Employment Related Supports: Opportunities and Challenges for the Idaho Home Choice Program

Prepared for the Idaho State Independent Living Council

By
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Executive Summary

This assessment was designed to examine processes and policies that impact employment potential for participants in the Idaho Money Follows the Person (MFP) program, referred to as Idaho Home Choice (IHC), and was conducted between December 2011 to March 2012. The results of this project will serve as a foundation for the development of supports and services needed for successful employment for individuals participating in the IHC program. A mix of qualitative methods was used to gather information for this project. These included findings from national reports on the Money Follows the Person program, research on employment supports and services designed for potential participants in the IHC program, and interviews with a purposive sample of key informants from agencies involved in the delivery of, or advocacy for, employment supports and services in Idaho. The findings were then organized using an ecological perspective that recognizes the complex interplay between the individual, the environment (family and community), and society (policies and norms) and the impact these influences have on health and well-being.

Approximately 17,000 individuals in 43 states, excluding Idaho, have transitioned into the community through the MFP program as of March 2011. The average MFP participant was 50 years old and the majority had physical and/or developmental disabilities. Information available about employment for participants in the MFP program is based on a small subset of the population. These findings indicate that those with developmental intellectual disabilities are most likely to be working with very few of the non-elderly participants with physical disabilities and none of the elderly participants doing so.

The following information, organized using the ecological model, identifies key findings gathered from the interviews and literature:
Individual Level Factors

- The interests, talents, and needs of individuals with physical disabilities, developmental disabilities, mental health concerns, and the elderly are diverse and must be recognized and respected.

- Support for basic needs (housing, income, food, transportation, assistive technology) and developmental needs such as mental health support, developmental and/or behavioral therapy must be available before employment supports can be implemented.

- Employment supports must be tailored to meet the needs of the individual and provide ongoing guidance for both the employee and employer.

Family and Community Level Factors

- Family, as defined by the individual and those providing direct services need to understand the individual’s unique goals and assets.

- Family and direct service providers must be aware of and continue to stay apprised of the programs and services available to assist IHC participants achieve their goals.

Systems and Organizational Level Factors: Infrastructure

- Capacity limitations exist, in terms of the kinds of and/or amount of services that are available to help individuals stay in the community, and obtain and maintain employment.

- Even individuals working within the system find it to be complex and sometimes difficult to understand, and thus rely on expert contacts to help them obtain accurate information and access services for clients.

- There is significant variability in knowledge and expertise among direct service providers.

Macro Level Factors

- Inconsistent funding.

- Difficulty of implementing system-wide change.

- Limited affordable accessible housing.

- Limited access to transportation.

Several themes emerged from the findings of this assessment. Most prominent was the recognition that an individual’s independent living needs must be addressed before employment
can become a sustainable option, and for participants in the IHC program this may require support from a wide variety of resources. Second was the importance of simplifying or, at the least, not further complicating an already complex system with additional tools, rules, and/or initiatives. Strategies to achieve this could include building on and enhancing existing support materials designed for individuals, family members, and/or direct service providers and being mindful of the impact that “add-on” initiatives can have on already stretched organizations. Finally, the ability to maximize information available from other states that have implemented the MFP program is a tremendous asset to Idaho. For example, the Ohio MFP program has taken specific action to address the challenge of integrating new service aspects into existing Home and Community Based Services (HCBS) and about half of the MFP states have implemented additional supports in the area of housing. These findings and others more specific to employment supports will be invaluable as Idaho moves forward with implementation of the Home Choice Program.
Introduction

When one considers the proportion of Americans that has a disability, the growing number that are at risk because of age or health related factors such as diabetes, obesity or injury, and the proportion of the population impacted by the disability of someone close to them, it becomes evident that disability in the United States is not a minority issue (Institute of Medicine [NRC], 2007). Culturally, we have begun to appreciate the complexity of individual needs and the interdependent relationships between the individual, their defined family/community environment, supporting systems, and societal norms (Szymanski, 2003; Szymanski & Hanley-Maxwell, 1996). This more ecological perspective of the challenges and opportunities related to supports for individuals with disabilities has expanded the discussion, but implementation of effective, efficient systems has not yet been realized (NRC, 2007).

Nationally, the goals of the Money Follows the Person (MFP) program are to both support the transition of individuals with disabilities and older adults from long-term institutional care into home and community-based settings, and to help improve the long-term care systems for Medicaid beneficiaries who wish to stay in their communities (Brown, Irvin, Lipson, Simon, and Wenzlow, 2008). Important aspects of the transition process include making connections with the community, accessing needed services, and if desired, engaging in employment opportunities.

The positive impact of having a job on one’s self-esteem and sense of purpose is a guiding principle in the provision of employment supports to individuals with disabilities and these outcomes have been shown to be consistent among individuals with varying degrees of disability (Foeman, 2009; Livermore & Goodman, 2009; Stamm, et al., 2006). Interest in and access to employment opportunities are shaped by beliefs, attitudes, and availability of resources at the individual, family/community, organization, and societal levels (Iowa Consortium for
Mental Health, 2001). These include concern that having a job may result in a loss of benefits, to gaps in services/supports needed to maintain employment, to societal norms that individuals with disabilities are not capable of holding down a job (Iowa Consortium for Mental Health, 2001). The Idaho State Independent Living Council (SILC) has received supplemental Medicaid Infrastructure Grant (MIG) funding from the Centers on Medicaid and Medicare Services (CMS) to ensure that employment supports and services are available to individuals who choose to participate in the state’s MFP program.

