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The Employment-Related Health Insurance and Service Delivery Needs of Persons with Disabilities

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INTRODUCTION

Health care services can play a critical role in supporting employment among people with disabilities and can sometimes be the difference between working and not working for those with disabilities.¹ The health insurance and service delivery reforms underway in U.S. will benefit persons with disabilities; however, the reforms may not fully meet the employment-related health care needs of many persons with disabilities. Increasing employment among people with disabilities is an important policy goal of federal agencies, including the Social Security Administration, the Centers for Medicare and Medicaid Services, the Department of Labor and others.^{2,3} While the employment rate of working-age persons with disabilities is less than half the employment rate of persons without disabilities, many people with disabilities are able to work successfully and many others want to.^{4,5,6}

The Affordable Care (ACA) act will expand access to insurance coverage for the uninsured and improve coverage for some currently insured persons with disabilities. Gettens and colleagues⁷ estimated that approximately 2 million persons with disabilities will be newly covered. ACA changes might help to improve employment among persons with disabilities. However, because the coverage standards for many newly insured will be comparable to current employer-sponsored insurance within states,⁸ the new coverage almost certainly will not cover, or not sufficiently cover, many employment-related health care services that support people with disabilities to work. Such services can include personal assistance services (PAS), certain durable medical equipment (DME), physical and occupational therapy, mental health services, medications and other services.

To address the unmet need for employment-related health care services among persons with disabilities, an alternative and potentially viable policy solution is the development of a new type of subsidized coverage to ‘wrap-around’ the new ACA coverage or other private and public coverage. Additional information on the employment-related health care needs of persons with disabilities is needed to inform the potential development of wrap-around plans. In this study, we conducted focus groups with employed and potentially employed persons with disabilities in Massachusetts to identify and describe the types of employment support needs these individuals experience and to inform the development of a future research to quantify the employment support needs.

METHODS

We conducted six focus groups at five different geographic locations in Massachusetts with a total of 54 participants. Focus group participants were purposively sampled and recruited through state agencies, community-based organizations, and disease-specific organizations that employ, serve or represent persons with disabilities. Recruitment methods were designed to ensure that some participants would have relatively high earned income and employer-sponsored health insurance.

Participants were selected that met the following criteria: (a) self-reported physical, psychiatric or sensory disability or chronic illness, (b) aged 21 to 64 years, (c) English-speaking, (d) community-dwelling, (e) employed or actively looking for work, (f) covered by private

health insurance or Medicare (may also be covered by Medicaid as a secondary insurance), and (g) able to consent to participate in the study.

The focus group discussion sought to determine participants' employment-related health insurance, health care and service delivery needs. Participants were asked to describe services that were critical to their ability to work. We also asked participants about unmet service needs, out-of-pocket costs for health care services, and how health care providers and the care delivery system affected employment.

Focus group discussions were audio-recorded and recordings were transcribed verbatim. Qualitative approaches were used to analyze the data. We conducted a thematic analysis of the transcripts, using an iterative, constant-comparative approach.⁹

RESULTS

Participants

The average age of participants was 46, ranging from 29 to 63. The education level of participants was high with more than half having completed a four-year college or postgraduate degree. Most participants were non-Hispanic and white. The distribution of income was bimodal with 47 percent of participants reporting earned income of less than \$10,000 and 32 percent reporting income of more than \$40,000 annually. Twenty-nine percent of participants had insurance through their employer and 46 percent had dual Medicare and Medicaid coverage.

Eighty percent of participants reported being limited because of physical, mental or emotional problems; 20 percent reported limitations in activities of daily living and 48 percent reported limitations in instrumental activities of daily living. Sixty-five percent met Social Security Administration disability standards as indicated by Medicare or disability-based Medicaid enrollment.

Current Health Care Services and Employment

Participants reported using a full range of types of health care services in the prior year, including inpatient, outpatient, primary care, behavioral health and other specialized care, prescription drugs, DME and PAS. Many participants reported relatively high levels of utilization:

I had back surgery so I had durable equipment; I had a hospital bed. I had a back brace. I have PAS that helps me with lower ADL management on a daily basis. Also my medicine. I have MS so I have a walker that I use at times. I have a cane and a mobile wheelchair.

Participants described the health care services that have allowed them to work. Services included those typically covered by most health insurance, those covered only by Medicaid, as well as services generally not covered by health insurance. An example of covered services included:

My nurse practitioner... without the antidepressants she gives me I would not be able to work. There is no way that I could get through the day without them.

