 billion in federal dollars matched by \$645 million in state and local programs are allocated annually to state VR programs (Kaye, 1998).

Researchers have studied the effectiveness of such programs over time by examining longitudinal trends in successful closure rates among state VR clients. (VR cases can be “closed” for a number of reasons, including employment placement, transfer to other programs, or lost contact, among others.) Andrews and his colleagues (1992) examined RSA-911 data (a data base of all persons using state VR services whose cases have been closed) from 1977 through 1984. They found that the percent change in number who entered or returned to competitive employment following closure increased among individuals with severe *physical* disabilities, but not for those with severe *psychiatric* disabilities. The amount expended on case services for VR clients with psychiatric disabilities in 1986 was roughly 15% less than for clients with all other disabilities (Conley, 1999). Less than half of all people with disabilities who exited the VR system in 1995 had completed their service plan and been employed for 60 days (Kaye, 1998).

Given the high level of social stigma attached to mental illness in American society, it is not surprising that people with mental disorders experience labor force discrimination. In employer surveys over the past five decades, employers have expressed more negative attitudes about hiring workers with psychiatric disabilities than any other group (with the occasional exception of intellectual and substance abuse disabilities) (Cook et al., 1994; Diksa & Rogers, 1996). In a national probability sample, one third (32%) of those with mental health disabilities reported having been fired, laid off or told to resign (22%), refused employment (14%), refused a transfer (6%), refused a promotion (10%), or refused a training opportunity (6%) *because of their disability* (NHIS-D, 1994-5). Looking closer at the question of earnings, Baldwin and Johnson

(1998) applied techniques used by economists to study race and sex discrimination through the development of multivariate models designed to explain wage differentials. Their analysis focused on the wages of men and women both with and without disabilities in 1984 and 1990. After accounting for productivity differentials related to functional limitations, and other productivity-related characteristics of individuals (such as education, occupational distributions, and part-time employment), large remaining unexplained variance in wage differentials suggested that those with disabilities were experiencing discrimination in the labor market. Moreover, among males with impairments thought to evoke "greater prejudice" such as mental illness and paralysis, the amount of unexplained variance attributed to discrimination and residual effects was greater than that among men with impairments evoking "mild prejudice" such as diabetes and back problems. (Small sample sizes prevented the testing of this hypothesis among the female respondents.)

Income Support for Mental Health Service Consumers: The Problems

A series of benefits and entitlements including cash payments, vouchers, and other income support mechanisms are currently in place to assist individuals with disabilities who are unable to work. Recent concerns are that these systems (SSI, SSDI, Medicare, Medicaid), designed for other purposes in times of different population demographics, no longer are viable without significant alterations. Many individuals with serious mental disorders qualify for and receive either supplemental security income (SSI), a means-tested income-assistance program, or social security disability insurance (SSDI), a social insurance program with benefits based on prior earnings. The number of SSI and SSDI beneficiaries with psychiatric disabilities has been increasing at a higher rate than total program growth for over a decade (National Academy of Social Insurance, 1994). Individuals with severe mental illnesses represent the single largest

diagnostic group on the SSI rolls -- 36% in December, 2001 (Social Security Administration, 2002). In 1999, people with psychiatric disabilities comprised over a third of working aged adults receiving SSI and over a quarter (27%) of all SSDI recipients (McAlpine & Warner, 2002).

One problem with this situation is that disability income is equivalent to poverty level income. As a national average, year 2000 SSI benefits were equal to around \$3.23/hour or almost \$2.00 less than minimum wage (Consortium for Citizens with Disabilities, 2000). On average, rental of a modest, one bedroom apartment costs 98% of year 2000 SSI benefits (ibid). Annual year 2000 SSI benefits averaged only 18.5% of the one-person median household income, dropping below 20% for the first time in over a decade (ibid). SSDI income has the capacity to provide annual income above the poverty level, but only for those with high annual earnings for at least three eligible years. Among those with disabling mental disorders participating in the EIDP, almost three-quarters (73.9%) were at or below the poverty level: 78% of those on SSI lived in poverty, while 59% of those on SSDI, 75% of those on both, and 87% of those on neither did so. Thus, income support programs for people with mental illnesses are inadequate to help them meet basic needs, including the requisites of job training and seeking.

Even given its inadequacies, mental health consumers rely heavily on disability benefits not only for income but also for their health care and psychotropic medication coverage. This is because individuals with major mental disorders experience discrimination due to lack of parity in health and mental health care, forcing them to rely on public systems of care (Sing & Hill, 2001). In a study of individuals with schizophrenia followed for a mean of five years after their first hospitalization (Ho, Andreasen & Flaum, 1997), 56% were primarily supported by SSI,

SSDI, or AFDC at one year post-discharge, and 72% relied on one or more of these public funding sources throughout much of the follow-up period. Thus, disability income support and health care coverage are inter-twined to the detriment of many recipients, especially those attempting to return to work.

The vulnerability of those who return to work while on the federal disability insurance (SSDI) rolls is evident in studies showing that most re-enter the labor force because of financial need rather than medical improvement (Schechter, 1997). Those who do return to work tend to be younger and better educated than those who do not. Their initial post-SSDI jobs are lower paying and for fewer hours than the job held prior to DI reciprocity, and they tend not to return to their previous employer. Moreover, the first job attempt after SSDI entitlement has the greatest chance of leading to successful labor force re-entry; the likelihood of positive outcomes decreases with subsequent job attempts (Hennessey, 1996). Finally, while workplace accommodations may extend the average duration of employment for those with disabilities (Burkhauser, Butler & Kim, 1995), there is evidence that some injured workers who receive job accommodations also receive lower wages, in essence "paying the price" of their own accommodations (Gunderson & Hyatt, 1996). Evidence that SSI/SSDI recipients with psychiatric disabilities return to jobs that do not provide health care, sick leave, or other benefits comes from the EIDP. Of all full-time jobs held by EIDP study participants over the two-year course of the study, only 24% provided medical coverage, 16% dental coverage, 8% mental health coverage, and 20% sick leave. Most SSDI recipients who re-enter the labor force do so at lower-paying jobs, for fewer hours per week, and with a different employer than the jobs they held prior to SSDI reciprocity (Schechter, 1997).

Disability program rules and regulations constitute a considerable disincentive to work that prevents people with mental illness from realizing their full career potential. Federal regulations mandate an administrative review of disability status upon return to work, effectively "punishing" those who obtain employment. Unlike SSI, which allows recipients to retain part of their income supports after substantial gainful employment, SSDI recipients encounter an income "cliff" once they exceed SGA for a specified number of months. Individuals who lose disability income status because of their return to work also experience an "implicit tax" because they risk losing other unearned income such as housing subsidies, utility supplements, transportation subsidies, and food stamps (Polak & Warner, 1996). SSDI beneficiaries must undergo a two-year waiting period before becoming eligible for health coverage under Medicare, while most SSI recipients become eligible for Medicaid immediately upon receiving SSI.

Unfortunately, recent legislation designed to remediate income support disincentives is likely to have limited impact on the return to work of individuals with psychiatric disabilities. One example is the 1999 Ticket to Work and Work Incentives Improvement Act known as TWWIA. TWWIA was intended to increase federal disability insurance beneficiary options for obtaining rehabilitation and vocational services, remove barriers that require choosing between health care coverage and employment, and assure that more Americans with disabilities would have opportunities to participate in the workforce and lessen their dependence on public benefits. However, economists have forecasted that TWWIA rules establishing milestone payment amounts to vocational rehabilitation providers provide too little financial incentive to serve clients with mental illnesses (Cook, 2002). By "backloading" the payment structure, TWWIA in effect "punishes" providers who serve a clientele that takes longer to prepare for movement into competitive jobs (Salkever, 2002). Moreover, by keying financial payments to

achievement of substantial gainful employment (SGA) level income, as currently structured, TWWIA provisions are unlikely to motivate providers to serve people with psychiatric disabilities and developmental disabilities (Wehman & Revell, 2003).

Another example of legislation with much initial promise but a largely disappointing impact is the 1990 Americans with Disabilities Act or ADA. The ADA gives civil rights protections to individuals with disabilities in employment, transportation, public accommodations, State and local government services, and telecommunications. ADA protections have become increasingly circumscribed for individuals with psychiatric disabilities (and others) as a result of recent supreme court rulings (*Sutton v. United Airlines*, 1999; *Murphy v. United Parcel Service*, 1999; *Toyota Motor Manufacturing, Kentucky, Inc. v. Williams*, 2002), declaring that ADA protections do not extend to workers with illnesses "controlled by medications" and those whose limitations are not considered "central to most people's daily lives" (Burnim et al., 2000). Additional evidence of the failure of the ADA to protect workers with psychiatric disabilities has been identified in the claims adjudication process (Ullman et al., 2001). Under a policy introduced in 1995, EEOC claims are classified into three tiers by field office investigators at intake, based on the investigator's subjective judgments as to whether or not discrimination has occurred. Given the subjectivity of such judgments and the failure of EEOC to validate the accuracy of their classification system, recent research (Ullman et al., 2001) focused on whether ADA claims filed by individuals with certain disabilities, such as mental illness, are more likely to be classified as low-priority. This research also attempted to investigate the relationship between priority assignment and the likelihood that a claimant received some benefit, either in the form of an *actual monetary payment* (compensatory damages, back pay, remedial relief) or *projected monetary benefits* assumed to co-occur with

hiring, promotion, or reinstatement. Results of this research revealed that the priority with the highest total benefit rate was significantly less likely to be assigned to claimants with psychiatric disabilities, while the category with the lowest benefit rate was significantly more likely to be assigned to those with mental illnesses. The authors of this study called into question the ability of untrained EEOC field investigators, using an un-validated classification system, to appropriately evaluate claims involving mental illness, and called for future studies of this question.

Populations Affected by these Problems

Problems with Employment. Adults with severe mental illness and youth with severe emotional disturbance (SED) are the primary groups affected by the aforementioned problems. Youth confronting employment issues are those in transition between school and work, which is defined as children between the ages of 16 to 25 years (Davis & Vander Stoep, 1997), who meet criteria for a psychiatric disorder. Adults of working age are typically considered to be those between ages of 18 to 64 years.

National household probability surveys find that anywhere between 18% to 21% of children meet the diagnostic criteria for a psychiatric disorder (Cohen, Provet & Jones, 1996), while the prevalence of SED (for which criteria are more stringent than those for psychiatric disorder and require significant functional impairment) has been conservatively estimated at 5% to 9% (Friedman et al., 1996). As of the year 2000, an estimated 6.5 million children in the U.S. have an SED diagnosis and are between the ages of 16 to 25 years of age.

The latest figures on adults indicate that 21% of the U.S. adult population experiences a mental illness (Surgeon General's 1999 Report on Mental Health). Estimates are that between 4.7 million (Kaye, 2001) and 8.2 million civilian, non-institutionalized adults have a disabling

mental/emotional problem (Willis et al., 1998). This means that a sizable number of working-age adults and youth are likely to be confronting one or more of the identified problems with employment.

Problems with Income Supports. As of December, 2001 (the latest date for which information is available), 4.7 million individuals were receiving SSI, with 36% of that group or approximately 1.7 million individuals having a diagnosis of mental illness (SSA, 2002). As of December, 2000 (the latest date for which information is available), 5 million individuals are receiving SSDI under the classification of disabled workers, with 27.4% of recipients or approximately 1.4 million individuals having mental disorders. This indicates the sizable nature of the population potentially affected by the aforementioned income support problems.