The purpose of this assessment was to examine processes and policies that impact employment potential for MFP participants in Idaho, with a focus on identifying service gaps. The results of this project will serve as a foundation for the development of supports and services needed for successful employment of MFP participants. Researchers with the Center for the Study of Aging were engaged to conduct this assessment because of their established expertise in community-based research and ability to provide an independent review of employment supports and services.

Money Follows the Person: National Context

Idaho’s Home Choice program began transitioning individuals into the community in 2011. Results from a recent survey by the Kaiser Commission on Medicaid and the Uninsured show that approximately 17,000 participants in Money Follows the Person programs in 43 states and the District of Columbia had transitioned from institutional to community settings as of March 2011. The average MFP participant was 50 years old, took nearly five months to transition, and had moved into an apartment, as opposed to house or small group home. Individuals with physical disabilities comprised 36 percent of the MFP population, the elderly 33 percent, and individuals with developmental disabilities comprised 23 percent (O’Malley Watts, 2011a).
It is worth noting, however, that the characteristics of those who have been transitioning through the MFP demonstration project have changed over the few years the program has been in place.\(^1\) A national evaluation of program activity through March 2010 found that the majority of initial MFP participants came from intermediate care facilities for the mentally retarded (ICFs-MRs).\(^2\) Individuals involved in more recent transitions have tended to be nonelderly with physical disabilities. The proportion of MFP participants who had a mental illness or a dual diagnosis grew over time but has remained small, rising from 1 percent in 2008 to 5 percent in 2010 (Irvin et al., 2011; Schurrer & Wenzlow, 2011).

Approximately two-thirds of individuals who moved into the community through MFP were under age 65. The elderly have generally been underrepresented, accounting for 75 percent of those eligible but just 35 percent of those transitioned. Nationally, the nonelderly with physical or developmental disabilities represented 62 percent of those transitioned but just 24 percent of the eligible population. In hypothesizing why the elderly were underrepresented in the MFP population, national evaluation researchers noted that a number of states that were early implementers of the MFP program had existing initiatives to downsize their ICFs-MRs. The researchers also highlighted earlier MFP reports which found that the elderly often preferred larger assisted living environments that did not qualify for MFP funds (Irvin et al., 2011).

**Post-Transition Outcomes**

Sufficient pre- and post-transition data were available for 4,746 MFP participants and 85 percent (n = 4,034) were able to remain in the community for at least a year. Nine percent (n =

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\(^1\) The Kaiser survey provides information on the MFP population through August of 2011 (about 17,000 individuals.) The national evaluation by Irvin et al. provides information on the MFP population through March 2010 (about 12,000 individuals.) The Kaiser survey provides more up-to-date data on the general characteristics of the MFP population but, unlike the most recent national evaluation, does not provide data on post-transition outcomes.

\(^2\) Transition and post-transition findings are based on a sample of 4,746 MFP participants who had moved into the community as of March 2010 and for whom there were sufficient baseline and employment outcome data (Irvin et al., 2011).
427) returned to an institution for at least 30 days and 6 percent (n = 285) died within one year (Irvin et al., 2011; Schurrer & Wenzlow, 2011). Those who transitioned generally reported a higher quality of life (Irvin et al., 2011; Simon & Hodges, 2011). MFP participants were more likely to report that they were satisfied with their living arrangements, that they experienced more choice and control, that they experienced more integration into the community, were well-treated by service providers, and had fewer unmet care needs than when living in an institution. Thirty-four percent of the sample, however, reported that they experienced barriers to doing things in the community. The non-elderly with physical disabilities were the most likely to report that this was an issue, with nearly half (48 percent) of these individuals reporting such barriers (Irvin et al., 2011).

Elderly participants leaving nursing homes were the most likely to be reinstitutionalized (13.8 percent) and individuals leaving ICFs-MRs were the least likely (3.6 percent) (Schurrer & Wenzlow, 2011). Reinstitutionalization typically occurred within the first six months, usually within the first three, as the responsibility for service coordination transitioned from those helping participants move out of an institution to those assisting with community-coordinated care (Irvin et al., 2011).

**Employment Outcomes**

By the end of 2010, sufficient post-transition data were available for 1,090 MFP participants, of whom 15 percent (n = 166) reported working for pay. An additional 8 percent (n = 87) reported volunteering. Individuals with intellectual disabilities (n = 265) were most likely to report that they wanted to work (57 percent) and were also the most likely to be working for pay (48 percent). Among non-elderly individuals with physical disabilities (n = 347), 37 percent

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3 Because of variations in data collection across states, this subsample overrepresents individuals with developmental disabilities and underrepresents both the elderly and the nonelderly who transitioned from nursing homes. Information on disability type was available for 76 percent (n = 831) of the individuals in this subsample.
wanted to work and just three percent were doing so. Among elderly participants (n = 219), 21 percent reported they wanted to work but none reported doing so. It is worth noting that individuals who were not working, but wanted to, were more likely to report difficulty doing things outside the home than individuals in the work force; 48 percent and 31 percent, respectively (Irvin et al., 2011).

Methods

A mix of qualitative methods was used to gather information for this project. The initial strategy involved a detailed analysis of national findings on the Money Follows Person (MFP) program, as outlined in the preceding pages, with specific focus on participants’ employment outcomes. This review was then expanded to include analysis of the research related to employment supports and services designed to address the needs of individuals who participate in the MFP program. In addition, Idaho specific resources and organizational structures related to supportive employment services were reviewed. The final strategy involved qualitative interviews with a purposive sample of key informants from agencies involved in the delivery of, or advocacy for, employment supports and services. All data collection activities occurred between December 2011 and February 2012 and an iterative process was used throughout the project, i.e., information gathered through the interview process lead to additional literature and document review.

