



New York **Makes Work Pay**

Developing a path to employment for New Yorkers with disabilities

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Medicaid Infrastructure Grant (MIG) Report

BUILDING A CROSS DISABILITY PEER EMPLOYMENT SUPPORT MODEL *Report to the New York State Medicaid Infrastructure Grant*

December 2009

Presented by:

New York Association of Psychiatric Rehabilitation Services
(NYAPRS)

With the Technical Assistance of the Collaborative Support
Programs of New Jersey (CSP-NJ)

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In collaboration with

New York Association on Independent Living (NYAIL)

Self-Advocacy Association of New York State (SANYS)



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Cornell University
ILR School
Employment and Disability Institute

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ABSTRACT

This report will illustrate a case for a peer employment support model as a viable resource to address the issues of unemployment, underemployment, and poverty impacting persons with disabilities. Research suggests that human, material, and social capital are essential to employment and economic self-sufficiency. Social capital is particularly important for people to obtain and maintain jobs as most individuals find their jobs and secure advancement opportunities through their informal social networks. The findings of this project suggest that peer support is an effective method to increase social capital impacting employment outcomes. Peer support can play a particularly important role in enlarging and diversifying the social networks of individuals with disabilities, and thus increase their access to employment connections and supports available outside of the disability community. Data from key informants was gathered to guide the development of principles, roles, and competencies for a peer employment support model. Recommendations are offered to further develop, test, and replicate peer employment support service models.

EXECUTIVE SUMMARY

Overview of New York Makes Work Pay

New York State's Medicaid Infrastructure Grant (MIG), *New York Makes Work Pay* (NYMWP) is a statewide initiative intended to dramatically improve the rate of employment among people with disabilities. It is funded by the Center for Medicaid Services for calendar years 2009 and 2010.

The goals of *New York Makes Work Pay* are to:

- Remove barriers to employment and a better economic future
- Improve cross-agency sustainable, coordinated systems of supports and services
- Engage the business community in collaboration with government and employment service providers to recruit, hire, retain and advance workers with disabilities

NYMWP will accomplish these goals by implementing its comprehensive strategic work plan with activities that improve employment policy and practice through research and materials development and dissemination. NYMWP engages with people with disabilities, their families, advocates, employers, disability services providers and other stakeholders to identify best practices, implement strategies consistent with its mission and evaluate the success of those activities. The Learning Communities that were held across the state during 2009 and that will continue in 2010 are examples of the way that NYMWP involves diverse stakeholders in dialogue and training to promote and disseminate knowledge exchange and employment best practices.

One of the NYMWP strategic planning goals is to improve the use of peer-driven employment services. This report describes barriers, facilitators and best practices for improving peer-driven employment services in New York State.

A growing body of literature and decades of programmatic experience have shown that peer support is an effective method for people with disabilities to assist one another in meeting their emotional, social, and practical needs. Public health research has long recognized supports provided by individuals with similar experiences as fundamental factors in ensuring health and quality of life. Self-help movements such as Alcoholics Anonymous and Narcotics Anonymous have accumulated decades of experience providing peer support to help members achieve substance abuse recovery. Since the early 1970's, Independent Living Centers have offered peer support through services controlled by people with disabilities. Through decades of experience, these Centers have documented the multiple benefits of supports provided by individuals with the lived experience of overcoming disability, such as peer counseling and independent living skills training. In the mental health field, empirical data is increasingly available describing the feasibility and

benefits of peer delivered supports. Additionally, the mental health consumer movement has conceptualized and documented the role of peer support in facilitating recovery and well-being for persons with psychiatric disabilities. Research among individuals with developmental disabilities also suggests benefits of interventions lead by peers in improving educational and social integration outcomes. In New York State, the self-advocacy movement has also made important contributions to assisting individuals with developmental disabilities in the areas of advocacy, independent living, and socialization, helping these individuals to be effective members of their communities.

Research focused on social networks and social capital has demonstrated that individuals and communities with strong and diverse connections have better outcomes in emotional health, overall wellbeing, civic participation, and employment and economic integration than those with limited networks. Labor research has also documented the important role of social connections in obtaining and maintaining employment, as well contributing to career advancement. Nevertheless, despite the evidence about the benefits of social and peer support to health and wellbeing, little documentation exists about the role of peer support in helping individuals with disabilities achieve employment and economic self-sufficiency.

The goals of this project included: (1) document existing peer employment support practices among people with disabilities in New York State, and (2) identify the elements for a cross-disability model for peer employment support. To this end, interviews and focus group meetings were conducted with sixty-five administrators, leaders, and staff representing a total of twenty-four peer-operated organizations, provider agencies with peer-operated programs, and advocacy organizations supporting individuals with physical, sensory, psychiatric, and developmental disabilities. This project adopted a broad and inclusive definition of peer support as giving and receiving help based on similar personal experience which can be implemented in several forms, such as self-help, peer-provided services, and peer-managed services.

Informants indicated that peer support has an important role in building the human, material, and social capital of individuals to gain and maintain employment. Peer support seems to be particularly important in providing supports in areas in which paid providers are not able to help, such as inspiring individuals with disabilities through the mutual sharing stories of employment success, providing emotional support to overcome the anxieties and fears associated with work and benefits management, providing hands-on knowledge and advocacy to access and navigate services, and helping individuals expand their social connections to obtain and maintain employment.

In summary, the findings of this project suggest that peer employment support provides four unique benefits and roles: (1) effecting a “narrative change” by building hope and self-efficacy around employment; (2) providing emotional support to cope with the process of job seeking; (3) assisting people with disabilities to access and navigate employment

services; and (4) building social capital by expanding social networks and creating ties of support and reciprocity.

While all of these roles are essential to achieving employment and economic integration, sociological and labor research suggest that building social capital can be one of the most essential contributions of peer support. Research has shown that most people obtain employment through their informal networks, rather than through formal mechanisms such as newspapers, the internet, or paid relationships. Furthermore, while “strong ties” (close relationships) with other individuals with similar experiences are key for improving emotional health and overall wellbeing, having “weak ties”/acquaintances (e.g., knowing the friend of a friend) is a crucial factor in getting a job. Thus, having large and diverse networks increases the likelihood of successfully achieving employment.