Evidence-Based Mental Health and Rehabilitation Services

The accumulated research evidence indicates that mental health service consumers can successfully participate in the labor market in a variety of competitive jobs. Competitive employment refers to jobs that are located in the so-called "regular" labor market (i.e., work settings not comprised solely of co-workers with disabilities), pay minimum wage or above, belong to the worker rather than an agency, and for which anyone in the labor market can compete. The service delivery approach with demonstrated efficacy in accomplishing this outcome is called supported employment. While a number of evidence-based supported employment models tailored specifically for people with mental illness exist in the field today, they all share a common set of features. All deliver carefully coordinated clinical and vocational services, provided by multidisciplinary service delivery teams including both mental health and rehabilitation professionals, with rapid job placement, into competitive positions, in client's preferred fields and settings, and with the availability of services and supports that are not time-

limited (Cook et al., 2002). In an 8-state, multi-site, clinical trials study of supported employment for people with severe psychiatric disabilities testing models meeting these characteristics (the EIDP study), over two-thirds of participants became employed at some point during the two-year follow-up, earning over 3.8 million dollars and working over 850,000 hours. These results are confirmed by individual, randomized controlled trials of supported employment programs for people with severe mental illnesses (Crowther et al., 2001) which find that supported employment is more effective in achieving competitive employment than prevocational training programs or standard non-vocational community care. Another study of services used by community mental health center clients over a nine year period in a rural Midwestern area of the U.S. found that consumers showed significantly greater improvement in role performance (including but not limited to work roles) in years when they used supported employment than in years when they used sheltered workshops (Landis, 1999).

While most consumers do not receive any vocational rehabilitation services at all, others receive supported employment services that are not organized or delivered according to best-practice standards. That is, they receive something called supported employment but not meeting the evidence-based standards defined above. Often, they receive vocational services from an agency or program that is separate from their clinical provider or program, with poor or non-existent coordination between the various parties. In other instances their career preferences and individual financial circumstances are not taken into account and they are offered generic job placements rather than ones tailored to their needs and career plans. In still other supported employment programs they are served by employment staff who have little or no knowledge of mental disorders, psychotropic medications and their side-effects, work-based stigma and discrimination specific to mental health conditions, and appropriate techniques for the

assessment of work potential in this population. Often, so-called "ongoing" supports have an explicit or implicit time limit, after which the consumer is encouraged to "graduate" and terminated from contact. An additional problem is that State-Federal VR services are funded for time-limited periods and provide no payment mechanism for ongoing job support, other than a "post-employment services" status that is rarely used, and even less so for people with psychiatric disabilities. Similarly, most vocational rehabilitation services are not reimbursable under Medicaid, creating a funding vacuum that helps to account for the vast underserving of this population.

Effects on Family Caregivers. The diagnosis of mental illness in a family member, be it an adult child, spouse, parent, sibling, or other relative creates a series of stressors that influence the financial planning and economic self-sufficiency of both relatives and their the ill family member. Families typically experience a sense of hopelessness and helplessness (Cook, 1988) that impedes their ability to assist their ill relative with assumption of adult roles that include dealing with finances. Families often are the primary caregivers for adults with mental illness, assisting with daily activities, such as meal preparation, household chores and transportation, as well as securing treatment services (Cook, Hoffschmidt, Cohler, & Pickett, 1992; Pickett-Schenk, 2003). Given the economic vulnerability of persons with psychiatric disability, families also are called upon to provide financial support to their ill relatives (Cook, Cohler, Pickett, & Beeler, 1997). This support includes, and is not limited to, helping ill relatives manage their money, paying rent and other living expenses, serving as representative payee, and purchasing needed items such as groceries, clothing, and hygiene supplies (Cook, 1988; Pickett-Schenk, 2003). In addition, many families assume the costs of their relatives' mental health treatment, purchasing expensive psychiatric medications and paying for visits to psychiatrists and other

service providers (Marsh & Johnson, 1997). Clark and colleagues conducted a study comparing 119 families of adults with dual psychiatric and substance abuse disorders to 127 families whose adult children had no chronic illnesses. Clark estimated that the families of people with dual diagnoses incurred costs from money, goods, and direct care ranging from \$9,703-\$13,891 per year, well over four times that of the comparison group (Clark, 1994).

Families experience several stressors as a result of providing financial support to adult relatives with mental illness. Cook and her colleagues (1994) found that older parents reported high levels of distress related to feelings of ongoing responsibility for their ill adult child in the areas of finances and shelter. Parents worried about what would happen to their children after their deaths, expressing anxiety that, without parental financial support, their ill children may become homeless and no longer receive needed treatment. Families also report frustration with providing care for relatives, who, if not for their psychiatric disability, would have achieved levels of financial independence similar to their same-age peers (Pickett, Cook, & Cohler, 1994). Monetary resources are drained by the high cost of housing and psychiatric care, forcing families to co-reside with their ill relatives, leaving little opportunities for respite from the ongoing problems associated with mental illness (Cook et al., 1997). Some have argued (Cook et al., 1997) that having a child(ren) with mental illness forces families to delay passage through normative life course stages such as the retirement and empty nest stage. Conversely, living with families can impede the development of money management skills among mental health consumers, as they are not in a situation requiring financial independence.

Summary. People with serious mental illnesses are disproportionately out of the labor force due to stigma, discrimination, lack of education, inadequate vocational supports, and marginalizing disabilities policies. Although SSA disability benefits are the first and last “safety

net” for people with severe mental disorders, participation in these programs creates considerable complexity in individuals’ personal finances, making financial planning critical for establishing economic well being. Mental health service consumers are often trapped by conflicting disability, employment, and income support policies, leaving little way out of poverty. As people with a severe disability, they should not be forced to live without financial security. Nor should families be forced to bear the brunt of their adult relative’s disability by acting as a source of necessary income. It is time to recognize the impoverished circumstances of many people with disabling psychiatric disorders and to include financial education and planning as key elements of coordinated services, along with establishment of financial security as a goal for disability policy.

Section C: Financial Planning Needs

In this section, we report empirical data on the financial situations, resources, and financial planning needs of people with mental illnesses living in the community. We draw on two primary sources for these data. First, we have descriptive quantitative data from a large, national study of people with psychiatric disabilities from around the nation. Second we describe the results of a qualitative analysis of a unique set of in-depth interviews and focus groups with mental health consumers (primarily), as well as family members, advocates, private and public sector service providers, and researchers.

Employment Intervention Demonstration Program

Overview of Sources of Income. The Employment Intervention Demonstration Program (EIDP) was a multisite, randomized controlled trial (RCT) of supported employment interventions for individuals with psychiatric disabilities. Funded by the Center for Mental Health Services of the Substance Abuse & Mental Health Services Administration, the EIDP is the largest study national cohort study of people with severe mental illness to date in the United States. Over 1,600 people were recruited in eight states to participate, and followed for at least two years by means of biannual in-person interviews, monthly records of services received, and weekly summaries of employment status with job details. The study and its results have been described more fully elsewhere (Cook et al., 2002; Cook et al., in press), and are available online at <http://www.psych.uic.edu/eidp/>. There are two facets of the EIDP that are of particular interest to this report. First, baseline data provides an overview of the financial situations of over 1,500 people with psychiatric disabilities living in the community; and second, the EIDP

included a substudy of 850 individuals and focused on learning more about their financial situations (the Personal Economy Study).

Of the 1,536 EIDP participants who were living in the community (i.e., not homeless or institutionalized) at their baseline assessment (baseline assessments took place from 1996-1998), roughly half were male (52%), Caucasian/White (49%), about a third were African-American (31%), and 14% were Latino/Hispanic. About one-third had less than a high school education (33%), 31% had a high school diploma or GED, and 25% reported some college education, but no associate's or bachelor's degree. Over half were never married (54%), 37% lived alone, and 21% lived with a child or children under the age of 18. The average and median age of the sample was 38 years, and participants ranged from 18 to 70. Not surprisingly, the participants reported very low levels of cash income. The average individual income in the month before the baseline assessment was \$589, and the average household income was \$986. Most of the participants (72%) depended on Social Security Administration disability benefits for income, with 35% receiving cash benefits from the SSI program only, 25% receiving cash benefit from the SSDI program only, and another 12% receiving cash benefits from both SSI and SSDI. In addition, 59% of respondents reported health care coverage through Medicaid, and 34% through Medicare; only 10% of respondents had private health insurance. About 15% of respondents reported receiving money from family or friends, and another 10% reported doing odd jobs or illegal activities for cash that was unreported to the government. Almost none of the respondents were receiving any cash benefits from other sources, such as: Social Security Retirement (2%); Veterans' Administration disability or pension programs (<1%); private retirement, investment, or savings programs (2%); or alimony or child support (2%). Because the EIDP recruited

participants who were not working, earned income from jobs was not a factor at the baseline assessment.

At baseline, the majority of individuals reported income levels that fell below the federal poverty line. Almost three-quarters (73.9%) of participants had incomes below poverty at their baseline assessment; 78% of those receiving SSI cash benefits were below poverty; 59% of those receiving SSDI cash benefits were below poverty; 75% of those receiving cash benefits from both SSI and SSDI were below poverty; and 87% of those receiving no SSA cash benefits were living below the poverty line.

The Personal Economy Study (PES). In the PES, an EIDP sub-study of participants' personal economies, results once again confirm that a large proportion of people with severe mental illness live in poverty and depend on public disability benefit programs (SSI and SSDI) both as an economic "safety net" and as a source of health and mental health care coverage. Yet, there has been little prior attempt to understand the economic behavior, incentives, choices and realities of persons with psychiatric disabilities living in the community. This is particularly important when considering issues related to money management and financial planning, since the context of poverty can interact with the often unpredictable course of mental illness to create uncertain economic futures for many.

The theoretical framework underlying the PES was Economic Development Theory (Krueger & Ruttan, 1989). This approach to understanding low-income people's economic behavior assumes that poor people make well-informed financial decisions when the risks are well understood. Our research viewed consumers as active agents making complex decisions to allocate scarce financial resources over competing obligations and desired outcomes. The purpose of the EIDP Personal Economy Study (PES) was to collect detailed financial

information from study participants in order to more accurately describe and characterize their personal economic situations. This substudy was funded by the Social Security Administration as a supplement to the larger EIDP in order to enrich our understanding of mental health consumers' monthly finances, including all types of income, expenses, assets, and the value of services received.

In the PES, participants were queried about seven areas of their personal finances: 1) amounts and sources of all cash income received in the past month, including whether this month was typical or atypical; 2) health and mental health services used; 3) types of non-cash assistance received; 4) personal financial assets; 5) amounts and types of monthly expenses; 6) SSI beneficiary history; and 7) SSDI beneficiary history. The PES interview schedule and documentation is included in the compendium, and is also available online at www.psych.uic.edu/eidp.

Cash and Non-cash Income, Assets, and Expenses. The following description of personal economies comes from detailed data gathered from 850 substudy participants surveyed between 1996 and 1998. First, the most common cash income sources in descending order of frequency were SSI, SSDI, employment income, and money from family members. Consumers receiving money from these sources reported a monthly average of \$423 from SSI, \$591 from SSDI, \$579 from their jobs, and \$90 from relatives.

In addition to cash income, many mental health consumers receive different types of non-cash income such as housing vouchers, food stamps, and supplements for utilities or transportation. While not provided to consumers in monetary form, these sources of non-cash income may be a critical resource in a consumer's micro-economy. Losing these benefits because of loss of SSI/SSDI eligibility can prove disastrous to an individual's micro-economic

situation. Over two-fifths of the EIDP PES participants were receiving transportation vouchers, at an average value of \$19 per month. Almost a quarter of mental health consumers were receiving housing vouchers at an average value of \$285 per month, and food stamps averaging \$99 per month. However, only 3% were receiving utility supplements, averaging \$70 per month.

The most commonly reported monthly expenses in descending order of frequency included rent (averaging \$275 per month), food (averaging \$144 per month), transportation (\$78 per month), and repayment of loans (\$42 per month). Across all study participants, individual monthly expenses averaged \$818, which is higher than the monthly average cash income. This is vitally important, because it demonstrates that, at least in this sample, mental health consumers were living in a negative personal economy, in which expenses averaged 105% of cash income. This empirical finding, based on analysis of detailed financial information presents a clear picture of what has been generally understood, that people with severe mental illnesses who are living in the community are living in very precarious financial situations, with little if any cash to manage beyond basic living expenses.

In addition to having negative personal economies, EIDP PES participants had little in the way of financial assets or equity to rely on, should they need to convert them to cash to cover expenses or pay off debts. For many consumers, this is due, in part, to Medicaid and other public benefit spend-down requirements that force consumers to divest themselves of assets in order to be eligible for benefits such as health care and housing. While 73% of all study respondents reported some type of asset such as a home, vehicle, or durable goods, the value of such assets for half of all mental health consumers was less than \$200, resulting in a very limited “safety net” to cover potential debts and monthly shortfalls.