Document Analysis and Literature Review

The researchers began with a search of the peer-reviewed literature, using the terms “employment and disability,” “vocational rehabilitation,” “supported employment,” “employment supports,” “employment program,” “employ* disability,” “community

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4 The difference between the two proportions was statistically significant from zero at the .01 level, at a two-tailed test.

For Idaho-specific documentation and information, including agency strategic plans, researchers consulted the websites of organizations such as the Idaho Department of Health and Welfare, the Idaho Division of Vocational Rehabilitation, the Idaho State Rehabilitation Council, the Idaho Department of Labor, the State Independent Living Council, the Idaho Council on Developmental Disabilities, the University of Idaho Center on Disabilities and Human Development, DisAbility Rights Idaho, the Living Independence Network Corporation, the Idaho Commission on Aging, Access Idaho, Witco Inc., Community Partnerships of Idaho, and others. The research team also reviewed communications and other materials related to the State Personal Assistant Workgroup.

**Interviews**

Potential interview participants were recruited through the use of an email message sent to 19 organizations from the Idaho Employment for People with Disabilities Stakeholder Group describing the purpose of the study and inviting them to participate in an interview. See Appendix A for recruitment message and list of agencies invited to participate in the interviews. Additional participants were identified during the interview process with interviewees asked to identify other key informants. The one-on-one interviews were semi-structured and focused on five primary research questions:

1. What kinds of supports do individuals who would like to transition from an institution into the community typically need?
2. What kinds of employment supports do these individuals typically need?
3. What kinds of infrastructure exist to meet these needs?
4. Where are there infrastructure gaps?

5. Are there any practices or policies that you feel might need to be reconsidered so that the community can better address the employment needs of individuals with disabilities transitioning into the community?

The interviews, scheduled for one hour, were recorded and participants were assured of the confidentiality of their responses. Separate interviews were conducted with two staff members at DisAbility Rights Idaho, one staff member at the Idaho Council on Developmental Disabilities, two staff at the Idaho Division of Vocational Rehabilitation, one staff member at the Living Independence Network Corporation, one staff member at Witco, Inc., and two staff at Community Partnerships of Idaho. Two staff at the Idaho Department of Labor were interviewed jointly, as were two staff at the Idaho Department of Health and Welfare. See Appendix B for list of organizations interviewed.

The interviews were transcribed and analyzed by the researchers to identify patterns. Any discrepancies or questions about how to interpret the findings were discussed until consensus was established. The findings were then organized using an ecological perspective, see Figure 1 on the following page. The ecological model recognizes the complex interplay between the individual, the environment (family and community), and society (policies and norms) and the impact these influences have on health and well-being. The ecological perspective dictates that when identifying gaps, action steps and/or designing programs, it is essential to recognize the external forces and interdependent systems that shape an individual’s behavior.
The four interdependent systems used to organize information gathered through the interview process were:

- Individual,
- Family and Community,
- Systems and Organizations, and
- Macro Level (social norms, policies, laws)

**Results**

**Individual Level Factors: Supports Typically Needed**

All of those who agreed to participate in interviews for this effort noted that individuals with physical disabilities, developmental disabilities, mental health concerns, and the elderly
vary in their personal needs, strengths, interests, and talents. However, participant responses fell into three broad categories regarding the kinds of support individuals generally need in order to transition into and sustain themselves in the community and in the workplace. These three categories included: Basic needs, Developmental needs, and Employment supports.

**Basic Needs**

Individuals eligible for the MFP program are low-income and not able to fully finance their own transition or HCBS. These characteristics make the provision of basic needs, such as food, housing, transportation, particularly important for this population. Themes expressed during the interviews regarding these needs included:

- Transition planning/service coordination assistance
- Material and/or cash supports to cover one-time expenses associated with setting-up a household, including security deposits, essential appliances and furnishings, etc.
- Affordable and accessible housing
- Food stamps
- Health insurance/health care
- Assistive technologies, which can range from something as simple as a cane, computer screen reader, or wheelchair ramp to specialized wheelchairs or other devices
- Help with personal care and chores
- Social Security income
- Transportation
- Access to accurate and timely information regarding Medicaid and Social Security benefits, as well as needed supports and services

**Developmental Needs**

As with basic needs, interviewees identified numerous developmental needs that participants in the IHC program may have. These included:

- Mental health support
- Some individuals will need developmental therapy which will teach independent living skills, such as self-care, home care, shopping, transportation, etc.
- Some will need behavioral therapy which will teach socially appropriate behavior
- Opportunities for regular exercise
- Opportunities to learn how to maintain a healthy diet
- Individual resiliency, or the capacity to adjust to surprises and challenges

**Employment Needs**

The employment supports were identified as specific to helping individuals with disabilities obtain and maintain employment.

