Beyond Breaking Even: The Personal Economies of People with Psychiatric Disabilities and the Influence of Employment

Judith A. Cook, Dennis D. Grey, and the Employment Intervention Demonstration Program

Personal Economy Study Site Investigators*

Judith A. Cook, PhD, cook@ripco.com, 104 South Michigan Ave., Suite 900, Chicago, IL 60603, 312.422.8180 X19

*The Employment Intervention Demonstration Program (EIDP) Personal Economy Substudy (PES) Site Investigators include (in alphabetical order): Laura Blankertz, Ph.D., Matrix Research Institute; Tony Lehman, M.D., University of Maryland, Baltimore; Cathaleene Macias, Ph.D., Fountain House; Neil Meisler, M.S.W., Medical University of South Carolina; Michael Shafer, Ph.D., University of Arizona, Tucson; and Marcia Toprac, Ph.D. Texas Department of Mental Health and Mental Retardation. The EIDP study is funded by the Center for Mental Health Services (CMHS) of the Substance Abuse and Mental Health Services Administration (Cooperative Agreement # UD7-SM51820). The PES received supplemental funding from the Social Security Administration (SSA); Crystal Blyler, Ph.D. of CMHS and Mark Green, Ph.D. of SSA serve as government project officers for the PES. The opinions expressed herein do reflect the official policy or endorsement of any federal agency.

Beyond Breaking Even: The Personal Economies of People with Psychiatric Disabilities and the

Influence of Employment

Introduction

A large proportion of people with severe and persistent mental illness live in poverty and depend on Supplemental Security Income (SSI) and Social Security Disability Income (SSDI), both as an economic "safety net" and as a source of needed health and mental health care. 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 employment, since the context of poverty can interact with the often-unpredictable course of severe mental illness to create uncertain economic futures for many. Economic development theory assumes that poor people make well-informed financial decisions when the risks are well understood. Our research views consumers as active agents making complex decisions to allocate scarce financial resources over competing obligations and desired outcomes.

The purpose of the Employment Intervention Demonstration Program (EIDP) Personal Economy Study (PES) is to collect detailed financial information from respondents in order to more accurately characterize their personal economic situations. This supplement to the EIDP multisite study (the larger EIDP study is described in another article in this issue of The Journal) is gathering data for a substudy funded by the Social Security Administration that will enrich our understanding of consumers' monthly finances, including all types of income, expenses, assets, and the value of services received. The PES supplement asks consumers questions about seven

areas of their personal finances: amounts and sources of all cash income received in the past month, including whether this month was typical or atypical; health and mental health services used; types of noncash assistance received; personal financial assets; amounts and types of monthly expenses; SSI beneficiary history; and SSDI beneficiary history.

Cash and Noncash Income, Assets, and Expenses

At this point in our investigation, participating EIDP sites have collected data from over 850 mental health consumers and we have learned quite a bit about their personal economic situations in the month prior to their interviews. The following presents a preliminary, descriptive look at the data gathered thus far. First, the four 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. The total average cash income across all EIDP participants was \$779 per month; however, half of all consumers reported cash incomes of only \$623 per month or less.

In addition to cash income, many mental health consumers receive different types of *noncash income* such as housing vouchers, food stamps, and supplements for utilities or transportation. While not provided to consumers in monetary form, these sources of noncash 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 participants were receiving transportation vouchers, at an average value of \$19 per month. Almost a quarter of 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 (\$144 per month), transportation (\$78 per month), and repayment of loans (\$42 per month). Across all EIDP participants, monthly expenses averaged \$818, higher than the monthly average cash income for the total group. This is important, because it creates *negative personal economies* for consumers in which expenses average 105% of income. Thus, on average, consumers' monthly expenses exceed their cash on hand to cover these expenses.

In addition to having negative personal economies, EIDP consumers have little in the way of financial *assets* to rely on, should they need to convert them into to cash to cover debts. For many consumers, this is due, in part, to Medicaid and Medicare spend-down requirements, which force consumers to divest themselves of assets in order to achieve eligibility for health care. While 73% of all consumers reported some type of asset such as a home, vehicle, or durable goods, the value of such assets for half of all consumers was less than \$200, resulting in a very scanty safety net to cover potential debts and monthly shortfalls.

Personal Economies of Working Versus Nonworking Participants

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. We wondered whether those consumers who were working would have better micro-economic situations than those who were not. Interestingly, we found that employed EIDP participants had a positive

personal economy, with an average ratio of expenses to income of 80%. Conversely, consumers who were not working had a negative personal economy, with a ratio of expenses to income of 140%

Case Examples

These points are illustrated by two case examples from our study. Jackie is a 49-year old, widowed, African American woman living in the Southwest. 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. Since joining the EIDP, she has held five different jobs lasting from one to nine months, ranging in pay from \$4.75 to \$7.65 per hour, and varying from twenty to forty hours worked per week. None of these jobs included benefits such as health care, dental care, sick leave, or retirement pension. She is currently unemployed and relies on a combined monthly SSI/SSDI income of \$509. She has three children and lives 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 no physical or mental health services received 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 a utilities bill of \$400. Jackie's personal economy is negative given that her expenses amount to 156% of her monthly income.

Another example is Roger, a 36-year old, single, Caucasian man living in the Northeast. He is a high school graduate currently residing in supported housing. At the beginning of the 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, 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 last 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 sole 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 a little under 100% of income. However, without his family's economic contribution, his personal economy would be negative, with his expenses totaling 113% of income.

Summary and Conclusion

As these examples illustrate, consumers are faced with complex decisions about allocating scarce economic resources, in which there is very little margin for error. On average, most consumers participating in this demonstration program designed to help them return to work had negative personal economies, meaning that 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 consumers to "break even" for the month and meet all their expenses.

But mental health consumers deserve more than an opportunity to break even financially.

As people with a severe disability, they should not be forced to live without financial security,

laboring under a system 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 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 case management as a linchpin of coordinated services along with financial security as a goal that is part of all consumers' recovery.