Personal Economies of Working Versus Nonworking Respondents. Finally, we looked at the personal economies of those consumers who were employed and those who were not employed during the target month of the PES interview. This question is of considerable interest since we know that most mental health consumers want to work, and that current federal and state disability policies provide more disincentives than incentives to employment. We computed a ratio of expenses to income, in which 100% meant that the individual “broke even” (i.e., had an equal amount of expenses and income for that month); less than 100% meant that the individual had a negative personal economy (i.e., monthly expenses exceeded income for that month); and greater than 100% meant that the person had a positive personal economy (monthly income exceeded expenses). Interestingly, we found that employed EIDP PES participants had a positive personal economy, with an average ratio of expenses to income of 120%. Conversely, consumers who were not working had a negative personal economy, with a ratio of expense to income of 80%. Chi square analysis revealed that this difference was significant at $p < .05$. This finding adds to the compelling evidence that employment is crucial to the well-being of people with mental illnesses living in the community.

Case Examples. The points described above are illustrated by two case examples from our study. “Jackie” is a 49-year old, widowed, African-American woman living in the Southwestern United States. She is a high school graduate who has taken some college courses. At the beginning of the study, her monthly income was \$381 from SSDI and \$109 from SSI for a total of \$490 in monthly cash income. After enrolling in the EIDP, she held five different jobs each lasting from one to nine months, ranging in pay from \$4.75 to \$7.65 per hour, and varying from 20 to 40 hours worked per week. None of these jobs included benefits such as health care, dental care, sick leave, or retirement pension. At the time of PES data collection, she was

unemployed and relying on a combined monthly SSI/SSDI income of \$509. She had three children and lived in independent housing with one of her children as well as a roommate. Her non-cash income included an \$86 per month housing subsidy and \$27 per month for transportation. She reported receiving no physical or mental health services during the month. Her monthly expenses totaled \$796: \$86 per month for her share of housing costs, \$200 for food, \$10 for transportation, \$100 for student loan repayment, and utility bills of \$400. Jackie's personal economy was negative, given that her cash income amounted to 78% of her monthly expenses.

Another example is "Roger," a 36-year old, single, Caucasian man living in the Northeastern United States. He is a high school graduate who was residing in a supported housing setting consisting of commercially available housing at which services were delivered by a service provider who visited the residence whenever needed. At the time he entered the EIDP study, his income was \$528 per month, with \$478 from SSI and \$50 from state social welfare benefits. At the time of the PES interview, approximately one year later, his monthly income had risen to \$844 per month and came from a larger number of sources. He was employed part-time, earning a monthly salary of \$250. In addition, he received \$494 from SSI and \$100 from his family. He reported that in the past month, he had made one visit to a hospital emergency room, one visit to an outpatient mental health provider, and two visits to a medical provider. He also received a \$17 transportation subsidy, \$120 in food stamps, six free lunches, and one free dinner. His only asset was \$30 in a savings account. His monthly expenses totaled \$842: \$395 for rent, \$175 for utilities, \$122 for food, \$100 for cigarettes, \$20 for transportation, and \$30 for entertainment. His personal economy was positive, with expenses amounting to

approximately 100% of income. However, without his family's economic contribution, his personal economy would have been negative, with his income totaling 88% of expenses.

Summary of PES Findings. As the foregoing case examples illustrate, people with mental illnesses living in the community face difficult financial planning decisions, and manage scarce financial resources with little room for error. On average, most consumers participating in this demonstration program designed to help them return to work had negative personal economies, and in general, their expenses exceeded their incomes. A notable proportion received cash income from relatives, and in some cases it was this extra contribution from families that enabled mental health consumers to "break even" for the month and meet all their expenses. Clearly, people with psychiatric disabilities should not be forced to live without financial security, laboring under a system that was designed for an earlier era in which disabling conditions were assumed to be temporary and other benefit and entitlement programs were available to cover economic shortfalls. Nor should families be forced to bear the brunt of their adult relatives' disability by acting as a necessary source of income. It is obvious from this research that financial case management should be a linchpin of coordinated services and not just an option or afterthought, and that financial security must be a goal that is essential to all consumers' mental health recovery.

NEFE Study of Financial Needs and Experiences of Individuals with Mental Illnesses

A large part of this report is devoted to summarizing the money management and financial planning issues identified in a study of mental health consumers, family members, advocates, providers, and researchers. This methodology for this study involved a series of in-depth interviews (N=25) and X focus groups with 19 research participants. Focus groups were conducted with consumers with diagnoses of severe mental illnesses. A total of 19 participated in

three different focus groups, each held in different parts of the Chicago area. One was held on Chicago's south side (a predominantly African-American area); one was held on the near west side (predominantly Hispanic/Latino); and one was held in a suburb (predominantly Caucasian). Of the 19 respondents, 58% were male, 53% Caucasian, 26% African American, 16% Hispanic/Latino, and 5% Asian American. Of the 25 interview respondents, 32% were male, 52% Caucasian, 32% African American, 8% Hispanic/Latino, 4% Asian American, and 4% Native American. Nine of the telephone interview respondents were consumers with severe mental illnesses, 5 were service providers, 5 were family members, 4 were consumer advocates, and 2 were researchers. Ages for both sets of study participants ranged from 19-64, with an average of 40 years. Interviews and focus groups were taped recorded and transcribed, and the resulting data were analyzed using the Constant Comparative Method of Glaser and Strauss (1967

The major finding that emerged from this study concerned the overwhelming need for financial education and planning among people with serious mental illnesses. Over and over again, people with mental illnesses, their families, and service providers described a sense of frustration at the difficult financial circumstances faced by these individuals. Respondents expressed how their lack of financial knowledge and planning has negative consequences for the circumstances in which they are living, the lack of places to turn for assistance, and the appreciation they felt at having a rare opportunity to describe their experiences and opinions about this issue that is of central concern to daily life. What follows are summaries and examples regarding the ten areas of inquiry in the NEFE study:

1. How financial planning, or the lack thereof, affects the lives of people with mental illnesses;
2. The most important financial planning needs of people with a mental illness, including:

- a. Things people with a mental illness want or need to learn about their finances
 - b. Reasons people with mental illnesses want to improve their money management skills
3. Ways in which people with mental illnesses manage their money
 4. Where people with mental illnesses turn for assistance with financial planning or problems with their finances
 5. Major problems, challenges, and hurdles faced in establishing financial security
 6. How mental illness affects people's financial planning needs in terms of hospitalizations, mental health crises, health care coverage, and especially prescription costs
 7. How mental health consumers' financial planning needs change over their lifetimes from youth to middle age and from retirement to old age
 8. Resources currently available to mental health consumers who want help with financial planning
 9. Financial planning techniques used by consumers including strategies that work well and those that work poorly
 10. What respondents themselves would like to be made available in the way of financial planning services for people with psychiatric disabilities

Results of the Qualitative Analysis

1. In general how has poor or good financial planning affected your life?

The majority of respondents described experiences that pointed to the effects of poor rather than good financial planning. Their life stories illustrated how, for many, the negative consequences of poor money management resulted in: an inability to pay bills, credit card debt,

bankruptcy, eviction, and homelessness. One of the most frequently mentioned consequences of poor money management was the need to file for bankruptcy due to large amounts of debt. After a four year spending spree with four credit cards, one participant amassed a debt of \$12,000 and filed bankruptcy. For the next seven years she worked to clean up her credit rating. Despite these efforts she went on to accumulate another credit card debt totaling \$11,000. For some, poor financial management and over-spending was cited as the cause of their current financial dilemma. One respondent explained, “Right now I’m in a predicament where I’m going to have to file bankruptcy for debt that I incurred a couple of years ago.”

The effects of poor financial planning for these respondents were complicated. Their lives did not simply reflect the results of poor planning, but instead reflected the challenges faced by individuals forced to manage a major mental illness while concurrently juggling the demands of life such as work, school, family, relationships, and loss. For some participants, stories of financial difficulties start with the onset of their mental illness, followed by the loss of their job, and the loss of 50 percent or more of their income as they move onto the SSI or SSDI disability rolls. A second group of stories show how financial troubles can be associated with the onset of manic phases of illness, that lead to spending sprees, resulting in massive debt and job loss, eventually ending in bankruptcy. Respondents who lost full time jobs due to the onset of their mental illness found it difficult to financially and emotionally cope with the *increase* in their medical bills along with the significant *decrease* in disposable income, loss of medical benefits, and subsequent reductions in their overall quality of life.

Respondents also shared life stories of how their experiences with poor financial planning led them to pursue and ultimately achieve good financial planning. After being evicted for not paying her rent, one participant attended a financial literacy class where she learned to better

mange her money. As a result of that education, she believes that good fiscal management has helped her to “stay on track,” by maintaining her housing, saving money, and beginning to plan for her financial future. She describes herself as being a more disciplined and less impulsive spender, qualities that she attributes to increased financial literacy through targeted education. Another participant, who currently works as a mental health counselor, described how growing up in an impoverished home taught her in an informal way how to manage money and become fiscally independent. Yet another respondent recalled that she grew up in a home that was “very, very, very poor.” Her mother was diagnosed with bi-polar disorder, as is the respondent, who explained how she learned from the experiences of growing up in a home that was impoverished and headed by a mentally ill mother. She was aware early in life that she did not want to become a recipient of public aid or as a person “in the system.” She knew that she wanted to “work and be a productive member of society.” As she put it, “I wanted to live my life differently.” There was a period of time when her mother’s manic spending resulted in large amounts of credit card debt, leaving the family without money for basic needs such as water, electricity, or rent. The respondent recalled that the family was eventually evicted and had to live in a van. Her mother’s inability to pay for her bills led to bankruptcy. These events led the respondent to make a conscious decision that this was not what she wanted for her life. She wanted to become solvent and this goal became very important to her.

2A. What do you think are the most important financial planning needs of people with a mental illness?

Respondents identified two categories of important financial planning needs. The first of these, **Basic Needs**, included planning that allowed them to pay their rent, buy food, and have health care coverage through either public disability benefits and entitlements, and/or a good job

that was not too stressful. This category describes the goal of many respondents to simply “survive” by having the fundamental elements of food and shelter. Such a goal is not unlike the Hierarchy of Needs theory proposed by Abraham Maslow (1943). One respondent explained, “As far as planning for any kind of future, there isn’t enough [money]. The money that’s left over after those things [bills], has to go toward food, medications, and transportation costs.”

In the second category of important financial planning needs, **Skills Training**, respondents felt that the most important skill required for financial planning was to learn how to: budget, juggle bills, use the banking system, save money, receive job training, and develop a written financial plan that maps out for them how their money is to be spent. In addition, they also described a need for further formal education about money management skills, given that the onset of their illnesses for many, particularly males, occurred during the teenage years, interrupting their formal schooling where they would have acquired such skills. A request for basic educational skills such as reading comprehension and mathematical computation appeared again in respondents’ comments in response to question 3, which asked what they wanted to learn about their finances. This suggests that respondents want to acquire a knowledge base that will bring them closer, if not equal to, the economic knowledge and skills used by the general public.

2B. What kinds of things do people with a mental illness want or need to learn about their finances?

This question generated similar responses from consumer and non-consumer study participants. Basically, respondents said they needed: basic financial education, financial management skills, education about the public benefits and entitlements system, and training in managing their emotions.

Basic Financial Education. Respondents described a desire to understand the larger economic world. Within this category, respondents described a desire to learn what resources were available at the bank (i.e., direct deposit), how to manage a checking/savings account, how to avoid the pitfalls of credit cards, as well as how to choose a credit card wisely. One respondent who had turned her spending habits around suggested that consumers needed to learn to avoid using the services of currency exchanges and pay-day loan businesses, because she felt they encourage fiscal irresponsibility.