- Counseling on how work will impact SSI or SSDI benefits
- Opportunities for education and skill development
- For individuals without a work history, opportunities to build a résumé
- Job search/application assistance
- Job development/job placement
- Access to transportation
- Assistive technologies, such as screen reading software, specialized computer keyboards, canes, wheelchairs, etc.
- Job coaching, which can include breaking a job into tasks, working as an on-site coach to help individuals learn routines or adjust to changes in the workplace, and helping bosses and co-workers understand how to work with individuals with disabilities
- Access to intermittent supports to allow individuals to respond to major changes at work or in their living environment

**Family and Community Level Factors**

Interviewees highlighted that family, as defined by the individual, and community supports are essential to creating and sustaining employment opportunities for individuals with disabilities. Family members and those providing direct services need to understand the individual’s unique goals and assets, as well as the programs and services that are available and will help IHC participants achieve their goals. Many of the items included here also apply to the individual and reflect the interdependent nature of the individual and family/community factors. Family/community level support needs include:
• Help with staying current on information that impacts access to supports for individuals with long-term care needs, such as access to qualified service providers, changes in eligibility standards, documentation requirements, deadlines, etc.
  ▪ The system is complex and has many separate components
  ▪ It can be time-consuming and challenging to figure out how to access supports
• Current information about the supplemental volunteer resources and how to access them
• Support for caregiver respite
• Best practices on how to work with direct service providers and manage frequent turnover among providers

**Systems and Organizational Level Factors: Infrastructure**

Interviewees were guided to focus on services and supports that facilitate transition into the community, maintaining independence, and work. Three major themes emerged from the conversations:

• Capacity limitations exist, in terms of the kinds of and/or amount of services that are available to help individuals stay in the community, and obtain and maintain employment
• Even individuals working within the system find it to be complex and sometimes difficult to understand, and thus rely on expert contacts to help them obtain accurate information and access services for clients
• There is significant variability in knowledge and expertise among direct service providers

**Macro Level Factors**

Participant responses also addressed factors at the macro level that impact an individuals’ ability to integrate back into the community, maintain their health and well-being, and obtain and retain employment. These included:

• Inconsistent funding
• Difficulty of implementing systemic change
• Limited affordable accessible housing
• Limited access to transportation
Money Follows Person: Idaho Implementation

The Idaho Money Follows the Person program, referred to as Idaho Home Choice (IHC), was implemented in 2011. It provides flexible financing for long-term services and supports that enables funds to move with the individual to the most suitable and preferred setting as the individual’s needs and preferences change. Program benchmarks include the successful transition of 325 individuals from inpatient facilities to a qualified residence by 2016. Specific target population benchmarks include the transition of 180 elderly individuals, 115 people with physical disabilities, and 30 people with developmental disabilities (Idaho Department of Health and Welfare [IDHW], 2011).

Additional benchmarks for the IHC program relate to rebalancing State Medicaid expenditures from institutional long-term care to providing support to individuals through HCBS. In Idaho there are two HCBS waiver programs, the Developmental Disability (DD) Waiver and the Aged and Disabled (A&D) Waiver for low-income, disabled and/or aging adults. As of 2009 SFY, approximately 2,323 and 7,813 individuals were served by the DD and A&D Waivers, respectively. In addition to these HCBS waivers, Idaho maintains Medicaid State Plan Services designed to provide additional supports to participants when choosing home and community based services versus institutional long-term care (IDHW, 2011).

Home and Community-Based Service Waivers

Through the traditional Developmental Disabilities (DD) Waiver, individuals with a developmental disability that require the level of care provided in an Intermediate Care Facility for persons with Intellectual Disabilities (ICF/ID) work with a “plan developer” to outline the types of services and supports they will need to live in a qualified residence in the community. Participants in the DD Waiver access needed services and supports through traditional providers who bill Medicaid. Individuals with developmental disabilities may also choose self-directed
care through the *My Voice—My Choice* program. Those who choose this option receive an orientation on self-direction from Medicaid staff and use a support broker to outline needed services and supports, as well as how they will access those services and supports. These participants use a fiscal employer agent to establish agreements with, and pay, their community support workers (IDHW, 2011 and e-mail communication, 2012).

The *Aged and Disabled Waiver* (A&D Waiver) is available to individuals requiring nursing facility level of care who are over the age of 18 if disabled or 65 years or older if aged. Participants must also meet financial requirements of income at or less than 300 percent of the Social Security Income federal benefit level. Individuals with a physical disability, e.g., deafness, blindness, a mental illness, or who have sustained a traumatic brain injury, are eligible for services available through the A&D Waiver. Participants access community-based supports and services through traditional providers who bill Medicaid (IDHW, 2011).

**Supports Unique to Idaho Home Choice (IHC) Program**

The IHC program provides a more comprehensive range of community services than those available through existing HCBS in order to support individuals’ successful transition into the community. The IHC target population includes individuals who have lived in a qualified institutional setting for at least 90 days (excluding rehabilitation stays) and who are Medicaid-eligible for at least one day prior to transition. In Idaho, transition into the community through the IHC program will be facilitated by *Transition Managers* (TM) who have specialized expertise and training in public and private programs, program eligibility, and development of transition plans that address individual needs and goals. TMs provide up to 90 days of support prior to transition and up to 90 days after transition, for up to 8 hours per month. On a case-by-case basis, it will also be possible for individuals to receive transition services for an additional 6
months, for up to 4 hours per month. The Idaho Department of Health and Welfare estimates that not all IHC participants will need TM support (IDHW, 2011).

Participants in the IHC program must qualify for HCBS services prior to their transition. Once they have transitioned out of an institution, they are eligible for supplemental services that are not typically reimbursable under Medicaid, such as a $2000 stipend to help an individual pay for moving expenses, utility or security deposits, furnishings, etc. (Irvin et al., 2011; participant interviews and e-mail communication, 2012). The supplemental services, which in Idaho are referred to as Transition Services, are only available to individuals who cannot cover these costs themselves or through other sources. IHC-funded services are available for 365 days after transition.