Paradoxically, traditional vocational programs have not effectively helped people with disabilities to expand their social capital for employment. Many programs do not help job seekers assess their family and community relationships and connections, or help them identify strategies to expand the social networks that can be instrumental in getting or maintaining a job. The findings of this project indicate that it is critical for peer support practices to not further isolate individuals with disabilities by creating segregated “peer” networks, that is, networks of people with disabilities that have strong ties to one another but are isolated from the social networks that can provide them with employment opportunities and broader socio-economic integration.

Therefore, while peer support has an essential role in creating “bonding” with other individuals with lived experience, facilitating “bridging” to supports and community members who are not individuals with disabilities or paid providers can open up opportunities for employment connections and accessing supports outside of the disability community. Thus, a key goal of effective peer support is to enlarge, diversify, and broaden the social networks of people with disabilities. Peer support ought to assist individuals to establish connections outside of their “peer” networks, by facilitating connections to others outside of the disability service and support system, including both “close” relationships and “weak” ties (e.g., acquaintances, people, institutions which are not part of a person’s regular contacts).

Habilitation, rehabilitation, and vocational services can also have a role in promoting such practices by training providers and developing person-centered programs that foster a diversity of community connections which are not limited to connections among service recipients. Advocates can have an important role in advocating for policies and funding structures that promote and reward programs that build the social capital of individuals that effectively support their employment, career, and economic integration goals. Programs should follow such practices and policies, and to develop staff competencies to build social networks. Similarly, services and competencies should be designed to enhance community integration, so people with disabilities are effectively supported to become

employees, colleagues, business owners, customers, classmates, neighbors, and active citizens in the communities where they live, learn, work, and socialize.

INTRODUCTION

Nature of the Problem: Under and Unemployment among People Living with Disabilities

People with disabilities (including physical, sensory, intellectual, and psychiatric disabilities) represent a large portion of persons who are unemployed or underemployed in the United States. The most recent data of the US Bureau of Labor Statistics¹ show less than 23% of Americans with disabilities aged 16-64 being in the labor force, versus over 77% of their non-disabled counterparts. In addition, people with disabilities who are employed often work far fewer hours per week than people without disabilities, and they are employed in “secondary labor market” jobs involving limited skills, resulting in limited hourly wages, limited job tenures, and possibly a series of jobs rather than a meaningful career. In New York State, it is estimated that 67% of people with disabilities are unemployed (33% are employed) whereas 22% of people without disabilities are unemployed (78% of people without disabilities are employed) (American Community Survey, 2008).

Poverty is a condition of not having the means to afford basic needs such as nutrition, healthcare, clothing, shelter, etc. Poverty rates for people with disabilities is estimated at 34%, in contrast to 10% for people without disabilities (American Community Survey, 2008). It is beyond question that under and unemployment is associated with a life of poverty, and indisputable that under and/or employment and poverty combined is bad for overall wellness in all dimensions of health.

Furthermore, research suggest that poverty contributes, in and of itself, to disability by limiting people’s access to adequate health care and preventive services, quality treatment, habilitation and rehabilitation and services, and assistive technology.

Furthermore, research suggest that poverty and unemployment contribute to disability by limiting people’s access to adequate health care and preventive services, quality treatment, habilitation and rehabilitation and services, and assistive technology (Fremstad, 2009).

Social Determinants

Unemployment, coupled with the experience of living at or below the poverty guidelines, can have significant negative impacts on physical, social, and emotional health and well-being. Both can impact: well-being (e.g., self-esteem/worth, sense of self-efficacy); mental health (e.g. depression, anxiety); physical health (e.g., low activity/sedentary life, development of illness and diseases,) and social inclusion (e.g, low participation in community, weaker natural support networks). Determinants of health across groups recognize that health is affected by many factors, including where we live, income, educational status and social relationships. These are known as "social determinants of

¹ Data retrieved from www.bls.gov/cps/cpsdisability.htm on December 19, 2009

health." *Social determinants* of health are the economic and social conditions under which people live that determine their health. Social determinants of health recognized by the World Health Organization (WHO) include: income and social status; social support networks; education and literacy, i.e. health literacy; employment /working conditions, social environments and physical environments; personal health practices and coping skills; child development; genetic factors; access to health services; gender; and culture (Wilkinson & Marmot, 2003).

Social determinants explain why members of different socio-economic groups, and in different social environments may experience varying degrees of health and illness. A social gradient in health runs through society, with those that are poorest generally suffering the worst health. Mortality (lifespan) and morbidity (rates of co-occurring serious medical conditions) among people with low incomes who live with disabilities is disproportionate. People suffer negative impacts on their physical health due to factors which include reduced ability to follow a healthy diet, reduced ability to access medical and dental care, the health aspects of substandard housing, and the psychosocial impacts of poverty. In addition, dealing with the stigma of living at or below the poverty guidelines/levels has a tremendous impact on self-esteem and self efficacy, and can lead to discrimination and social exclusion/social isolation.

Social isolation is the absence of social interactions, contacts, and relationships with family and friends, neighbors, and society. Social isolation is considered a risk factor in the development of diseases, and can have bad impacts on disability-related symptoms. People who are isolated often do not have access to forms of instrumental, practical, and emotional support. People of limited means lack the resources to engage in various social and communal activities where they could help develop personal networks.

Limited social networks fuel the poverty and isolation trap. People who have limited social networks may not have resources that can help them find and keep jobs. Despite all other resources, personal networks are a major source of locating positions which people actually get and keep. Social networks can be a good buffer to help people deal with episodes of stress or bouts of symptom exacerbation – a friend can provide practical and emotional support to manage their condition and return to independent functioning.

People also turn naturally to their social networks for counsel, companionship, solace, and the networking which expands the size and scope of their networks. It is therefore obvious that people with limited social networks are more likely to be isolated and un- or underemployed.