Financial Management Skills . Many respondents reported needing and wanting to learn how to budget and better manage their money. Many respondents had an awareness, however vague, of the basic concepts of budgeting and money management. For some, budgeting has helped them to gain “greater discipline and do less impulse spending.” However, their stories reveal how the process of successful financial planning is more complicated than simply learning a skill. Many respondents described difficulty budgeting their money due to the small monthly allotment that they receive from the government. Thus, some expressed the need for education specifically focused on managing a *small income* while also coping with the expenses related to a *major illness*. For example, respondents said they needed help with adhering to a budget while dealing with the interference of symptoms or a long psychiatric hospitalization. (The effects of psychiatric symptoms and hospitalizations on financial planning are also described in responses to question 6). However, aside from aspects related to their illnesses, a recurring theme throughout the data is that SSI/SSDI payments do not provide enough income to permit financial planning and allow for saving. As one respondent put it, “You can’t plan much of anything if you haven’t got anything to plan with.” However, despite their awareness of the realities and

difficulties of budgeting, consumers continue to display an earnest interest and desire to learn how to manage their finances.

A general consensus is that the government entitlement/benefits system is difficult to understand and navigate. A consumer who described herself as being of average intelligence described the SSA information that she found on the internet or in pamphlets as “gibberish.” Seeking help from those who are considered to be familiar with the system is also sometimes fruitless. Consumers and non-consumers both acknowledge that many mental health case managers are just as confused by government programs and rules as are their clients. A few respondents pointed out that those who worked within these government programs were also confused, sometimes unable to keep up with all of the changes. These reports describe a system of government representatives who are unable to translate and communicate their knowledge into a framework that a consumer or even a non-consumer can grasp and apply.

Education about the Public Benefits and Entitlements System. When asked what people with mental illness need to learn about their finances, respondents said that they needed to better understand how the public disability benefits system works, how government budget cuts affect their benefits, and how to get a job and still keep their SSI/SSDI and health insurance benefits through Medicare and Medicaid. The ability to balance employment and SSA benefits was a repeated concern throughout the data. Respondents knew enough about the regulations to know that earning too much money endangered their benefits, but beyond that, there was generally confusion. Employment was thus approached with trepidation and fear. Many spoke about the negative fiscal as well as emotional consequences of not leading an informed life. As one respondent put it, “They need to know what they’re entitled to. If not, they will lose a great deal of help.’

Emotional Control . The intertwining of fiscal and emotional issues was evident in these comments. As one individual explained, “People need to learn two things: first, how to set up a budget; and second, how to cope with the stress of not having enough money.” Respondents described a type of emotional control they felt they needed in order to manage their finances. They wanted to learn how to handle the emotional strain, depression, and increased psychiatric symptoms that accompanies living in a financial situation where there are more needs than money to meet those needs. One respondent reported that he wanted to learn how to “cope with having a lot of bills, current and past due.” This chronically stressful situation was described by one respondent, as “...a constant emotional state of depression. Because of your finances, you feel like they’re a mess and it’s not necessarily your fault.” The connection between mental and financial health is expressed repeatedly throughout the data. “If financial health is unstable, it can exacerbate mental health symptoms because of the stress.” The exacerbation of psychiatric symptoms due to stress was felt to have produced suicidal ideation for some respondents. “I don’t know what kind of income I’ll have at that time [retirement] since I can’t save for it. It’s a scary thought. I have suicidal ideations.”

Not only did respondents want to learn to manage their emotional health related to money, but there was also a need expressed for additional emotional support to be present during times of financial strain. This area of service delivery has seldom been commented on in the mental health services literature. One respondent explained that the most important thing for her to have available is emotional support when she gets down to her “last dollar.” The stress and strain make her want to “give up” and she becomes suicidal. To deal with this she is honest with the staff at her mental health center, and lets them know that she is in need of a lot of emotional assistance and encouragement not to isolate herself and become depressed. She suggested that

case managers should be aware of the need to be “real vigilant” with clients who are having financial struggles, even when they say that they are doing “fine.” This vigilance includes monitoring clients for increased symptoms and suicidal ideation. The role of clients during this time is to be honest with themselves and staff about their stress (in terms of informing staff about what is going on) and take responsibility for their actions.

Respondents’ answers clearly showed that coping techniques and strategies are both needed and wanted to help them learn how to deal with the daily stresses and strains of impoverished living. This includes learning how to replace feelings of guilt, panic, or suicidal ideation, with meditative responses such as deep breathing, self-affirming statements, and other calming strategies before emotions get out of control. It appears to be very important to seek and receive emotional support from professional service providers such as case managers. Such support should be focused on helping clients become aware that the emotional pain they are experiencing may be due to financial strain and to adjust their responses to such symptoms accordingly. Financial education for service providers might do well to include methods for adjusting treatment approaches during their clients’ times of financial crises as well as the chronic stressors of day-to-day life below the poverty line.

2C. What are the main reasons why people with a mental illness might want to learn to manage their money better?

Respondents discussed four major reasons why mental health consumers would want to manage their money more effectively. First they wanted to meet basic needs; second, they wished to achieve financial control over their lives; third, they wanted achieve a sense of normalcy in their lives and finally, they wanted to be able to have a greater range of options to choose from and, so, enhance their levels of self-determination.

As mentioned earlier, respondents expressed a desire to purchase commodities such as food, clothing, housing, and prescription drugs. The desire to achieve financial control over their lives provides insight into what motivates people with a mental illness to learn effective money management techniques. Respondent's answers reflected a practical bent, and showed a desire to take a proactive rather than a reactive approach to the role of money in their lives. They described wanting to be able to achieve better control of their money in order to avoid: borrowing money, depleting funds too quickly, becoming homeless, or having a negative cash flow. At the same time, they wanted to have money for: recreation, emergencies, and achieving goals such as higher education or upgraded quality of housing. Ultimately, they want to be able to make their limited income last longer and go farther.

The notion of achieving normalcy grew out of some the desire, as one respondent put it, "To feel normal, [to] buy things like everybody else." Another respondent defined this state of desired normalcy as, "To be just like everybody else. To have a house, security and not have too worry." In these discussions, respondents expressed their dreams of wanting to own a house or condominium, purchase a car, or get married and have children. Clearly, the motivation for better money management for these respondents is not that different from the general population. They want to achieve the American dream just like everyone else.

On the other hand, some respondents talked about how, for people with mental illnesses, the goal of having a "normal lifestyle," in comparison to people with incomes of ten's of thousands more, could be detrimental, discouraging, and lead to great debt. One respondent that this type of thinking and associated behavior could be dangerous, offering the suggestion that consumers needed to learn to live within their means and avoid the "keeping up with the Jones' syndrome."

A number of respondents saw money management for people with mental illnesses as a means to becoming more independent and self-sufficient. Answers in this category show respondents wanting to pursue goals of self-actualization, becoming a self-determining individual, one who is fully integrated into the fabric of life.

3. Can you describe ways in which people with a mental illness manage their money?

Respondents felt there was tremendous variability in how people with a mental illness manage their money. For example, some thought that consumers who lacked a future orientation might suddenly spend all that they have, or might not have the “future time orientation” required to live within a budget. On the other end of the spectrum, some respondents discussed their ability to adhere to a budget in order to meet basic needs and even save money on as little \$125.00 a month.

This wide range of responses may be due to the myriad factors that influence how those with mental illnesses manage their money. These factors include: the availability of resources, presence and severity of symptoms, type of diagnosis (within our data those with a bi-polar disorder confessed being challenged by the need to control their impulsive spending), level of mathematical computational skills, literacy level, amount and type of medication (some medications are sedative and cloud thinking), and rural versus urban living (given that the cost of living was lower in rural areas while the availability of resources might be more limited than in urban settings). Other factors include susceptibility to product advertising, predatory lending practices, accumulating credit card debt, and the desire to seek normalcy, as well as a host of other factors.

Money management issues were different for three groups of respondents: those who budget independently; those who rely on case managers and representative payees for budgeting

and structuring expenditures; and those who do not budget and have no planned spending approach. Those who budget described procedures in which they paid rent and other large bills first, followed by setting aside money for food, medication, and transportation. When there were more bills than money, which was typically the case, respondents reported altering their lifestyle for that month to accommodate the lack of funds. One man in New York described cutting back by buying generic brand cigarettes, eating less expensive food, eating out less, driving less and walking more, and using public transportation. A respondent who lives in Florida reported using similar techniques when money was short and she needed to buy medications. However, although her techniques allowed her to pay her bills and demonstrate financial planning skills, they were detrimental to her mental and physical health. For example, instead of buying cheaper food she would eat less and instead of driving less she would isolate herself at home. Living in a rural community, with the closest store located fifty miles away, she was forced to consider whether any trip outside her home would be worthwhile. Consequently, she had stopped going to church, stopped seeing friends because she couldn't afford the social lunch or movie, and subsequently developed agoraphobia to the point where is fearful about leaving the house even when her financial means permit. Her financial story shows how living on a severely limited income and using self-denial as a money management strategy, can decrease community integration and increase psychiatric symptoms such as suicidal ideation and agoraphobia.

Others respondents used case managers or representative payees (either a case manager or a family member) as their “money management strategy.” For example, some meet with their case manager once a month and review which bills need to be paid. These respondents are then given what money is left over to manage for the rest of the month. The few people who said they used family members as representative payees did not describe a process where bills were

discussed and paid but instead, left the impression that they were removed from the process and provided with what amounted to an “allowance” as if they were children.

While no one respondent characterized their money management strategies as “haphazard” or “irresponsible,” some acknowledged that this had been the case in the past. However, it must be acknowledged that mismanagement of funds does exist among those with mental illnesses. Some respondents observed that they had seen friends or clients spend money according to no particular plan, as soon as they got it. One provider made the following observation, “They get the check and they start purchasing in excess...they just spend money however, it’s nonsensical.” She noted that this spending style is common among the adult offspring of other parents in a family support group that she leads. One consumer also observed this behavior among her peers, but went one step further in trying and explain it, “The instant gratification of spending is like their source of recreation.” Others described disorganized spending habits but provided a justification they considered to be reasonable. This was the case for a group of men residing in a high crime rate urban setting.

“I can’t stop because as soon as I get money in my hands, I get nervous and start spending it. ... I’m afraid somebody might jump me for my money, or I can’t handle it in my hands.”

“I think when I have money, you know what, I may not be here tomorrow. Look at my friend who passed away suddenly. My illness has that a lot, like I don’t care about the end of the month.”

As these consumers saw it, having money in an urban area can make one a victim of crime if they held onto it, so money should be spent quickly because life can be short. These orientations may be “learned responses” resulting from viewing the deaths of friends or seeing

others robbed. These comments suggest that there may be a set of reasonable beliefs, at least in the eyes of the consumer, at the core of what appears to be erratic spending. This points to the importance of understanding the reasons behind seemingly erratic spending behaviors, before putting in place a budgeting strategy that is realistic and makes sense to the client.

4. Where do you think most people with mental illnesses turn for help with their financial planning or problems with their financing?

Respondent's answers focused more on the latter part of this question, that is, on whom they would turn to if they had problems with their financing (i.e., low on money) rather than on whom they could turn to for help with their financial planning. Using reactive rather than proactive financial planning strategies may be due to participants' belief, one that is echoed throughout the interviews, that in order to plan or save money one must have enough to start with.

When respondents were experiencing problems with their finances they reported primarily turning to their family and/or case managers. Only a few respondents said they turned to peers for assistance. Although case managers were frequently cited, one respondent said she was embarrassed to seek help from a case manager because this made her feel like a failure. Some respondents noted that they had no one in their lives to turn to for help with financial problems. Similar responses were given to question 8A, which asked respondents to describe financial planning resources that were available to them.

5. What are some major problems, challenges, or hurdles that people with mental illnesses face in establishing financial security?

The following respondent answer summarizes the problems, challenges and hurdles that interrupt or stall the establishment of financial security for people with a mental illness. This

short statement shows the complex and sometimes negative dynamic between employment, mental illness, and living on disability. The last sentence echoes the need for respondents to learn emotional control, as identified in question 2B. It points out and starts to corroborate the effect of financial strain in engendering psychiatric symptoms.

“[The problem is]...the dollar amount that most people on disability receive. The difficulty of obtaining employment that pays well enough to get off disability or that makes them comfortable enough to take employment. The work place is good as far as being a source of money, but it also exposes them to more stigma. Symptoms can also be a challenge to finding financial security. And financial worries can sometimes compound symptoms.”