**Employment Supports**

Access to employment benefits is structured by income, type of disability, and level of support needed for independent living (participant interviews, 2012). Employment supports may include worksite assessment, job assessment, assistance completing or managing job applications and correspondence, aptitude testing, job placement or job development, coaching to address extended learning requirements or changes on the job, addressing behavior difficulties, and/or addressing transportation issues (Idaho Division of Vocational Rehabilitation, 2011; participant interviews, 2012). Long-term employment benefits are available through the state Extended Employment Services (EES) program, as well as the DD and A&D Waiver programs. Each of these programs is a component of Medicaid and receipt of benefits is thus predicated on income. Specifically which program an individual fits into is based on disability type. Employment supports are generally accessed through the Idaho Division of Vocational Rehabilitation (IDVR) and are paid for through the A&D and DD Medicaid Waivers, as well as Idaho’s EES program.

The EES program is paid for with state general funds (participant interviews and e-mail communication, 2012). Individuals participating in traditional waiver programs are directed to
IDVR-funded Community Resource Providers (CRPs) to access services. Through the federal Ticket to Work (TTW) program, SSI and SSDI beneficiaries between the ages of 18 and 65, and who have a disability or are blind, are able to access employment supports through IDVR or through a CRP that has been designated as an Employment Network. Individuals participating in the My Voice—My Choice self-directed program contract with Community Support Workers for their services. Individuals who have experienced long-term institutionalization and who would like to work will likely need education, training, and opportunities to build a résumé (participant interviews, 2012). Individuals can access some education and training, assistance with job search, the job application process, and receive job coaching through VR-funded Community Resource Providers (CRP). Individuals with developmental disabilities enrolled in the self-directed program can directly hire individuals to provide employment supports.

Those who have more severe disabilities may need customized employment which involves identifying the skills an individual has which have an economic benefit and then creating a position that utilizes those skills. Individuals may also need job coaching. A job coach helps persons with disabilities learn the tasks and skills that an employer needs for a particular job and also helps them understand the work culture. Some of our interview participants reported that job coaches may also need to support employers in understanding how to work with individuals with disabilities.

**Literature on Best Practices for Employment Support**

While the information gathered from the interview process provides a rich description of the needs and employment supports that may be needed by individuals participating in the IHC program, there is a dearth of literature on evidenced-based practices related to community integration and work opportunities. As highlighted in *The Future of Disability in America* report prepared by the national Institute of Medicine, more research on and dissemination of
interventions that help individuals function in community life is needed (NRC, 2007). And, in response to the start-and-stop history of many employment support programs, the translation of research into practice must be done in a collaborative manner with a focus on sustainability.

As in much of applied research that involves the testing of an intervention or program, research on employment supports for individuals with disabilities has focused on a specific population and/or a particular intervention or implementation strategy (Razzano & Cook, 2005; Bond et al., 2001; Iowa Consortium for Mental Health, 2001). Best practice guidelines for specific populations are available, but often quite general. For example, best practices identified for the Senior Community Service Employment Program (SCSEP) included strong community collaboration, leadership, and infrastructure support and a focus on the whole person, but little guidance on specific programming or system design (National Council on Aging, 2001).

The results of a review of 27 initiatives designed to support employment among individuals with disabilities conducted by Livermore and Goodman (2009) found that few programs had the capacity to implement the type of study design and/or collect the evidence needed to document program impact. These findings were not presented to discredit the initiatives, but rather to highlight the need for caution in identifying initiatives as a “best or promising practice.” Recommendations included the need for “bolder” initiatives, more resources for evaluation, and patience with the process of system change (Livermore & Goodman, 2009).

Research on programming for individuals with disabilities is further complicated by the vast array of funding and service agencies and organizations involved, i.e., Department of Education, Department of Labor, Veterans Affairs, Social Security, Internal Revenue, Centers for Disease Control and Prevention, Medicaid, Medicare, with no federal agency charged with oversight or coordination. The following statement from the Idaho Real Choices Change Project
report reflects the frustration generated by this complex and disjointed system. “One of the common distresses of people with disabilities and those who provide their services and supports is that much talk about change occurs, but nothing changes,” (Stamm, et. al., 2006).

**Discussion**

**Individual Level: Independence before Employment**

Individuals transitioning out of an institution are more likely to remain in the community, and to consider work, if they are able to meet their independent living needs, to access services that will keep them healthy and connected to the wider community, and if they know that working will not jeopardize important and sometimes hard-won supports (Irvine et al, 2011; IDHW, 2011; participant interviews, 2012). Overall, individuals with disabilities often have a higher level of basic needs relative to those without disabilities, a lower earning capacity, and are more likely to experience poverty (Palmer, 2011). In 2010, 9.5 percent of Americans between the ages of 18 to 64 reported having a disability and these individuals reported median household incomes of $25,550 (DeNavas-Walt, Proctor, & Smith, 2011). This was 43 percent of the $58,736 reported for householders who did not state a disability. In addition, Idaho employment data document the need for more work opportunities. The Idaho unemployment rates for individuals with limitations in activities of daily living or self-care are 10 percent greater than national rates; see Table 1 (Center for Personal Assistance Services, 2009).
Table 1. Unemployment rate among working-age adults, by disability status in Idaho and the United States, 2009

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<tr>
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<th>Limitations with Activities of Daily Living</th>
<th>Limitations with Self-Care</th>
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<tr>
<td>Idaho</td>
<td>33%</td>
<td>28.1%</td>
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<tr>
<td>United States</td>
<td>21.1%</td>
<td>18.2%</td>
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**Supports Are Essential but the System is Complex**

Experience in Idaho has shown that lack of awareness of HCBS can lead individuals back to institutional care (IDHW, 2011). A major theme that emerged from participant interviews and from the literature is that the system that has evolved to help individuals meet their long-term independent living and employment needs has many separate components and it can be time-consuming and challenging to figure out how to consistently access supports (Grabowski, Orfaly, Cadigan, Miller, Stevenson, Clark, & Mor, 2010; participant interviews, 2012). It will be important for participants in the IHC program to understand how to interact with a complex array of federal, state, and local systems in order to consistently access the full range of supports they will need to remain in the community and to go to work.