Capital for Employment: A framework to understand the role of employment services and supports

Labor and sociological research suggests that different forms of “capital” (or resources) are essential for people with disabilities to successfully achieve and maintain employment. In order to inform this project and better understand the employment support needs of people with disabilities, the research team adapted Potts’ operationalization of

employment capital (Potts, 2005) and identified three forms of essential capital for employment:

- **Human capital**, which refers to the training and skills that make individuals able to perform a job (e.g., education, specialized skills),
- **Material capital**, which encompasses the economic and tangible supports that need to be in place for individuals to work (e.g., safe and stable housing, reliable transportation, work tools), and
- **Social capital**, which refers to the relationships and connections that make it possible for people to obtain and maintain a job (e.g., social networks producing job opportunities, peer support to cope with job stressors).

From this perspective, obtaining and maintaining employment are more likely when an individual's human capital is supported by broader material and social capital available to them. This suggests that a comprehensive approach to employment services ought to incorporate the human, cultural, social, and material dimensions in order to ensure that the necessary "capital" is available to individuals with disabilities to obtain and maintain employment. Traditionally employment services for people with disabilities have prioritized a focus on developing people's human and cultural capital (e.g., providing skills training, interviewing skills, resume building) and have developed significantly less capacity at addressing the structural supports required to build material capital (e.g., ensuring stable housing, improving financial resources) or social capital (e.g., expanding social support networks) (Condeluci et al, 2008; Parris & Granger, 2008).

Figure 1 below illustrates the connections between the different forms of capital and employment outcomes.

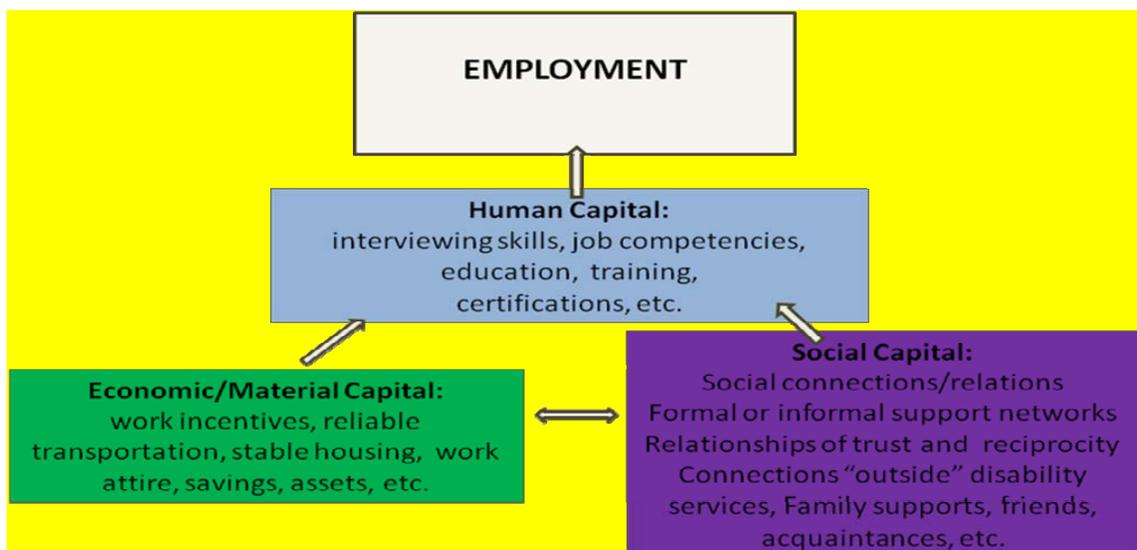


Figure 1: Connections between the different forms of capital and employment outcomes

Human capital needed for employment includes competencies and skills which demonstrate job qualification to employers, and enable execution of job tasks, and increases the likelihood of successful job performance and retention. Examples of human capital include formal training, specialized competencies and skills, education, and certification (Potts, 2005). Findings of this project and existing literature on employment among people with disabilities provide a strong basis to argue that another essential form of human capital is the individual's self-efficacy, that is, a person's attitudes and beliefs about their own ability to work. Research has shown that self-efficacy and optimism are some of the most important predictors of successful job outcomes (Bakker et al, 2009; Booth et al, 2008). Awareness and knowledge of supports such as job opportunities, job supports, and workplace culture can also be classified as human capital.

Individuals with disabilities require certain economic and material resources in order to successfully obtain and maintain employment, such as stable housing, reliable transportation, and resources to acquire adequate work attire or childcare. As stated previously in this report, over thirty percent of people with disabilities live in poverty. Therefore, it is understandable how accessing these essential resources to find and keep a job are limited to people with disabilities.

Overwhelming research has shown that the social relationships and connections of individuals are fundamental in achieving and maintaining employment (Condeluci et al, 2008; Granovetter, 1974; Potts, 2005; Parris & Granger, 2008). A large number of non-disabled individuals, if not the majority (40% to 70%), obtain jobs through their personal networks (and not through formal mechanisms such as newspapers, websites, and employment agencies). Research has also suggested that social networks may facilitate access to human capital and economic and material capital (Zippay, 2001). Social networks can be instrumental for individuals to become aware of job opportunities, receive effective recommendations for employment, access information about services and supports available, receive emotional support to adjust effectively to new environments and roles, and access necessary practical supports (e.g., transportation, childcare) (Potts, 2005). Potts lists several reasons for finding jobs through contacts. First, through networks, people get information about more job opportunities, including those in the "hidden job market." A helpful advantage of finding jobs through contacts is that the job contacts often have an "in" with the employer. Using networks and contacts to find jobs is often more effective than other methods and also tends to connect people with higher paying and more desirable job prospects (Potts, 2005).