The above statement also captures many of the themes found in the answers to this question: inability to find and maintain employment, unstable mental health, lack of access to funds or to ways to increase funds, and lack of knowledge about financial planning.

There was a raw negativity in how respondents viewed the relationship between mental health and financial security. One respondent feels that “Financial security is essentially unattainable by 99 percent of people who have a disability.” Other respondents asserted that achieving financial security was “almost impossible” or that “people with a mental illness can’t do this.” The reasons behind these beliefs echo those described earlier. Respondents pointed to the small amount of money received from disability, the inability to get or maintain employment, the potential of lost benefits, or dealing with a government system that doesn’t understand mental illness and penalizes psychiatric growth. One respondent, explained the catch-22 inherent in recovery from mental illness by making the point that when peoples’ mental illness

does start to remit there is no financial security to reach out for because they have never had the ability to create a foundation for stability during the time of their illness.

In order to achieve monetary security one first needs money. The amount of SSI and SSDI that most respondents received was described as too small, and certainly not enough money to cover their basic needs. Employment then became a seemingly logical solution to supplementing income and achieving financial security. However, this solution had multiple hurdles and challenges of its own. Respondents identified numerous barriers to employment and thus financial security in the following list of difficulties: an inability to compete in today's job market, an inability to find meaningful employment that pays a livable wage, the need to find a stress free or low stress job, the difficulty of handling a job while first experiencing symptoms, the inability to handle any stress, the difficulty of keeping a job while experiencing psychiatric symptoms, the hurdle of finding a stigma-free work environment, and the lack of employment skills and experience. One woman had never held a "real job" due to the fact that she did not complete high school; thus, she had no resume and no job experience. This had left her with little motivation to look for employment. As she put it, "I don't think I would last long in the job market." The achievement of financial security was also blocked by a lack of skills needed to manage finances, to understand how money could be spent more efficiently, and the ability to get and maintain credit.

6. How would you say that mental illness affects people's financial planning needs in terms of hospitalizations, mental health crises, health care or prescription costs?

Respondents' medical coverage varied from those who were covered by Medicaid or Medicare, to those covered by private insurance (which was very rare), to those who had no health insurance at all. A few respondents, who lacked private and public coverage, were lucky

enough to reside in states where they had their medical and/or medication needs taken care of through community mental health programs. Regardless of their source of coverage (or non-coverage), all agreed that having a mental illness was very expensive. For example, respondent co-payments for their psychiatric medications ranged from \$1.00 to \$10.00 per prescription.

One respondent explained:

“Mental illness is a very expensive disease due to doctor visits, loss of income, because you are unable to work, loss of medical benefits, having to use Medicaid, and trying to get Social Security benefits is very difficult.”

“Well I’m on the medical card (green card) and I still have to pay a co-pay on prescriptions (3 dollars per prescription). And I’ve got 4 prescriptions so that is something else that eats away at the little bit of money that I’ve got.”

Another kind of “cost” paid by respondents lies in the poor quality of care received by those covered by public insurance. One provider observed that her clients, most of whom received Medicaid, “were seen as poor, given very little respect, and consequently received the worst service.” One respondent also paid the cost of losing the ability to determine her treatment plan when she signed up to receive medication from her local community health center. This agency policy required that, in order to receive medication from a psychiatrist, clients must see a psychotherapist, regardless of their desire for therapy. This respondent was thus “forced” into therapy when she preferred to spend her time working with one of the agency’s case managers on financial planning. To date she had been unable to achieve this goal.

Another cost to consumers is the potential loss of psychiatric stability when they can’t afford their medications and are forced to go off of them for a period of time:

“When it comes to prescription costs for me I’ve just had to do without prescriptions for a while until I was able to connect with the VA to get prescriptions at a much lower rate. But it still is a big chunk, like about 15 percent of my income.”

Thus, the cost of having a mental illness for these respondents is a loss of money, respect, mental stability, and therapeutic self-determination.

It is well known that hospitalization is the most costly form of mental health service. However, this study’s respondents identified another seldom-mentioned financial consequence of hospitalization, that is, its ability to wreck havoc on the financial planning that may be occurring in a consumer’s life. As pointed out in the statement below, in order to survive, a consumer has to grow comfortable with the reality of being able to control nothing and lose everything.

It’s just that you can’t plan for anything and you have to live with the reality of the consequences of hospitalization. You have to grow a thick skin so that you don’t become fearful of what may happen to you financially [when you go into the hospital].”

This statement was corroborated by another respondent who noted how, “Hospitalizations interrupt the structure you have in place for paying bills, and then you get hit with late charges when bills don’t get paid.” The financial consequence of hospitalizations mentioned above include: loss of SSI payments (if a patient’s stay extends beyond thirty days), inability to pay bills (due to lack of money when SSI payments cease or because consumer has no means to send in a payment), incurring late charges, and becoming homeless due to eviction for failure to pay rent during a hospitalization. It would be difficult indeed for most people deal with such devastating financial loses, even with a “thick skin.”

The presence of a mental illness has numerous effects on a consumer's ability to manage their money. First, consumers resemble the general population in that they represent various levels of skill, knowledge, and learning abilities. Everyone is different and everyone has different circumstances, experiences, and resources. Consequently, the presence of a mental illness and its effects on an individual life and cognitive abilities are best viewed on a continuum. The respondents in this study described many effects of their mental illnesses on financial planning abilities including problems with memory, inability to think or plan clearly due to medications, presence of symptoms such as grandiose thinking or impulsive spending, difficulty remembering details, or the presence of a psychiatric crisis overshadowing financial planning.

“When you are in a state of psychiatric crisis you are not concerned with financial planning. There is more of an emphasis on getting the medications that you need and paying for prescriptions.”

These examples emphasize the need to understand the importance with which financial planning is viewed by the individual with mental illness, relative to other pressing needs. Once again, according to Maslow's first level of the Hierarchy of Needs, the individual seeks to establish safety, food, and shelter. Only after these basic needs are met is the individual capable of pursuing the next level. This theory may help to explain why some consumers may not feel that they are ready to pursue financial planning. For those who are in the early stages of recovery, their primary goal is to address the first level. Trying to survive, at this point in their lifetimes, does not allow for what they may consider the “luxury” to plan for an uncertain future.

7. How would you say that mental health consumers financial planning needs change over a lifetime from youth to middle age to retirement and old age?

Many respondents addressed this question from the perspective of long term financial planning for individuals without a mental illness. They talked about “retirement,” even though they were not working, less from the reality of exiting the labor market and more from the perspective of what a ‘normal’ life course should be like and how it should occur. “Well, I suppose if your life progresses in any kind of normal way, like the American Dream, at the start of things you really don’t have much money. So there isn’t a lot of financial planning going on. But when you start making more money, [then] you want to prepare for the future or for your children’s college, or whatever.” Respondents acknowledged that, as individuals get older, their needs change in that they may encounter physical illnesses resulting in higher health care costs and a resulting decrease in income that might negatively affect their “quality of life.” However, even though they responded to this question “in the ideal, ” they were well aware that this developmental perspective was less relevant for their particular situations. As one respondent acknowledged, “...a lot of people with mental illness don’t have what’s called the norm when it comes to finances, unless they come from a family with money. So, a lot of times people with mental illness do not have the same progression as the norm. It’s probably similar to what I have going on, which is just eking out an existence with very little money, and not much possibility to financially plan much.”

Given that most respondents struggled to survive on a daily basis, the notion of setting aside money for their “golden” years seemed implausible. Most were theoretically aware of the importance and need to save for their “old age.” However, they reported being stalled by the reality of their low monthly income. For some, thinking about the need and the inability to save for the future is frightening. “The idea of getting to retirement is one of the biggest things that scares me because I don’t know how I’ll be able to afford to live.”

8A. What would you say are the best resources currently available to mental health consumers who want help with financial planning?

Some respondents answered this question by mentioning resources that are available to the general public such as: public aid office, the library, legal aid, and credit consolidation services. In the community of the virtual world, the Internet and its various resources were also cited. Others described services available at their mental health agencies (such as money management classes), or help from a case manager, benefits counselor, or representative payee as a resource. Family and friends were natural supports in the community who were also mentioned as resources.

However, many respondents did not feel that there were any resources, particularly free resources, which would help them with their financial planning. They believed that more benefits counselors and case managers trained to provide financial education and planning assistance should be available. They wanted to receive such services available in their local mental health centers, which were seen as the most accessible location.

8B. What are some of your own financial planning techniques that you use? What has worked for you and what pitfalls have you encountered?

Those respondents who said they used financial planning techniques described strategies similar to those that would be found in money management guides or used by the general public such as: banking, budgeting, saving, computer programs, and money saving strategies. In addition, checking accounts, direct deposit, and automatic savings withdrawals were banking strategies that some respondents used to structure and organize their money. One respondent acknowledged that, as a recovering gambler, having a checking account allowed her to “get the money out of the house and away from me.”

Another frequently mentioned technique was defined by one respondent as “mapping out your money. Figuring out which money is free money and which money is for food and bills.” This notion of “free” money (meaning money not already earmarked to pay bills) was a unique and compelling notion. For those respondents who could, budgeting their money was a primary tool to understand, manage, and control where their money went. Some respondents initially saw this task as difficult. But, over time, many felt that it became easier and that it was invaluable because it taught them to be more disciplined spenders. In addition, keeping track of money spent by recording expenditures, saving receipts, or entering expenses into a computer program helped respondents see where their money was going and led to better management.

Respondents’ answers uncovered an unexpected and efficient budgeting technique that is best described as “financial forethought”. The crux of this technique was to engage in financial planning using a short-term future orientation. One respondent described this practice as “Being aware of when you’re spending and on what. Looking ahead to the bills due in the next month as a guide to how you spend in this month.” This was a means of helping consumers avoid being caught off guard later by bills that would otherwise have been forgotten. Looking ahead was the key action here, although the length of financial forethought and planning varied. Some respondents budgeted ten days in advance of the arrival of their check, whereas others budgeted a year in advance. For instance, one respondent described identifying and making a special plan for all of the months of the year that are “five weeks long,” (e.g., periods when checks are received 29 to 31 days apart; months with more than four weekends) allowing her to anticipate when she would need to stretch her monthly allotment over what would seem like one week longer than usual. Consequently, she would plan to spend less money in the month prior to a “five-week” month.

Respondents were asked to describe any strategies they used for saving money while living on a limited income. Opening up a traditional savings account was identified as being difficult because these accounts usually required a minimum start up fee of a \$100. To circumvent this problem, some respondents described creating an emergency fund or savings account in a “money jar.” Denominations from ranging a quarter to a dollar were then deposited in the jar on a regular basis (e.g., once a week or once every two weeks). Respondents proudly described how they found these savings on a tight budget by buying one less can of soda pop, smoking 3-4 less cigarettes a day to save the cost of a pack a week, or walking rather than taking the bus. Once money had been set aside, it was important for some respondents to get it out of their sight or out of their homes by giving it to trusted individuals for safekeeping. Techniques for saving also include techniques to avoid spending such as carrying little or no money in a wallet, foregoing window shopping, and avoiding stores that had led to impulse spending in the past.

Within this discussion of financial planning techniques respondents placed more emphasis on money stretching than money saving techniques. Collectively their accounts generate a list of community resources/strategies that they frequently used, such as: thrift, discount, and outlet stores, and warehouse clubs (i.e., Costco, Sam’s, or Price Club). They also clipped coupons, comparison shopped, purchased only items that were on sale, stocked up on staples, and visited food pantries. Despite using these strategies and resources, respondents still felt that few money saving options were available to them and many expressed a desire to learn more.

9. What would you like to see in the way of financial planning/education services for people with psychiatric disabilities?

This question yielded the most input from respondents than any other. The answers were detailed, innovative, insightful, and creative. Respondents seemed to enjoy being included in the process of conceiving of a tool intended to address their needs. Consequently, their answers uncovered critical information that could make a financial planning product or service more effective. Five categories emerged from this data: Financial Planning Resources in the Community, Types of Financial Instruction Tools, Tool Design, Language/Format, and Content.