Several interview participants reported that rules and regulations for Social Security, Medicaid, Medicaid for Workers, and/or for employment services through the VR are intricate, can be hard to understand, and that it can be difficult to keep up with changes. In addition, there are some supports that Medicaid does not explicitly address or does not address in a timely manner, such as specialized clothing or building wheelchair ramps, so individuals and their support teams will need to know whether there are volunteer or non-profit organizations in their community that can help. Agencies and organizations involved with advocacy and service provision maintain online resource directories or links to information but connecting individuals
to the specific supports they need is complicated by the wide variability in both individual need and availability of community-level resources.

One participant who has long-term experience, both connecting a family member to supports and helping other individuals connect to supports, stated that different agencies and organizations have their own policies and guidelines and that they do not always provide the same information about eligibility requirements or how to access programs and services. Even individuals working within the system find it to be complex and sometimes difficult to understand, and thus rely on expert contacts to help them obtain accurate information and access services for clients. It takes time and persistence to sort out how to access supports and this complicates the issue of caregiver fatigue, a recognized challenge for families and one for which there is a lack of resources to address. Locally, just over half (53 percent) of the respondents to the Idaho Real Choices survey were caregivers and these individuals reported significant changes in quality of life since taking on care giving responsibilities (Stamm, et. al., 2006).

Because individuals with disabilities have a wide range of needs, goals, and resources, and because the system that helps individuals access supports is complex, direct service provider expertise and experience is very important. Interview participants also reported, however, that there is generally a high level of turnover among direct service providers and significant variability in their level of experience, expertise, and reliability. This perception is supported by findings from a statewide survey of members of the Personal Assistant (PAS) workforce conducted in 2011 that found that 21 percent had worked as a PAS for less than 1 year with the majority (66 percent) working in the profession for less than 3 years (Access Concepts & Training, 2011). The complexity of the system, unique needs of the individual and high level of turnover among the PAS workforce can lead to confusion and inconsistency for individuals trying to access services.
**Limitations of Available Research**

Combined, the initial findings from the MFP Demonstration project, participant interviews, and literature indicates that consistent access to HCBS will be essential for individuals transitioning into the community. The importance of sustained support from family and direct service providers must also be recognized. Despite extensive searches, we were unable to find a literature base that responds to the broader question of how to assure that individuals can consistently connect to service providers and organizations/agencies. And as articulated by one interview participant:

> Part of the problem of adopting a best practice is that it always gets adopted as an add-on and there’s always interests that maintain the models that precede it. And there are people who don’t want to leave the original model that they had and so every time we have a new best practice, it becomes a new expense because we have to maintain everything else and maintain this new best practice.

This sentiment, while recognizing the need for system-wide change, also highlights the importance of capitalizing on existing successful practices when making recommendations and/or adjustments.

**Recommendations Specific to the IHC Target Population**

At the national level, states participating in the MFP Demonstration Project reported that a lack of accessible and affordable housing, limited availability of transportation, and inadequate community-based services and support infrastructure were major challenges to successful community transitions (Irvin et al., 2011; O’Malley Watts, 2011a). Reinstitutionalization of MFP participants typically occurred during the first few months, during which responsibility for service coordination transferred from the institution to HCBS (Irvin et al., 2011). In Idaho, prior experience with transitions from institutional to community living suggests that a lack of awareness of HCBS services can lead to reinstitutionalization (IDHW, 2011).
Opportunities

Housing and Transportation

Twenty-nine of the 44 states participating in the MFP project highlighted the importance of coordination between MFP programs and local housing authorities (O’Malley Watts, 2011a). Ohio’s Home Choice program has several unique initiatives focused on housing and transportation (O’Malley Watts, 2011b). Program staff have partnered with Housing and Urban Development to connect MFP participants to housing vouchers, developed a web-based toolkit to help individuals understand how to use Medicaid to support permanent housing, and have been working to establish housing and services cooperatives that are funded by MFP dollars and contracted through Centers for Independent Living. Part of the focus of these cooperatives will be development of an inventory of resources for housing, assistive devices, and home modifications, as well as a transportation brokerage. Idaho currently has a transportation brokerage, which is managed by American Medical Response (AMR).

- Opportunity: The Ohio response to the issue of locating appropriate housing for MFP participants appears to be unique among states participating in the MFP Demonstration Project.
  - Consider contacting Ohio MFP program staff about progress to date, how they have integrated new service aspects into existing HCBS, and how their systems have (or have not) addressed the question of local variation in housing and transportation.

Locating housing that is accessible and affordable for MFP participants has proven to be so complicated that 19 states have hired housing coordinators. These coordinators work with both Transition Managers and individuals in the transition process to locate both housing and resources for home modifications, when needed. In Idaho, interview participants highlighted the idiosyncratic nature of both housing and transportation availability, particularly in the more rural parts of the state.
• Opportunity: Although housing coordinators are used by nearly half of MFP participating states, there is little research to date on the efficacy of this addition to Home and Community-Based Services.
  ▪ Consider contacting a sample of states, again asking about progress to date, how this position has been integrated into existing HCBS, and how the question of local variation in housing has been addressed.
  ▪ Also consider asking whether it would be reasonable to establish personnel who handled housing and transportation, rather than just housing.