Sociologists and researchers often refer to the set of social networks and resources arising from such connections as "social capital." Attempting a definition, Putnam (2000) describes three key elements of social capital: (1) social networks; (2) norms and obligations, and (3) social values. Social networks refer to the set of relationships and connections which can be formal or informal, and can encompass strong or "weak" ties. Norms and obligations reflect a sense of reciprocity amongst the members of a social network or community. Reciprocity triggers the sharing and pooling of valuable resources which may strengthen both human capital and economic and material capital. Social values such as trust and tolerance help to

break down social barriers and facilitate reciprocity as well as social networking (Siisiäinen, 2000).

Putnam describes two functions of social capital: bonding and bridging. Bonding is described as being exclusive and serves as a foundation for reciprocity and mobilizing solidarity. Bridging is inclusive and pertains to networking to link to external assets and for information diffusion (Putnam, 2000). This distinction is particularly important since research has shown that while having “strong ties” (close relationships) can have a positive impact on physical and emotional health, having “weak” ties/acquaintances (e.g., knowing the friend of a friend) that can be most crucial to obtaining employment (Granovetter, 1974; Potts, 2005). In other words, it is likely that the “bridging” function of social capital can be as important, if not more important to individuals than the “bonding” produced. This assertion has certain implications in defining or redefining the role of peer support for employment, as it suggests that peer support can be most helpful not only when creating strong bonds among individuals with disabilities, but more importantly when creating bonds with others outside of the networks of people with disabilities and their providers.

Statement of Problem

Given the issues of poverty and unemployment among persons with disabilities living in New York, and their lack of social capital as it relates to employment, we sought to examine barriers and existing or needed resources in order to develop a proposed model of peer employment support.

Methodology

Participants and Setting

Key informants for this project were identified as leaders, administrators and, staff, of peer-operated programs, provider agencies with peer partnerships, and grassroots advocacy groups supporting individuals with mental health, physical, sensory, and developmental disabilities. Twenty four (24) organizations participated and a total of 65 individuals participated (interviews and participatory workshops). Fifty-one participants engaged in the face-to-face interview and group discussions. The remaining fourteen participated through a phone interview. Interviews ranged from 60 minutes to 120 minutes. Focus group meetings of four hours in duration were conducted in fall, 2009. One was held in New York City and one in Albany (See Appendix I for Participating Programs and Organizations).

Organizations were identified through the three statewide organizations collaborating in this project (the New York Association of Psychiatric Rehabilitation Services {NYAPRS}, the New York Association on Independent Living {NYAIL} and Self-Advocacy Association of New York State {SANYS}).

All thirty independent living centers (ILCs), which are members of NYAIL, were invited to participate. The research team was only able to conduct meetings with those ILCs that promptly responded (N=10). Utilizing the NYS-OMH data base, the team identified approximately 40 mental health provider agencies with both peer-delivered programs (e.g., advocacy, peer support) and vocational programs. Of those, the team was able to conduct interviews with representatives from mental health programs which responded most immediately to the interview request (N=10).

Advocates and representatives from SANYS were invited because of their strong leadership role in that organization (e.g., Board of Directors, Regional Coordinators). One representative from a developmental disability provider was invited to participate in one of the group discussions based on her strong interest and leadership in peer employment support initiatives.

In total approximately 30% of the total number of independent living centers and mental health agencies with both vocational and peer programs were represented

Procedures and Instruments

A semi-structured interview protocol and guide were developed for this project. Interviews were scheduled and conducted with stakeholders using an interview guide. Open-ended questions were constructed to explore the following dimensions:

1. employment barriers,
2. supports that individuals served need in order to achieve employment (capital needs,)

3. services delivered and methods utilized by peers to facilitate employment,
4. value and roles of peers in supporting achievement of employment goals, and
5. ideal principles, roles, and competencies of peers in a 'model' peer employment support program.

This project was exploratory in nature, thus a qualitative approach seemed best to gather experience in order to better understand the needs from key informants. Interviews included a series of semi-structured questions designed to gather qualitative data about needs and resources related to employment for persons across disabilities. The semi-structured approach seemed important since

1. peer support involves multiple human dimensions which can be most fully captured through qualitative methods, and
2. there was a significant wealth of experience on providing peer support seemed to lie in the stories and accounts of key informants.

Data was collected through interviews (in person and by phone) and through two scheduled focus group meetings. Informants were asked the same questions (Appendix II- Interview Guide). In addition to the interview questions, participants who attended the focus group were also presented with some of the preliminary findings from individual interviews, and were asked to identify what they believed should be the overriding principles, role and competencies of an effective peer employment support model.

Limitations

It is likely that organizations participating are those which tend to value peer support the most, and are most enthusiastic about pursuing a cross-disability peer employment support model. Because of this, the findings of this study cannot be fully generalized. More specifically, the findings may not fully represent the variety and strength of peer employment support practices across disability groups, or the diversity of perceptions among peer-operated programs about the potential of a cross-disability peer employment support model.

Analysis of Qualitative Data

All interviews and focus groups were recorded and transcribed. Two project team members independently reviewed the transcriptions and coded these to identify

1. themes across perceived employment barriers,
2. supports that individuals served need in order to achieve employment (capital needs),
3. services delivered and methods utilized by peers to facilitate employment,

4. value and roles of peers in supporting achievement of employment goals, and
5. benefits, ideal roles and competencies of peers in a 'model' peer employment support program.

A summary document was developed to organize and describe the themes identified (See Appendix III, Summary of Interviews and Focus Groups).

Major Findings/Discussion

The major findings will be discussed with links to existing literature (social capital, peer support, peer delivered models), including:

1. perceived employment barriers,
2. supports that individuals need to achieve employment (capital needs),
3. services delivered and methods utilized by peers to facilitate employment,
4. value and roles of peers in supporting achievement of employment goals; and
5. benefits, ideal roles and competencies of peers in a 'model' peer employment support program.

Perceived Barriers to Employment

"Culture change is a slow process. It requires buy-in and people to maintain it. You have to work at all levels to be effective" (Independent living center interviewee).

Informants were asked to identify barriers to employment. The findings will be discussed on the following levels: individual, interpersonal, organizational, community, and societal or public policy levels.