PAS and more extensive coverage for DME are examples of services covered by Medicaid but not typically covered by other insurance types.

I do need it [Medicaid] to cover the PCAs [PAS] primarily, but also to cover durable medical equipment. I use a chair, I use a walker, and that's not something that the primary insurance would typically cover.

Unmet Need for Services

Participants' were asked about services they needed for employment that were not being met by their health insurance. Responses were generally in two categories. The first included services covered by insurance; however, because participants encountered limits on the quantity or type of service available there was an unmet need. The second category included services that are not typically covered by insurance.

In contrast to the substantial unmet need expressed by some participants, other participants reported low levels of unmet need. Low levels of unmet need were most often reported by participants with Medicaid (known as MassHealth) as secondary coverage.

I have Medicare and Mass Health...I went to the doctor's today and to the endocrinologist two weeks ago, everything is covered. I have to get a bone scan and that is covered. I am there all the time so I feel lucky. I have no problems with my medications, they cover everything.

Cost of Services

Participants reported a wide variety of costs for premiums, co-pays and deductibles, and for non-covered services. Many participants found the costs burdensome and reported cost-related problems obtaining care and foregoing other needs in order to pay for health care. In order to meet medical expenses some participants reported limiting food purchases, delaying payment on student loans, sharing housing costs with others, and delaying payment on bills.

Professionals with a good salary also face difficulty; It's a constant juggling deciding what to pay for, what food you eat, what bills to pay. I don't live lavishly but it is definitely hard. My rent is quite high, but where else am I going to live.

While many participants reported high out-of-pocket costs, some participants reported low out-of-pocket costs. Those with low out-of-pocket costs were generally either persons with low levels of health care utilization or low-income persons with Medicaid secondary coverage.

I haven't been able to say much because I don't have that many problems...Mass Health and Medicare pay for everything for me practically. And I have no trouble with co-pays.

Service Delivery

Participants were asked about their experiences with health care service delivery, whether anyone was coordinating their care and whether they have had conversations with their doctors about employment. Most participants were managing their own care. "Yes, I am my own case

manager; that's a full-time job in and of itself." There were exceptions, with some participants receiving care coordination from a social worker or mental health provider, or a family member.

Many participants reported that the efforts to coordinate their health care, disability-related services and activities and employment were often overwhelming. The complexities of coordinating care seemed most burdensome for people working full-time or near full-time because of the constraints on available time.

There is a piece that gets very wearing. [It is] so unstable, you work and work and work and finally get it to come together, and the next thing you know it is falling apart. Hearing all this reminds me of how hard we work on trying to do the medical aspects of things. How do we find time to work on top of this? Because a lot of times it is like a full time job.

SUMMARY AND CONCLUSIONS

Even though focus group participants were all covered by health insurance, many reported substantial unmet health care needs, high costs, or a high burden to manage their health care, disability and employment. The unmet need includes the need for services currently limited by insurance plans, long-term services and supports, and other disability services. The need for services currently limited by insurance plans included durable medical equipment, physical therapy, mental health services and prescription drugs. Participants' unmet need for long-term services and supports included personal assistance services and home care services. Many participants reported that the efforts to coordinate their health care, disability-related activities and services, and employment were often overwhelming, with the complexities of coordinating care being most burdensome for people who worked full-time or near full-time. Health care costs were also a concern. Many participants found their health care costs to be burdensome and reported cost-related problems obtaining care and foregoing other basic needs in order to pay for health care. Some reported low out-of-pocket costs, generally persons with low levels of health care utilization or low-income persons with Medicaid secondary coverage

Many currently insured, employed and potentially employed persons have unmet employment-related health care needs. Current health insurance reforms may not fully alleviate these needs and a potentially viable policy option is a new form of subsidized coverage to wrap-around persons' primary coverage. The needs for wrap-around coverage are varied and include the need for services limited by persons' current insurance plans, long-term support services, other disability services, care coordination, and cost protections. Our findings suggest that full-time or near full-time workers are an important subgroup to consider for wrap-around coverage; such coverage could potentially alleviate costs and increase work incentives among this subgroup. Additional research is needed to quantify the employment-related healthcare needs. There is also need for policy analysis to further assess the feasibility and design options for a wrap-around program.

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