Mental Health

Nationally, individuals who have a mental illness or a dual diagnosis are not participating in the MFP program in significant numbers (O’Malley Watts, 2011a). Locally, interview participants reported that the state’s formal system provides few mental health benefits, although several reported that supports could be as simple as making sure someone is maintaining their medicine. One participant stated that supports currently come primarily after hospitalization.

• Opportunity: Continue to monitor MFP evaluation reports for promising practices related to providing mental health services.

Benefits counseling

Interviews with local service providers indicate that many local SSI and SSDI beneficiaries are still unsure whether they will lose their existing supports if they go to work. With the understanding that individuals will need to know that they can maintain independent living and still work, counseling on how employment impacts Social Security and Medicaid benefits is very important. Sorting this out is complex and one interview participant described it as, “so complicated and so fraught with red-tape and bureaucracy, very few people can simply navigate that process on their own.”

Counseling is available to SSI and SSDI beneficiaries through the Work Incentives Planning and Assistance (WIPA) program. Two staff at DisAbility Rights Idaho have participated in a year-long certificate program through the Virginia Commonwealth University
WIPA National Training Center and counsel individuals on how wages will affect their benefits. Benefits counseling is also available to participants in the Ticket to Work (TTW) program through some Employment Networks (EN), depending on staff training and expertise. Witco Inc. is an example of a local EN that has trained staff who are able to provide benefits counseling to TTW participants.

- Opportunity: While creating a self-directed online course is an option, interview participants indicated that the program is intricate and complex and that it may be difficult for individuals to sort out without guidance.
  - Consider expanding access to the Keys to Accessing the Power of Work curriculum through guided video conferences.

**Increase Understanding of Employment Supports**

A consistent theme in the majority of interviews was that it takes time to learn how HCBS systems work and there are many local idiosyncrasies. Employment support is just one component of a complex system that Transition Managers, Transition Service Coordinators, and self-directed individuals have to learn.

- Opportunity: A Transition Manager Employment Module has been developed and implemented.
  - Consider expanding the Transition Manager Employment Module to contain information about specific VR requirements and deadlines.

**Build Bridges to Competitive Employment**

Several interview participants highlighted that the economic downturn means that there are fewer employment opportunities for all job applicants, not just for individuals with disabilities. It’s harder to tailor positions according to certain individual strengths or challenges and, as one participant explained, “For anyone who doesn't have the particular job skills, you just don't even come into consideration.” Participants also commented that individuals who have experienced long-term institutionalization may need opportunities to develop job skills, and learn workplace routines and communication skills. We are not suggesting that individuals with
disabilities be placed in volunteer positions in lieu of paid employment, but several interview
participants suggested that volunteer opportunities may provide a bridge to competitive
employment. Well-structured volunteer experiences have the potential provide work-related
experience, bolster an individual’s résumé, and demonstrate to an employer that an individual is
serious about working.

- Opportunity: Consider dedicating an AmeriCorp position to learn about and connect
  individuals with disabilities to community volunteer opportunities.

**Capacity Limitations**

While the expertise and experience of service providers is essential to helping individuals
with disabilities connect to needed supports, another major theme that emerged from participant
interviews is that the system of agencies, advocacy organizations, and service providers has been
stretched by the national recession and recent years’ budget shortfalls. Individuals receiving
services and agencies/organizations providing services are trying to do more with lower funding
levels, and capacity limitations exist in the kinds of and amount of services that are available to
help individuals stay in the community and obtain and maintain employment.

**Direct Service Providers**

Overall, MFP states have reported a shortage of qualified direct service providers,
particularly in rural areas, and many states reported working to improve capacity by elevating the
field’s professional standing through compensation, benefits, and authority (O’Malley Watts,
2011a). In Idaho, advocacy and provider organizations reported that compensation rates and the
number of service hours allowed are often such that it is difficult to offer competitive wages and
thus difficult to keep qualified staff.

- Opportunity: Continue to support efforts that enhance employment stability among the
  personal assistance workforce.
- Opportunity: As reports become available, follow national efforts to raise the professional
  standing of direct providers within HCBS system.
Support for Academic Development

Individuals have access to vocational or technical courses through IDVR and can sometimes also qualify for assistance to pay for tools that are needed for a specific trade. These programs, however, do not provide support for more general academic courses, such as English or math that might be needed to complete a certificate program. One interviewee stated that the Department of Labor has been exploring the possibility of connecting IHC participants with the AmeriCorp program. This would provide for a wider range of education and employment opportunities. Further exploration of this potential is needed to identify program requirements and the level of interest among IHC participants.

- Opportunity: Expand opportunities for academic skills development such as writing, math, and access to G.E.D. or high school equivalency programs.

Flexible Funding Policies

Individuals who receive benefits through the Medicaid Developmental Disability (DD) waiver program currently have a fixed-budget with which to address their support needs. They are able to access employment services as long as there is room in their budget to cover both their independent living needs and employment supports. Individuals who need a higher level of support to maintain their independent living may not have enough room in their budget to pay for services related to obtaining and maintaining employment. In the past, those who needed a higher level of support to maintain independence in the community were able to apply to Medicaid for a larger budget by demonstrating their individual circumstances warranted it.