The *individual level* refers to a person's knowledge, attitudes, skills, and behaviors. Informants highlighted, for instance, that people with disabilities they serve commonly lack the education, as well as the "soft" and professional skills for obtaining and maintaining employment.

The *interpersonal level* encompasses the relationships and interactions between the individuals and family and friends, as well as broader social networks which can influence a person's behaviors and access to resources, information, and support. Informants indicated that people with disabilities often experience isolation and some level of segregation to programs for only for people with disabilities. Consequently, it is likely that people with disabilities may have limited social networks to provide them with essential information, connections, and formal or informal supports to achieve employment.

Clinicians and program staff represent another influential aspect of interpersonal resources. Providers are in a position to serve as motivators or sources of discouragement for individuals. For instance, clinicians or support staff members who have some combination of

1. misinformation about the therapeutic value of employment and the existing work incentives that allow individuals to work without jeopardizing valuable public benefits, and/or
2. negative personal attitudes about the value of work for people with disabilities may become barriers to individuals attempting employment or even exploring their career dreams.

The *organizational level* consists of the environment of organizations and social institutions that shape the services, supports, and dynamics to which individuals are exposed. The availability of programs that effectively support individuals to achieve employment was mentioned as a key barrier to people with disabilities. For instance, respondents indicated that state agencies such as OMRDD have traditionally overemphasized availability and access to sheltered workshops or day programs as opposed to more integrated and competitive employment options. Some noted that even in light of OMRDD's current efforts to downsize sheltered workshops and transition individuals out of those settings, many people with developmental disabilities are being enrolled in day habilitation programs that do not encourage employment or provide a meaningful path towards work.

Another *organizational barrier* affecting the access by individuals to effective services and supports which was identified by respondents is the great deal of "fragmentation" and compartmentalization of services. For instance, for individuals with dual diagnoses (e.g., physical and mental health, mental health and developmental), it is often difficult to access all the comprehensive services they need to participate successfully in the labor force and in their communities. In the same vein, respondents noted that many programs have difficulty using braided funding streams, and that navigators put in place in some programs to help reduce the impact of fragmentation have not been fully effective towards that goal.

The *community level* involves other important agents affecting the employment outcomes of people with disabilities, such as employers. The perceptions of employers about disabilities, their willingness to hire individuals with disabilities, and their capacity to provide accommodations were all factors regarded by interviewees as key in determining employment outcomes. Many participants expressed that employers have negative perceptions about the employment potential of people with disabilities and lack competency in providing reasonable accommodations. Thus, a predominant perception was the need for education and advocacy to employers to demonstrate the capacity and abilities of people with disabilities as well as to inform them of the incentives and benefits for hiring people with disabilities.

Lastly, the societal, or public policy level, refers to the laws, social norms, and broader culture shaping employment services and opportunities for people with disabilities. State

policies and funding were frequently mentioned as barriers by interviewees in this project. The social security benefits system was frequently noted as a significant barrier to employment. Informants expressed that there is a lot of fear and anxiety among people with disabilities about losing benefits and not being able to support themselves. Losing benefits by becoming employed was stated as a disincentive for many people with disabilities, as evidenced by this statement of a developmental disability advocate: “a [fear of] losing benefit is holding people back from working full time.”

Human Capital Needs

Informants indicated that people with disabilities often lack much of the human capital that is needed for them to achieve employment. While in some cases this is a direct result of the disability (e.g., inability to perform certain physical or intellectual tasks specific to some jobs), or due to the paradox that lack of employment detracts from the ability to develop and maintain the human capital needed to get and stay employed, our findings suggest that acquiring this human capital is often limited by factors related not to the disability itself but to the environment of individuals. For instance, the education system seems to pose significant barriers to people with disabilities. Informants noted that people with disabilities in New York State will often receive a special education diploma (Individualized Education Plan- IEP) instead of a Regents diploma. While these diplomas certify that the person has finished high school, they do not necessarily represent or assert qualification and are undervalued by employers. One informant reported that many of their clients do not have any kind of diploma, as it is a common occurrence for individuals with psychiatric disabilities to interrupt their schooling at the onset of psychiatric symptoms.

Job skills and work experience were frequently listed as essential capital for people with disabilities to obtain successful employment. Whether it is a result of low employment expectations, systems barriers, or individual attitudes about employment, many people with disabilities do not have work experience or job skills (beyond "soft skills") needed to be “marketable” for competitive employment. Several of the agencies interviewed noted that employment services and supports should enhance the following: interviewing skills, resume writing skills, and workplace “etiquette” of individuals with disabilities. These informants reported the following: “as with diplomas, employers look for previous work experience on resumes.”

Informants reported that often students with disabilities do not integrate with non-disabled students and therefore become isolated. As a result, their development of communication and social skills tends to be limited. The need for relationship building was highlighted by a participant from the developmental disability community who commented that teaching social interaction skills is generally emphasized only for people with “social disabilities.” In her opinion, this is a competency that is needed by all people with disabilities due to the great deal of isolation that predominates in this population.

Hope and a sense of self-efficacy are also two important aspects of human capital which people with disabilities need in order to achieve employment. Informants stressed that it is important for people with disabilities to have a positive outlook on their own capability

and potential, and for their supports and environment to reinforce optimism and hope. Furthermore, one informant asserted the following: "There needs to be a transformation. We need to raise kids [children with disabilities] to believe they are capable and expected to work." This person indicated that, contrary to this more hopeful expectation, young people with disabilities are commonly taught to be dependent on a benefits system which fosters a sense of learned helplessness. Informants reported that adults with disabilities, many of whom have been dependent on public benefits for years, also struggle with a sense of helplessness and lack of hope. Consequently, informants concluded that improving hope and sense of self-efficacy about work ought to be priorities for all employment services, including those provided by peer support.