When some respondents discussed the kinds of education or services they needed for financial planning, their thoughts and answers returned to the community, particularly their local community mental health center and its staff. They suggested that “financial planning services could be attached to a community social service agency.” One respondent went so far as to say that these services should be mandated to be available at every mental health center, and that staff in these centers, including psychiatrists, doctors, therapists, and case managers, should know where to refer clients needing help with financial planning. Some suggested that a qualified benefits counselor should be on staff at every mental health or social service center. Respondents wanted to see financial planning education and assistance in the form of classes, support groups, didactic presentations, and one-on-one counseling. They also requested assistance (such as help with filling out paperwork, obtaining needed documentation, and advocacy) that would allow them to receive items such as medications at reduced costs.

Respondents’ ideas included the larger community when they suggested that free financial planning classes should be available at public schools, county health departments, and residential facilities. A final innovative idea is to have professional financial planners donate their time and skill to the clients of mental health agencies.

Respondents envisioned a wide range of potential formats for financial planning tools, which were both typical and atypical. More typical formats included: pamphlets, workbooks, spreadsheets, and videos. Atypical suggestions included a computer game, CD-ROM, musical tape, and board game. The most frequently mentioned formats were book/booklet, class/group, and one-on-one counseling. Of these options, one-on-one counseling was seen as more effective than a book, and an easier format for garnering information.

Ideas were also presented on how the tool should look. Many people noted that it should be colorful. Others suggested that it should have a fun inviting look that catch people's attention and "make them want to pick it up." Respondents thought it was important to avoid the cold kind of design they felt was usually found on materials dealing with financial planning. Use of pictures of people from different ethnic groups was suggested as were scenes depicting them making a living and doing well in life. Also recommended were visual graphics such as pie charts and bar graphs to illustrate things also presented in numerical form.

Regarding language, the most frequent suggestion was to keep the language simple and easily understandable. A few respondents went so far as to specify that it should be written for an eighth grade reading level, due to cognitive dysfunction and reading problems experienced by some people with a mental illness. Others noted that the formatting and organization of the information should be easy to follow and access.

Regarding content, respondents had many opinions about what information should be included. Some felt that it was important to explain to consumers the importance of budgeting and why they should consider establishing and adhering to a budget. Requests were made for information on how to create and maintain a budget, as well as examples of the process and what one looks like in the body of the materials. Respondents noted that budgeting examples would

need to be based on someone who is living with a mental illness on a fixed disability income. It was also suggested that tips on how to open up and maintain a checking and savings account should also be included.

More than one respondent suggested presenting financial education and planning information from the perspective of one or more consumers who tell their stories of going from poor to good financial planning. These characters could illustrate the instructional points made in the materials and show how they could be applied in the real lives of people coping with mental health problems.

Many felt that the book should have an “additional resources” section, offering names, phone numbers, addresses, and web sites for information, assistance, and services that could further aid consumers in their financial planning. Since medication is such a great expense and certainly a primary concern for people with a mental illness, it was suggested that the “additional resources” section should include numerous methods for obtaining low-cost or no-cost medications, which are often available through pharmaceutical companies. Finally, artistic expression and visual graphics should be used throughout the book(let) to help people learn and use the information more easily.

Summary

The two studies summarized in this section provide a wide array of interesting results and food for thought of use to anyone concerned with improving the financial education and status of people with mental illnesses. One major conclusion that can be drawn from these findings is the most fundamental rule of education, to know your audience.

Our findings about the dire financial straights of many people with this disability also suggest to tool developers that they should not focus solely on the more traditional approach to

financial planning (e.g., make a list of all your expenses, then add them up, then subtract, etc.). Such an approach makes the assumption that its audience leads lives in which planning and following through on one's plans is usually effective and rational. This is not always the case for individuals living with an unpredictable disability, in impoverished circumstances, surrounded by a society in which stigma makes them objects of ridicule and scorn and in which the institutions that purport to help them unintentionally trap them in poverty and deprive them of their dignity and, occasionally, their civil liberties. Instead, an equal emphasis should be placed on helping users of these products make their money go further, by providing money saving ideas such as resources for free or low cost goods and services. Once users feel that the tool can be of immediate value they will be more motivated to use it for short-term gains with the possibility of building on earlier successes to work toward longer term financial planning and stability.

One of the major findings of this research is the existence of many interconnections between mental and financial health. Respondents observed that the strained and desperate state of their finances engendered an increase in stress and psychiatric symptoms. For some respondents, their heightened psychiatric distress led to depression and thoughts of suicide. Respondents overtly and covertly described their financial situation as hopeless, chronically chaotic, and unalterable. Unless this belief is addressed in the design and execution of an instructional tool, its benefits and effectiveness will be jeopardized. It is important to appreciate the need for providing the kinds of financial planning assistance that restores hope, enhances motivation to take control of one's life and illness, and does not create one more failure experience for those who use it. To close with the thoughts of one mental health consumer:

“You need to communicate hope to the individual. That is probably more important than anything that you are going to tell them or teach them. There has to be hope that we can learn these skills. That it is doable. That even if our finances are a mess, we can do something about it. I think that’s the most important thing...to communicate hope.”

Section D: Financial Planning Tools

Despite the obvious need for financial education and financial planning tools specifically designed for use by people with mental illnesses, there is remarkable little currently in existence. The educational programs and tools that do exist primarily are targeted toward family caregivers or providers of services to people with mental illnesses.

Consumer-Oriented Tools. According to a report by the Institute for Socio-Financial Studies (ISFS) commissioned by the FannieMae Foundation (2000), financial education services are proliferating, and currently can be found in a variety of community settings. Some of these settings may be directly accessible to consumers of mental health services, including: the workplace; faith-based organizations; not-for-profit community service organizations; and educational institutions. Most of the programs surveyed by ISFS focus on three areas of financial education which are as relevant to people with mental illness as they are to the general population: budgeting and money management; savings and investing; and credit and debt. However, although the ISFS report surveyed 90 different financial education programs across the United States, *only one* of these programs specifically mentioned people with disabilities as being part of their targeted audience, and none of them were oriented toward mental health consumers.

The one program that did mention people with disabilities is the Mississippi Housing Initiative (MHI), a 6-8 hour course targeted to low- to moderate-income households, including people with physical and developmental disabilities. The MHI uses a collaborative public and private sector model, with partners from the Cooperative Extension Service, non-profit housing associations, the FannieMae Foundation, commercial mortgage lenders, and real estate

professionals. The main purpose of the MHI is to provide information and counseling to first-time homebuyers before, during, and after purchase through individual consultation, workshops, and classes.

In Illinois, the University of Illinois Extension has developed a 16-hour financial education course along with a train-the-trainer program. It was designed to assist staff and volunteers in community agencies and social service organizations to teach resource-limited clientele about money and related concerns. Although not designed specifically for people with disabilities, the “All My Money” program has been used by at least one disability services organization in Chicago, but again, without a specific focus on people with mental illnesses. However, this curriculum is designed for participants who have low literacy levels, and is reported to be an effective tool (ISFI, 2000). In particular, clients of the program attribute its success to entertaining learning activities that are relevant to daily life. The curriculum consists of eight lessons, which can be taught individually or as part of a series: (1) Making Spending Choices; (2) Envelope Budgeting; (3) Planning Your Spending; (4) Understanding Credit; (5) Handling Credit Problems; (6) Building Consumer Skills; (7) Taking Consumer Action; and (8) Managing a Checking Account. Each lesson includes a description of contents, background information, an overview of the session, a lesson plan, and teaching materials.

We contacted the disability services agency that was using the curriculum, and found that they had asked their part-time accountant to take the train-the-trainer course, and to teach the curriculum. We interviewed her about her experiences with the curriculum. She said that the agency had been offering minor incentives to their clients, such as bus fare cards or supermarket gift cards, in order to motivate them to complete the money management course before pursuing employment services. They had been successful in filling the classes, although no outcome or

satisfaction data were available to evaluate the impact of the course. The course instructor described some of the more notable aspects of her experience with the curriculum. First, in the exercise in which clients compute their income and expenses, the ratio almost always is negative (i.e., expenses exceed income). However, as part of the group exercise, clients realize that despite their negative economies, they are “making it,” somehow. The instructor felt that it was motivating to clients to see that they actually use a variety of methods, often ingenious, for getting through each month, including finding odd jobs, selling crafts or found items, or juggling a series of small loans. The shared experiences of course participants led to greater class involvement by clients and the genesis of a group feeling of validation that the instructor felt was very powerful. In general, the instructor felt that the “All My Money” curriculum was effective and appropriately geared to the education and experience of the participants. This was especially true of the weekly group budgeting exercises, which could be made entertaining and fun. Not all the chapters were relevant (such as checking accounts) and the instructor could pick and choose as she saw fit. Despite her generally positive experience with the curriculum, the instructor noted that it remained difficult to convince people that although money management wouldn’t change their lives dramatically (i.e., make them wealthy), it was important to avoid further “money traps” such as predatory lenders and unscrupulous landlords. Clients had to be educated that even respectable firms like H&R Block do not act in the clients’ best interest, and will actually cost them money for services that may not be needed. The instructor felt that even if course participants did not maintain their budgets, they were at least more aware of potential financial pitfalls and bad habits as a result of taking the classes. This curriculum has been almost completely translated into Spanish, and may be made available on the Internet in the future. In

addition, there is a follow-up, train-the-trainer curriculum for clients who are just returning to the workforce or trying to improve their job situation. This curriculum is available on CD-ROM.

Currently, there is an internet-based tool specifically designed to help people with disabilities plan their finances as they relate to disability benefits and employment. This program, *WorkWORLD*, was developed by the Employment Support Institute at Virginia Commonwealth University, and is funded by SSA. The intent of the program is to foster self-determination among people with disabilities by facilitating informed choices about employment and benefits, while saving government resources. Although SSA provides funds to maintain and update the software and website, an evaluation of this tool has not yet been funded or conducted. However, in interviewing the Project Manager, we were able to find out that over 60,000 help pages on the site are opened each month (meaning that 60,000 times in a month people are looking into the software and its use). In addition, 2,500 individuals have signed on to the program's email update notification list. As has previously been described, disability benefit, employment, and welfare programs interact in complex and sometimes incompatible ways, providing considerable disincentives to individuals who wish to improve their financial situations. The following is an overview of case examples from the *WorkWORLD* program (more detail and examples are included in the compendium):

Frank has been working as a cashier at a Community Rehabilitation Provider (CRP) worksite earning \$7.00/hr. and working an average of 15 hours a week under a NISH contract. (NISH stands for National Industries for the Severely Handicapped. NISH is the national nonprofit agency designated to provide technical assistance to Community Rehabilitation Programs (CRPs) interested in obtaining federal contracts under the Javits-Wagner-O'Day (JWOD) Program.) He receives Supplemental Security Income (SSI)

and Medicaid. His combined income from his SSI cash benefit each month (\$377.50) and earned income through the JWOD contract (\$420/month on average) is \$797.50.

Frank, however, wants to grow on the job and pursue new opportunities. He has the opportunity to increase his work hours and his hourly wage, which will raise his earned income to \$840/month, which exceeds the \$780/month amount for Substantial Gainful Activity (SGA) under the Social Security Administration's (SSA) rules.

Frank feels he can accept a reduction in his SSI cash benefit, even if it goes to zero, as long as his net income increases sufficiently and he can keep Medicaid. Frank and his counselor use *WorkWORLD* to model alternatives to discover his best net income possibility and to learn how he can maintain his Medicaid coverage. These results will be shared with significant others who are concerned that Frank will lose his eligibility for SSI benefits and Medicaid if he makes too much money.

SSA also provides benefits planning tools, both online and in hardcopies that can be ordered by telephone, such as SSA's *Red Book: A Summary Guide to Employment Support for People with Disabilities Under the Social Security Disability Insurance and Supplemental Security Income Programs* and B.E.S.T. an online Benefit Eligibility Screening Tool. Examples of these are included in the compendium. However, in general, consumers report that SSA-generated materials are difficult to use at best, and often are confusing or intimidating.