This changed under HB 260 and individuals with disabilities currently are able to extend their budgets only for medically necessary services (Idaho House Bill 260, 2011; participant interviews, 2012). The impact on employment for these individuals is, as one participant stated,
that “it’s the employment part that they naturally sacrifice because you don’t give up things that help you live.” Another interviewee was aware of clients who had lost their employment supports as a result of the medically necessary provision.

For individuals hoping to access the state’s Extended Employment Services (EES) program, the program was committed at 100 percent prior to cuts made in response to budget shortfalls. As a result of cuts, individuals who had been receiving employment benefits through EES experienced significant reductions in their supports and newly-eligible individuals were put on waiting lists that extended up to three years in some regions. While the EES program has recently had some of its funding restored (e-mail communication, 2012) the issue of how EES funding is allocated remains. EES funds are currently channeled directly to CRPs, and individuals with disabilities accessing services through the EES program must select a CRP without knowing when their selected provider will have the capacity to serve them or how long they will be on a waiting list. The Idaho Division of Vocational Rehabilitation reported that the practice of allocating funds directly to service providers is currently under review (email communication, 2012).

The Ticket to Work (TTW) program allows SSI and SSDI beneficiaries between the ages of 18 and 65, and who have a disability or are blind, to access employment supports through an EN or through Vocational Rehabilitation. However, TTW compensates providers only after individuals obtain employment. This, combined with performance targets in the overall employment system, has some concerned that there are disincentives to serving those individuals who are the hardest to place, e.g., individuals who cannot read or write, or do not have a college education, or do not have transportation, and/or require long-term supports.

- **Opportunity:** Continue to advocate for adequate and flexible funding policies.
Limitations of Study

Although the methods used to examine employment supports for individuals participating in the IHC program were sound, several limitations must be recognized. First, the reliance on a purposive sample of participants who agreed to participate in the key informant interviews limits the generalizability of the findings. While each participant had specific expertise and represented a key agency or organization related to employment supports, the information provided may not represent all aspects of the employment network in Idaho. For example, none of the interviewees who agreed to participate were from agencies or organizations operating in rural areas although many had statewide responsibility or oversight. Second, no individuals representing potential IHC participants were interviewed. This limitation was primarily due to the fact that individuals representative of IHC participants would be considered a vulnerable population and university research protocols require that researchers working with vulnerable populations have specialized training or expertise regarding that specific population. Several interview participants, however, shared experiences of accessing supports for a family member who has a disability and provided helpful insight from that perspective. An important next step in this assessment will be to conduct interviews with individuals who have transitioned through the IHC program into a community setting and have expressed an interest in working.

Conclusion

Based on experiences in other states, the availability of consistent, reliable connections to services for participants in the IHC program is paramount to their successful transition to the community. Idaho is fortunate in that information from MFP efforts in other states can be used to guide changes and adjustments that will be needed to support not only the transition to independent living, but also integration into a complex and multi-faceted system of supports. Not only will participants need assistance with housing, but they will also likely need some sort
of income through SSI or SSDI, and access to health care and independent living supports provided through Medicaid waiver programs. Many IHC participants will not be able to meet all their needs through Social Security and Medicaid and so they will also need to learn how to tap into non-profit and volunteer resources, such as local food banks and organizations that donate services and materials. In addition, there are numerous advocacy and direct service organizations that either provide information or direct services to individuals with disabilities, and those interested in employment will also likely access employment supports through the Idaho Division of the Vocational Rehabilitation.

The vast array of services that may be needed highlights the importance of family members, Transition Managers, and other direct service providers to the success of the IHC program. It is imperative that these key resources are equipped with the tools and knowledge needed to assist participants in the IHC program and that changes be implemented in a manner that builds on and extends existing strengths in Idaho.
References


Appendix A: Recruitment Message and Organizations Invited to Participate in Interviews

Dear Members of the Idaho Employment for People with Disabilities Stakeholder Group and other Partners:

As you may know, the Idaho State Independent Living Council (SILC) has received Medicaid Infrastructure Grant (MIG) funding through Idaho’s Money Follows Person (MFP) project to ensure that employment supports and services are available to individuals who choose to participate in MFP. One of the outcomes of this MIG initiative is the review of existing policies and processes (i.e., a needs assessment) that impact employment potential for individuals with disabilities and older adults in Idaho. The findings from this effort will be used to guide the implementation of supports and policies that maximize employment opportunities.

We, Kathleen Mullen, Shraddha Benjankar, and I, will be in contact with many of you over the next several months as we work to catalog and describe existing employment related policies and supports and identify potential gaps and barriers. In addition, we are in the process of conducting a review of the literature on evidenced-supported practices related to employment supports for individuals with disabilities and older adults and welcome your input on sources of information for this review. Please send your suggestions to kathleenmullen@u.boisestate.edu.

As documented by MFP initiatives in other states, the likelihood that individuals will sustain themselves within the community is greatly increased if they are successful in securing meaningful employment. Our goal is to use this opportunity to maximize employment opportunities for individuals with disabilities and older adults in Idaho.

We welcome your input and look forward to working with you.

Organizations Invited to Participate in Interviews

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<td>DisAbility Rights Idaho</td>
<td>Independent Living for Everyone, Inc</td>
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<td>Idaho ADA Taskforce</td>
<td>Living Independence Network Corporation</td>
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<td>Idaho Commission for the Blind and Visually Impaired</td>
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<td>Idaho Council on Developmental Disabilities</td>
<td>Valley Ride</td>
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<td>Idaho Parents Unlimited</td>
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### Appendix B: Organizations Included in Purposive Sample of Interviews

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