Economic and Material Capital

As Reported by Informants

*"The Bronx is the poorest Borough, we have difficulty with jobs; people who are deaf have no access to ASL interpreting and don't have computers. The problem is that people are poor."
(Independent Living Center interviewee)*

"Transportation is a major problem for more rural counties. It's very difficult to get people jobs without transportation." (Mental health informant)

Informants revealed that while having the right attitude and the skills to work are crucial to employment, these factors have limited potential without adequate "wrap-around" supports. Financial stability and resources needed for employment were recurring themes. Responses to our interview questions suggest that some employment needs are directly related to the disabilities, while many others are related to poverty. A representative from the Bronx Independent Living Center exemplified this as follows: "The Bronx is the poorest Borough, we have difficulty with jobs; people who are deaf have no access to ASL interpreting and don't have computers. The problem is that people are poor."

Several informants noted that lack of access to computers, the Internet, and modern technology make the process of seeking jobs difficult. "People need access to technology and awareness of how to use it." (Mental health informant). Having limited access and skills to use technology such as computers, the Internet, e-mails, phones, and fax machines is a disadvantage to finding and applying for available jobs.

It seems apparent that living in impoverished areas can be a barrier to employment. One apparent issue is that people living in unsafe neighborhoods (especially people with disabilities) may be especially reluctant to travel into or out of their neighborhoods in the dark, this limiting some kinds of employment and access to adult education. Employer perceptions of neighborhoods and people's prejudices about poverty may be another mechanism by which a person's place of living impacts their ability to get a job. For instance, Bertrand & Mullainathan (2003) noted that "applicants living in better neighborhoods receive more callbacks but, interestingly, this effect does not differ by race"

Another resource needed for employment (but a barrier for many people with disabilities) was transportation. For various reasons², many people with disabilities do not drive or do not have a personal vehicle and public transportation is scarce or inadequate in many areas (and in many places may be limited to rush hour travel). This was noted from agencies across the state in both rural and urban areas: *"Transportation is a major problem for more rural counties. It's very difficult to get people jobs without transportation."*

An advocate reported that people often need to take two or three buses to get to work. It takes an hour where by car it would only be a few minutes. For some, the issue is a lack of knowledge and awareness of existing transportation services: "not many people know how to use it [Access-a-Ride]. Some people do not know how to use the bus and the train." (Developmental disability advocate).

Another issue related to transportation is the under-utilization of resources available. For instance, an informant indicated that in her perception people with disabilities and their providers are unaware of discounts and travel training resources and therefore these go underutilized.

Two other material capital deficits which were mentioned as barriers were childcare (particularly for single parents who are mandated to work), and the fact that that many people with disabilities do not have appropriate clothing to work and agencies are not able to provide this resource. This may also be a barrier where staff training can improve results, as some cities have donated work clothing systems, and people have been known to get childcare during training programs covered by VESID, and childcare during employment covered or subsidized by local Workforce Investment Boards (WIBs).

Social Capital

"The social piece is the missing piece." (Interviewee)

"If disability narrows the set of jobs one is qualified to fill, then having the right channels of job contacts to get access to that smaller set of job opportunities may be even more crucial to employment success." (Potts, 2005)

One informant explicitly identified social capital as being important to employment success: "The social piece is the missing piece." To reiterate, Putnam describes two important functions of social capital. These are bonding and bridging. Bonding is an internal but exclusive form of social capital. It refers to the relationships and supports that take place within a social network (Schaefer-McDaniel, 2004). Bridging refers to activities that include various people of different origins that work towards a common cause. This describes connections of individuals within a network to other networks (Ibid). Both of these functions were expressed as employment support needs.

² One of those reasons is the recurring paradox of poverty. You need a decent paying job to buy, maintain, and insure a car, and you need a car to get and keep a decent paying job.

First, emotional support was expressed as an employment need by several of the informants. Putnam (2000) explains that bonding social capital can facilitate emotional or psychological support. Also, expanding social networks was discussed as a need. “Bonding” with other individuals with lived experience, facilitates “bridging” to supports and community members who are not individuals with disabilities or paid providers and can open up opportunities for employment connections and accessing supports outside of the disability community. Participants expressed that more integration must occur in several sectors, stressing the importance of bridging social capital. Some informants stated that they would like to see more integration of people with disabilities in schools with the more general student population. Several participants indicated that people with disabilities need to be more integrated with mainstream society.

There are several reasons to believe that people with disabilities have smaller and less diverse social networks. Knox & Parmeter (1993) observed “that the social networks of young adults with mild intellectual disabilities lacked complexity, with few interconnections among the network nodes.” Lippold and Burns (2009) stated that interventions for people with disabilities have been focused on promoting their social presence and integration. However, previous studies have shown that this does not always lead to the formation of social relationships. Wojciechowska, Walczewski, & Cechnicki (2009) indicated that the extent of some social network subfactors (the range of network, the amount and localization of support and size of extra-familiar network) is negatively correlated with psychiatric symptoms (smaller networks were correlated with more intense, frequent symptoms for some people living with schizophrenia).

We believe that smaller and less diverse social networks are associated with the following reasons: First, the social isolation that has been discussed is a likely barrier networking. Also, people with disabilities often experience long-term services for their disabilities. In receiving these services, social contact is often limited to the “paid relationships” with their providers. Therefore there is little opportunity to branch out to acquire new acquaintances.

As aforementioned, a barrier to social integration may be stigma and societal perceptions of people with disabilities. Several participants spoke of the need for advocacy and education for employers and society as a whole to change these perceptions. Some self-advocates in New York City are advocating to change the perspective of people with disabilities as being burdens to one that recognizes this community as a resource, contributors to local communities, and effective and loyal employees.