Provider Assessments & Case Management. Money management is one of the Instrumental Activities of Daily Living (IADL) that is, or at least ought to be, commonly assessed by psychosocial rehabilitation service providers. Although many tools exist for providers to use in assessing financial management skills, these are often cursory in nature and not supported by adequate training and resources for the assessor. However, the Program of

Assertive Community Treatment (PACT) includes a fairly comprehensive financial support and money management assessment. PACT is an evidence-based best practice in community-based treatment for persons with severe and persistent mental illness. In the PACT model, teams of providers, usually consisting of a psychiatrist, a nurse, a vocational specialist, a substance abuse specialist, and an assistant, provide individualized and comprehensive services to people with mental illness in the communities where they live. PACT team visits can take place in people's homes, in coffee shops, libraries or other community venues. In the PACT comprehensive client assessment tool, financial resources and management skills are assessed in terms of: amount and source(s) of income; dependents; cash, credit, or checking economy; third-party control of money; use of banks; monthly expenses; living expenses; adequacy of income; tax liability; borrowing and lending patterns; stressfulness of budgeting; interest or desire for help with money management; strengths and weaknesses as assessed by the team; and an assessment, recommendations, and treatment plan (Allness & Knoedler, 1998).

Although there is growing acknowledgement among mental health program administrators as well as case managers of the importance of including money management services and training as part of the standard of care, they face the challenge of how best to meet these service needs. A study from the field of psychosocial rehabilitation demonstrates this gap in service delivery. Ware and colleagues (1997) conducted an ethnographic study of 118 consumers in Boston as part of a research demonstration project on housing stability and mental illness funded by the federal government's Center for Mental Health Services. The authors describe a number of "informal economic rehabilitation strategies" that were developed in conjunction with group housing and supported employment programs. Consumers undertook group entrepreneurial ventures to increase their cash flow (such as leasing parking spaces or

laundry facilities owned by the group residence). In addition, consumers pooled small amounts of money into larger group funds in order to stretch their finances through the purchase of a wholesale club membership, and to provide a lending source from which individuals could borrow small amounts of money. Although the alleviation of poverty was an integral part of this psychosocial rehabilitation program, the absence of money management or financial planning skills training was a notable obstacle. The authors of the study note that the nonprofit organizations that managed the housing were reluctant to have residents handling group funds, and that residents, in turn, were uncomfortable handling shared monies, “citing a lack of confidence in their money management skills.” Although psychosocial rehabilitation and mental health services providers clearly recognize the importance of financial skills for consumers, generally they lack the training and resources to meet this need.

There are a number of resources available to providers that focus on navigating the complex world of benefits and entitlements. In addition to SSA manuals and online documents, there are independent training curricula designed to help service providers assist their clients in managing benefits and entitlement including SSI, SSDI, food stamps, housing (Section 8), and utility supplements. One such training coordinated by the University of Illinois at Chicago - Illinois ACT Training Institute is entitled “Benefits and Entitlements Training: What You Need to Know.” In this training, the presenter focuses on entitlement and welfare benefits administered by Social Security and the Illinois Department of Human Services (Public Aid). The training includes a 200-page handout of government documents and forms to guide participants through the process of gaining and maintaining benefits and entitlements for clients. Participants also learn the difference between SSDI and SSI, how to apply for and obtain benefits, appealing negative decisions, obtaining representative payee status, how work affects

SSA, health, and public aid benefits, how to handle spend-down requirements, and how to advocate for clients with federal and state workers. Although benefits management is more often recognized as a role for service providers than is money management or financial planning, many service providers find it an onerous task, or are personally not qualified to perform it well.

Family Estate Planning. The National Alliance for the Mentally Ill, the largest advocacy organization for family members of people with mental illnesses, sponsors a financial planning program for families called the Planned Lifetime Assistance Network (PLAN). Currently, the National PLAN Alliance is made up of 22 independent PLAN programs in 18 states, serving approximately 4,000 families. The mission of the not-for-profit programs is to help families develop a future-care plan, establish the resources for payment, and identify the person(s) or program(s) responsible for carrying out the plan. Most PLAN programs also provide current services that relieve parents of part of the daily burden of care. Currently, throughout the country, there are 22 PLAN programs in operation serving approximately 4,000 families. Information about PLAN and local program contacts are available through the NAMI website.

One of the most common financial planning tools used by families is the Special or Supplemental Needs Trusts (SNTs), which can be first-person (set up by the benefiting individual themselves for later use) or third-person (set up by a relative or other). In either case, the advantage of SNTs over traditional Trusts is that the funds can be directed to specially defined needs, such as food, shelter, medical care, travel expenses (as approved by a professional fiduciary), and therefore do not count as part of the beneficiary's income. This point is particularly important for people with mental illness who are receiving government benefits through means-tested programs such as SSI, Medicaid, Food Stamps or Section 8 housing. However, these plans are not without cost in terms of legal and administrative fees.

The Role of Representative Payees. Third-party control of a consumer's funds can be formally arranged through a representative payee, who may be a provider, a family member, or someone else in the community such as a member of the clergy. SSA offers an online self-guided training program and manual for organizations and individuals who wish to become representative payees. As defined by SSA, a representative payee is "an individual or organization that receives Social Security and/or Supplemental Security Income (SSI) payments for someone who cannot manage or direct the management of his/her money. Payees should use the funds for the current and foreseeable needs of the beneficiary and save any remaining funds for the beneficiary's future use." The SSA manual instructs newly appointed representative payees on the knowledge and skills needed to competently perform their duties. In sixteen units, payees learn: Social Security programs, overview of representative payment, selection of a representative payee, duties of an organization representative payee, reporting responsibilities, use of benefits, improper use and misuse of benefits, bank accounts and proper titling of their accounts, collective accounts and proper titling of these accounts, dedicated accounts, keeping records and accounting for benefits, monitoring organizational payees, payment for representatives payee services, direct deposit, and best practices.

The SSA manual is large and daunting, but there are some alternatives available to people or organizations interested in learning about representative payeeship. The first is a manual entitled, "Representative Payee Services and Custodial Account Management," produced by Thresholds, Inc., a large psychosocial services provider in Chicago. This manual contains only four chapters: (1) The pro's and con's of representative payee services; (2) Staff qualifications, training and performance expectations; (3); Consumers' perceptions of payee services; and (4)

How to set-up and operate a custodial account. The manual is user-friendly and very detailed. For example, Chapter 4 outlines the steps and procedures needed to manage a custodial account. A selection of these steps include: creating agency policies which will govern procedures and practices, choosing a bank and completing bank paperwork, choosing the format for record keeping, setting-up the account ledger, and making deposits to the custodial account. In addition to the four chapters, the manual features approximately 30 pages of appendix that offer sample documents and illustrations of how these documents are to be completed. Blank worksheets and forms, suitable for copying, are also included.

The second representative payee education product is a manual entitled “Creating Community Linkages: A Guide to Assertive Outreach for Homeless Persons with Severe Mental Illness” prepared by the University of Illinois at Chicago National Research and Training Center on Psychiatric Disability. As the title suggests, the focus of this manual is to teach case managers how to best provide outreach services to a transient population. However, of the ten units that discuss various psychotherapeutic aspects of clients’ lives, one unit is solely devoted to client money management. This unit, “Establishing financial security: Introduction to public entitlements” provides readers with an in-depth introduction to the government benefits/entitlements system that includes: Supplemental Security Income, Social Security Disability Insurance, Medicare Part A and B, Medicaid, Temporary Assistance for Needy Families, and the Food Stamp Program. In addition, case managers are taught how to navigate through the benefits system including how to apply for entitlements, work with government agencies, and manage client money.

Little research has been done on the prevalence or outcomes of representative payee programs. One study that did attempt to assess the prevalence of such programs was a 1996

survey of community mental health centers (CMHCs) under contract to the Illinois Department of Human Services (Hanrahan et al., 2002). This study found that 59% of CMHCs were direct providers of representative payee programs, and the majority of these programs provided such services to clients under the mandate of SSA. In these CMHCs, more than one-third of clients receiving intensive services (assertive community treatment, supportive housing, or residential extended care) were enrolled in their representative payee programs, and frequently cited criteria for enrolling candidates were lack of financial skills, lack of rent money, and substance abuse. Other studies have tried to identify the characteristics of mental health consumers who have representative payees. Conrad et al. (1998) identified such clients as being more likely to have a diagnosis of schizophrenia, to be homeless, to lack rent money and to be long-term recipients of SSI/SSDI income. On the other hand, a North Carolina study of outpatient commitment found that the majority of study participants with psychiatric disabilities had their finances managed by a family member representative payee (Elbogen et al., 2003). These consumers were also more likely to have a diagnosis of a primarily psychotic disorder (such as schizophrenia), to have substance use problems, and to have annual incomes below \$5,000. Research into the outcomes of representative payee programs has been mixed. Luchins and colleagues (1998) found that representative payee programs could be effective in reducing psychiatric hospitalization stays. However, Rosenheck et al. (1997) found no evidence that third-party money management programs improved outcomes among dually diagnosed (i.e., those with mental illness and substance abuse disorders) homeless consumers. Of additional concern is research that suggests that CMHCs regularly use representative payee programs to coerce clients into attending or adhering to clinical services (Ries & Dyck, 1997).

Summary. Despite the obvious need for financial planning tools dedicated to the needs of people with mental illnesses, existing financial planning tools are either limited in scope (for example, focusing only on planning for benefits and entitlements), or aimed at too broad an audience, and not specifically tailored to the issues faced by people with mental health concerns. The University of Illinois Extension's "All My Money" curriculum seems to be an effective tool for low-resource clients. Other relevant resources have been developed by psychosocial rehabilitation service providers or by mental health researchers who needed to train their own staff and found that no materials were available.

Section E: Recommendations for Education & Dissemination Strategies

Based on a national survey of 1,000 adults from the general U.S. population, Cutler and Devlin (1996) developed a model of financial literacy encompassing two dimensions: knowledge and confidence. They found that an important element in developing consumer confidence is that personal finance education should be socio-culturally sensitive. In addition, the following factors enhance confidence among students of personal finance: the opportunity to undertake a specific action that challenges one's sense of self-sufficiency without overwhelming it; the presence of supportive and reassuring others; and the experience of succeeding at something, with confirming feedback from others (ISFI, 2000, p. xiii). These concepts of socio-cultural sensitivity and confidence are equally important to consumers of mental health services.

Because of the severe nature of individuals' disabilities and because of the recurring nature of periods of impairment, people with serious mental illnesses may lack confidence in their ability to comprehend complex information about financial education and planning. In addition, the uncertainty that accompanies many forms of remitting and relapsing mental disorders may create the impression for individuals with this disability that financial planning is simply "not worth it." Thus, it is important that financial education materials for individuals with psychiatric disabilities develop their sense of self-confidence along with the capacity to learn and apply the information to continually changing life and illness circumstances.

Efficacious Strategies for Consumers. A major new development in the field of mental health services that has implications for financial education is the use of consumer self-help and peer-to-peer services (Cook & Jonikas, 2002). This type of assistance encompasses alternatives ranging from informal interventions such as volunteer-led support groups all the way to large,

legally incorporated consumer-run agencies in which all organizational governance and client assistance is provided by individuals who are in the process of recovery from psychiatric disability. One of the major principles underlying this mode of intervention is Social Learning Theory (Bandura, 1977), which holds that behavioral change is more likely to result from interactions with peers vs. non-peers because the former enhance self-efficacy due to their credibility as role models. This addresses the need for encouragement identified by Cutler and Devlin's research. Another theoretical construct underlying peer support is that of Social Comparison Theory (Suls & Wheeler, 2000), which holds that individuals seek others who share the same condition, problem, or illness, in order to achieve a sense of normalcy and an understanding of the world. Here, the emphasis is on "normalizing" the condition of psychiatric illness and disability, with the financial education focus being that of normalizing the life skill of financial planning in the face of an unpredictable illness. Thus, one potential mechanism for the dissemination and delivery of peer support, with demonstrable efficacy in other areas, is that of peer-to-peer information sharing and support for financial planning. Such an approach also complements the finding of Cutler and Devlin that personal finance education is more effective in the presence of supportive and reassuring others who can provide confirming feedback.

A number of education modalities are likely to be successful in financial education and planning. These include instructional booklets and self-study guides, classroom or one-on-one educational curricula, and electronic information technology (IT) such as interactive CD-ROMs. Paper and pencil formats have the advantage of being lower cost, less intensive approaches that are easy to duplicate and disseminate. They can be used in private and at the user's own pace, which may be preferred by some consumers. While they can be written in such a way as to encourage confidence and maximize some aspects of socio-cultural sensibility, in and of

themselves, they offer fewer opportunities for role modeling and interpersonal support for financial planning efforts than other options.

Classroom and one-on-one instruction provides more opportunities for enhancing both confidence and the ability to tailor education and financial planning activities to recipients' specific cultural and socio-emotional needs. This is particularly the case when the course is taught or co-taught by another person with mental illness, especially someone from the recipient's own culture and social class. The presentation of the material over multiple sessions or individual meetings enables participants to receive the information in small doses. This format also offers the advantage of enabling the instructor to gauge learners' level of understanding and correct misperceptions or offer clarifications of complex material. In cases where an individual's symptoms or medication side-effects impair cognitive functioning, instructors can further tailor the materials to take account of cognitive deficits so that information is presented in multiple formats (e.g., written, verbal, and visual). Disadvantages of this modality include the expense of hiring and training instructors, logistical difficulties such as transporting users to the training or education settings, and hidden costs such as securing a classroom or training location. Also, some consumers may dislike a group approach to learning and applying this information because of stigma related to mental illness and personal embarrassment about past financial problems.

A third modality involves the use of decision-support software, in the form of an interactive CD-ROM or a web-based interactive software program. CD-ROMs for example, can incorporate multimedia content such as sound, pictures, and video clips to provide consumer users with information, after which they can be assisted to create a financial plan specifically tailored to their needs and preferences. Such an approach is currently being used in a CD-ROM

called *AD-Maker* to educate people with mental illnesses about advance directives (ADs) and to assist them in the creation of their own directives for medical and psychiatric care in situations of impaired decision making (Sherman, 1998). Another example is *WorkWORLD* (Hill, 2002), a program of decision support software designed to be used by people with disabilities (including mental illness) who wish to increase their employment income while taking into account Federal and local incentives and benefit restrictions tied to rules and regulations of SSI, SSDI, Food Stamps, Section 8 Housing Assistance and other public programs. One advantage of this approach is that the software can be customized to the user's local area, providing information about state and regional variations in public rules and regulations. Another advantage is that accurate, updated information can be added quickly and efficiently through the creation and distribution of new releases, without needing to retrain instructors or reissue written materials. Yet another advantage is the ease with which highly individualized plans can be created with this approach. For example, after evaluating information about an individual's personal situation, the program develops reports or spreadsheets showing how changes in income or savings might affect an individual's financial future. The interactive nature of the software generates follow-up questions based on an individual's prior responses, making the plans increasingly detailed as more and more information is added. Research on the use of *AD-Maker* (Sherman, 1998) by individuals with mental illness (85% with diagnoses in the schizophrenia spectrum, bipolar disorder, and depression) found that, even though 65% reported having little or prior experience using computers, almost two-thirds (39 out of 60 or 65%) were able to use the software and complete an AD within an 80 minute time limit.

Efficacious Strategies for Service Providers. Another source of financial education information and planning assistance is the group of service providers with whom many

consumers come in contact on a repeated basis. These helping professionals already are providing important information, such as education about the causes and course of mental illness, treatments such as medications and their side effects, and assistance with applying for benefits and entitlements for which the consumer is eligible. Some consumers have providers designated as “case managers” who offer assistance with budgeting and money management on a day-to-day basis. However, not all individuals have this kind of assistance and not all case managers have the knowledge and skills necessary to engage in accurate and timely financial education and planning, beyond how to apply for and retain SSI and SSDI. Given the central roles of impoverishment and financial need in the lives of many of the consumer participants in our project’s focus groups and individual interviews, and the research on poverty and mental illness, one recommendation of this report is that the provision of financial education and planning be considered a “standard of care” for individuals with major mental disorders.

Obviously, service providers can make use of the same modalities as those described above. That is, they can read and complete, for or with their clients, financial education and planning workbooks and self-study guides. They can teach classes or provide one-on-one financial education along with assistance in short-term and long-term budgeting and planning. They also can be important sources of support and assistance to consumers in the use of interactive decision-support software.

Additional modalities of use to service providers include the use of assessment tools developed to help them identify which consumers on their caseloads are in need of particular types of assistance, or screen for those whose need is most acute and compelling. Such tools might be modeled after depression screening instruments currently used to detect clinical depression and to identify those needing treatment among large populations. In this case, a

financial planning needs assessment screening instrument might use a short list of indicators (e.g., skipping meals due to lack of money, housing income exceeding a fixed percentage of monthly disposable income) to identify those in need of immediate financial outreach, education, and intervention.

Efficacious Strategies for Family Members. Yet another source of financial education information and planning assistance is the individual's family. In the case of families who wish to plan for the futures of their financially dependent relatives, education is needed regarding estate planning and inheritance taxes, as is assistance with setting up trusts and arranging powers of attorney for the management of their relative's finances after their own deaths. Families and other caregivers need to know that they are not alone in their concerns, and family support and advocacy organizations can provide needed practical information as well as emotional support. For these individuals, web sites can be an important source of information and referrals to legal professionals who are experienced in setting up trusts for financially dependent family members.

The term "family" can also be applied loosely here to include significant others with whom consumers have deep emotional bonds and come into contact on a repeated basis. In impoverished communities, where members lend each other money and share durable goods and commodities (e.g., automobiles, cigarettes), consumers may have significant others not related by biological or legal ties, who nevertheless have a vested interest and genuine concern for each others' financial stability and security. These individuals can act as "natural supports" for financial planning and assistance. The term "natural supports" is taken from the vocational rehabilitation field and refers to individuals who are part of naturally occurring support networks and can therefore assist a disabled individual to find and maintain employment (e.g., friends, neighbors, co-workers, landlords). Here, natural supports can assist with financial education

efforts and support consumers' attempts to use information imparted through the different modalities already described.

Mental Health Stakeholders' Reactions to Different Modalities. One of the topics addressed during a conference call held with the NEFE project Advisory Committee on September 24, 2003 was "promising practices" in financial education strategies, materials, and methods. The group discussed the pros and cons of creating educational materials in booklet form, CD-ROM, or a series of pamphlets, and emphasized that materials should be aimed at different target groups (e.g., consumers, service providers, representative payees, family members). Committee members also discussed how variations in educational materials would be needed by those at different literacy levels, interest levels, those with cognitive impairments, those with a preferred language other than English, women (especially those with young children), and those in different geographic regions of the country.

Committee members discussed how the concept of "planning" can have a different meaning for someone who does not have much money with which to do any planning. Some members also questioned the existence of consumers' motivation for engaging in financial planning. One suggestion was to design self-assessments, in which people could be helped to identify all sources of actual and potential income as well as the advantages and disadvantages inherent in receiving public disability income support (which some members viewed as a "trap" into poverty due to limitations on earned income and Medicaid spend-down and divestment requirements). Another suggestion was that case managers and other service providers should be mandated to receive training in and to provide financial education and planning assistance. There was a general feeling that the first order of importance was to educate and assist people in developing the skills necessary for living on very limited monthly incomes, meeting basic needs,

and engaging in successful financial planning with only subsistence level cash income and noncash resources. The group urged that consideration be given to the creation of separate educational materials targeted to different groups of individuals (consumers, providers, family) or at least that subsections of any materials created, be targeted to these important stakeholder groups. Finally, group members had concerns that the use of pamphlets and workbooks alone might trigger feelings of depression and hopelessness among individuals in desperate financial circumstances. The involvement of peers, relatives, service providers, and natural supports was suggested as a way to avoid negative emotional reactions to difficult life circumstances.

Additional feedback on this issue was provided by the National Advisory Board (NAB) of the UIC National Research and Training Center's (NRTC) on Psychiatric Disability at its annual meeting in Chicago on October 1, 2003. This Board is composed of nationally recognized experts in psychiatric rehabilitation including consumers, family members, psychiatrists, peer providers, a former state mental health commissioner, and other advocates. Board members suggested the promising practice of using "success stories" about consumers who had climbed out of poverty and regained economic control over their lives, as both a motivational and instructional method. Particularly noted was the need to include the experiences of consumers who had exited the public disability support rolls, paid off substantial debts, and achieved higher levels of economic self-sufficiency through using financial education and planning strategies. NAB members suggested ways in which the goals of the NEFE Project complemented the President's New Freedom Commission on Mental Health Report's emphasis on benefits planning and counseling as part of the Ticket to Work and Work Incentives Improvement Act (TWWIIA) legislation, which is just now being implemented in many states. Also discussed was new legislation regarding Medicaid Buy-In programs for people with mental

illness, enabling them to return to work, earn substantial income, and still retain their health insurance through Medicaid. It was strongly suggested that any materials created for consumers be accurate and current with new policy developments and legislative mandates that might affect financial planning for this group of individuals.

Summary. A number of different best practice training modalities are available for use in designing effective tools to provide financial education planning and assistance to mental health consumers. Many of these meet the standards identified by research on “what works” in providing successful finance education to the public at large: materials that are challenging without being overwhelming, provision of support and reassurance along with education, creation of culturally sensitive products, and designing educational approaches that enable individuals to succeed at financial planning while receiving confirming feedback from others.

These modalities include instructional written materials, video tapes, in-person group and individual training, and the use of interactive software by consumers themselves, consumer peers, mental health professionals, family members, and natural supports in the individual’s own social environments. Reactions to these modalities from the project’s Advisory Committee, a Psychiatric Rehabilitation Research and Training Center’s National Advisory Board, and participants in the NEFE Study of Financial Needs and Experiences of Individuals with Mental Illnesses endorsed the viability of many of these approaches. There was agreement that materials needed to be sensitive to issues of culture, gender, race/ethnicity, and geographic region, and that educational approaches should be “personalized” to fit situations common to many individuals with mental illness. Recognition that financial education needs to be presented differently to those living in poverty as well as those who are coping with upsetting emotions and chaotic life circumstances also was echoed in the feedback from these groups. The advice to

“know one’s audience” was also given, along with suggestions about the need to develop materials that were colorful, engaging, and creative in portraying the lives of “real people” with mental illness who had used financial planning successfully to take back control of their finances and move on with their lives. The importance of keeping it simple and developing products that use language at no higher than an 8th grade comprehension level was emphasized, as was the need to create materials for non-English speaking audiences. Also highlighted was the need to create materials that could be used by multiple mental health stakeholders, including consumers themselves, their service providers (especially representative payees), peer-to-peer supporters, family members, and the natural supports in their social networks. Finally, tool designers were encouraged to take account of the many interlinkages between mental health and financial health for people with serious mental illnesses: how the need for expensive medications interacts with a lack of prescription drug coverage to strain already stretched financial resources; how psychiatric symptoms can exacerbate fiscal irresponsibility and vice versa; and how dire and unremitting poverty can diminish hope and the motivation to plan for an uncertain future.

At the same time, feedback from the advisory groups and research participants offered compelling evidence of the resourcefulness and courage of consumers in the face of overwhelming economic circumstances. This included those who were too poor to open bank accounts yet were able to scrimp together coins and dollar bills to save in “money pots;” individuals raised in families affected by poverty and mental illness who fought mightily to avoid the very circumstances of their childhoods; those who labored for years to pay off school loans, credit card debts, and medical bills; workers intent on saving enough money from their earnings to buy a small piece of the American Dream such as owning a car or a home of their own; and people planning ahead for those “5 week” months so that they wouldn’t have to skip a

meal, a medication, or a chance to have lunch with friends. Surely this evidence of motivation on the part of people with mental illnesses to better manage their meager finances in the face of all odds points to the value of financial education for this group of American citizens. While their problems are complex and daunting, the possibilities for enhancing their lives are virtually limitless. It is they who challenge us to take a chance much smaller than the chances they take every day in simply surviving, while dreaming of a better future.

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Section II. List of National Organizations for Resources & Dissemination

This section is available upon request from the University of Illinois at

Chicago Center on Mental Health Services Research & Policy.

However, information is only current as of January, 2004.

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Section III. Compendium of Primary Source Information

*This section is available upon request from the University of Illinois at
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