Participants from some of the Independent Living Centers indicated that people with different types of disabilities are also isolated from one another. Often people with disabilities have pre-conceived notions about other disability groups and make assumptions based on their respective “functioning level.” As the non-disabled community may have these notions about the capabilities of people with disabilities, comparable thinking can exist between disability groups. In their opinion, this limits the valuable interactions and sharing of resources that could occur. A solution to this problem would be to foster more integration across disability groups by, for instance, holding more peer

support groups with individuals with multiple types of disabilities. Their rationale was that while people with different disabilities may experience some challenges that are unique to their specific disabilities, what is most important is that they share experiences of “overcoming,” such as dealing with systems barriers, isolation, managing public benefits, etc. Thus, members of cross-disability groups would be able to offer one-another emotional and informational support by tapping into their diverse talents and assets, and inspiring and teaching one another. An additional value to a cross-disability approach is that individuals with different types of disabilities may also have access to different social networks as a result of their involvement in different service structure and their varying levels of participation in the community. Fostering connections between people with diverse disabilities therefore brings together a larger pool of information, resources and connections. Cross disability peer support may have a unique potential to improve employment outcomes.

Why a Cross Disability Approach

In addition to the aforementioned values of breaking down barriers, and maximizing the synergy of various strengths, cross-disability services and supports, there are two other strong reasons for services and supports being delivered with a cross-disability approach. One is the efficiency of services. Density of services outside of our cities is low, and services specific to given disabilities can tend to be so dispersed that workforce members spend most of their time traveling between appointments, and face-to-face support groups become rare and sparsely attended. When services are combined, a support worker posted at the county college can serve all of the students with disabilities, and a job development specialist going into a hospital can look for employment opportunities for people with a range of special needs.

The second reason is the relative low visibility of rehabilitative services in the larger community. Even in systems close to the disability service system (medical care mental health care, child protection, criminal justice, etc.) people have little awareness of the kinds of supports and services available to people with disabilities. Seeking a service for someone becomes a challenging and discouraging series of “no right door” contacts. A county level social worker trying to find some community services for an adult with autism may make several calls, land at an MRDD service setting, be quickly told that the person seems to have more mental health issues than typical people with autism, see that person referred to an OMHS service, see that person then referred to VESID for employment services, etc. Having a “cross disability employment service home” increases people’s chances of getting to a helpful service with greater speed and less frustration.

Peer Support for Employment as a Viable Model

Peer providers are used in a variety of settings, ranging from mental health services to Independent Living Centers (ILCs) to addiction treatment continua. In many ILCs and addiction treatment services, peer providers are a majority in the workforce. We can make the clear case that traditional (non-peer-delivered) services in support of employment have had disappointing outcomes, and therefore that peer-delivered employment services

are worth a meaningful trial to attempt to demonstrate greater efficacy in helping people with disabilities choose, get, and keep meaningful employment.

Peer provided employment resources can be a source of strength for people with various kinds of health conditions and disabilities, including: credibility, an understanding of the service system based on experiential knowledge; and possibly a better understanding of the social and practical impacts of the condition or disability.

People with disabilities who move further from poverty and social isolation are likely to need less expensive institutional services than people who stay impoverished. This result can be possible through a combination of having better healthcare and diets, having their own transportation resources, having a more stable place to live, having personal networks to help them through periods of unemployment, debility, and homelessness, and having close family and friends who can assist them in community living. Institutional services are a costly drain on society, whether up to \$5,000 per month in an adult day program or day habilitation service, \$4,000-10,000 per month in a nursing home, or over \$10,000 per month in a developmental or psychiatric center. In New York State, it is estimated that the cost per individual served in a sheltered workshop within the mental health system is approximately \$27,000 per year.

People with disabilities who do choose, get, and keep meaningful careers which bring them past the need for public benefits can and do become taxpaying members of society. Many people can achieve self sufficiency, and others may only need to access minimal public supports and services. People with disabilities who earn incomes spend a portion of those incomes on items on which the government collects sales taxes. This includes homes, cars, fuel, and personal goods.

In addition, a case can be made that unemployed people with disabilities represent a loss of intellectual capital which our society sorely needs. Visible employment of people with a variety of disabilities in various roles sends a valued message to other members of the community who are not working, and may help increase employment and productivity overall.

Peer Employment Support: Enhancing Social Capital

Peer Support Models and Practices

There has been a growing body of literature describing the effectiveness of peer support for people with similar life experiences (for example, people living with psychiatric, physical, and/or intellectual disabilities) as an important factor in assisting others in need with emotional, social, and practical needs. In the mental health field empirical data is available describing feasibility and benefits of peer delivered models (Davidson et al., 1999; Doughty & Tse, 2005; Solomon, 2004; Swarbrick, 2009b). Peer support provides a form of social support which public health and medical research has long recognized as a necessary condition for quality of life and healthy living.

Peer support has been defined in the Substance Abuse and Mental Health Services Administration (SAMHSA) recovery consensus statement as *“Mutual support-including the sharing of experiential knowledge and skills and social learning-plays an invaluable role in recovery. Peers encourage and engage other peers in recovery and provide each other with a sense of belonging, supportive relationships, valued roles, and community”* (Department of Health and Human Services, 2006).

Peer support is a way of giving and receiving help among people who share a common life experience or challenge. Also called self-help, mutual aid, or mutual support, it has long been used by people with a variety of physical health issues, social issues, mental health problems, and substance abuse issues to share their strengths, help each other cope and grow, and find understanding with like-minded people.

A characteristic of peer support is that it is a sharing among a community of equals, rooted in compassion for oneself and others. Peer support is based on the notions that a) people who share common experiences are best able to understand and empathize with each other, and can offer each other the benefit of what they’ve learned, and b) people who give help to their peers benefit as much or more than the people receiving the help.

Peer support can be seen as a natural human response to shared difficulty. Most people who have been through hard times empathize with and have an urge to help others whom they meet who are struggling with problems that seem similar to their own. It not only helps the person receiving the assistance; it makes the helper feel valued and needed. An important aspect of peer support is that people freely choose to participate. Peer support is for people who want to be part of it, not people who’ve been told they need it or are either required or mandated to participate. The voluntary nature of peer support is believed to create more natural trusting connections and relationships.

Peer support is based on mutuality. In order to offer support, a person needs to listen and just “be with” a peer in an affirming and accepting way. Peers communicate to each other that we matter and are accepted the way we are. The relationship is the foundation of peer support. The more authentic that relationship is the more powerful is the ability of two people to grow and heal together.

As an organized practice, peer support may have developed out of these basic human impulses to help people like ourselves. Probably the best-known self-help group, Alcoholics Anonymous (AA), was started in 1935, and has since affected the lives of millions of recovering alcoholics worldwide. AA was the first of what came to be known as 12-step programs, which came to include groups such as Narcotics Anonymous and Gamblers Anonymous. The 12 steps are a set of spiritually-based guiding principles for recovery from addictive, compulsive, or other behavioral problems. AA and other 12 step programs are also characterized by the absence of professional treatment staff, and a reliance on the fellowship and help of others who share one’s struggles.

With its origins in the civil rights and consumer movement of the 1960’s, the Independent Living movement postulates that people with disabilities are the best experts on their

needs, and therefore they must take the initiative in designing and promoting more effective solutions for and by people with disabilities. A crucial element of the Independent Living philosophy has been cross-disability, that is, the inclusion of all individuals regardless of diagnoses.

Since the 1970s, Independent Living Centers (Centers) have offered peer support through services controlled by people with disabilities. These Centers were created to offer peer support and role modeling, and are run and controlled by persons with disabilities. According to the IL approach, the example of a peer, somebody who has been in a similar situation, can be more powerful than a non-disabled professional's interventions in helping a person analyze his/her situation, assume responsibility for his/her life, and develop coping strategies. Through decades of experience, these Centers have documented the multiple benefits of supports provided by individuals with the lived experience of overcoming disability, such as peer counseling and independent living skills training. (Fleischer, 2001; Pelka, 1997).

Research among individuals with developmental disabilities also suggests the benefits of interventions lead by peers in improving educational and social integration outcomes (Carter, et al, 2005; Haring & Breen, 1992). In New York State, the self-advocacy movement has also made important contributions in assisting individuals with developmental disabilities to develop advocacy, independent living and socialization skills.

Peer support has a political frame of reference (Mead & MacNeil, 2006), and grew out of a reaction to social, physical, and other barriers for people with physical disabilities, Peer support provides many people with disabilities a source of hope and optimism about the future, promotes the sharing of personal stories, creates opportunities to learn or improve coping skills, facilitates the sharing of information and resources, and helps expand social networks outside of the peer/provider networks.

Types of Peer Support Models

There have been a variety of methods of categorizing peer support models (Davidson et al., 1999; Mowbray & Moxley, 1997; Solomon, 2004). Peer administration providing mutual support was characterized as *self-help*. Peer-administered organizations delivering conventional social services are generally characterized as *peer provided services*. An important issue is the degree to which the organization or service is managed and led by peers (wholly, in partnership with non-peers, or by non-peers). Generally the extent to which the role is something that is uniquely performed by a peer also distinguishes programs within the peer services category. The following will attempt to define each category more specifically. Table I provides a summary of the pros, cons, and examples of peer support models as it relates to employment.

Self-Help

Self-help is best described as mutual support groups, i.e., is a resource available where people voluntarily gather to help one another at their own convenience in some generic location. Most self-help groups are facilitated by peer volunteers, and usually have no

formal connection to conventional services. Generally, finances are casual – dues may be optional, optional contributions maybe solicited, and all work is done by volunteers. While some “pure local initiative” groups exist, many follow national or international models, and have some relationship to the organizations which develop, train, and spread those models. Examples of such organizations in mental health peer support are GROW, Recovery International, Double Trouble in Recovery, and the Depression and Bipolar Support Alliance (DBSA). Increasingly, self-help groups exist online in the form of threaded discussion boards and “chat rooms.” While some online self-help is associated with traditional national and international self-help organizations, others are true grass-roots initiatives, formed by a person or tiny group using free group and board systems which are readily available.

Cross disability peer support groups are examples of self-help in New York State. Interviewees from multiple independent living centers described such types of self-help groups. Some of these are run by individuals with disabilities, receiving support from the respective ILCs (for things such as meeting space) but are autonomous to determine their mission and ongoing programming. While these groups may have a general goal, employment is often an issue discussed in those groups. For instance, a peer support group for people who are blind or visually handicapped hosted by the Independent Living of Newburgh. While the focus of this support group is on taking responsibility for personal wellness, employment is often a topic of discussion and mutual support.

Another specific example of a self-help group described in our interviews is the Cross Disability Peer Support Group on Employment at Independent Living Center of the Hudson Valley, Inc.. This peer support group was launched a few months ago with the purpose of creating a space for individuals with any type of disability to receive support in the process of obtaining employment (e.g. mutual encouragement, resume-building). While this group meets at the independent living center, the direction and agenda of its activities was determined by the group. At the time of the interview, this group was having difficulty in meeting on a regular basis and had decreased in number of attendees.

A slightly different form of self-help is the self-advocacy groups of the Self-Advocacy Association of New York State (SANYS). These groups are very diverse in their focus, leadership and outreach, and have strong leadership and awareness about the key areas that affect the quality of life of people with developmental disabilities, such as housing, community inclusion, transportation, and employment supports. The strength of self-advocacy groups seems to be in their capacity to advocate for individuals to access services that can make a difference in their lives, and to collectively advocate for systemic/policy changes. Leaders and members of several self-advocacy groups discuss their concerns about, for instance, the overemphasis of the OMRDD (Office of Mental Retardation and Developmental Disabilities) on day habilitation programs and not on expanding employment supports and opportunities. Some other self-advocacy groups have a strong focus on issues that have an indirect but important impact on supporting the employment of members. For instance, an Albany area self-advocacy group has done extensive research about transportation resources and opportunities that could be expanded (e.g., vouchers,

Capital District Transportation Authority-CDTA corporate “swiper” discount programs), and utilizing web-based resources to strengthen social networking and communication between peers and with other community members (e.g., Facebook).

Self-help is an ideal model for people contemplating action towards employment or education. It can serve as a niche for people contemplating work or a source of social, instrumental and practical support for people with disabilities seeking to maintain employment. Systemic costs can be minimal and may be as little as a donation of space, or may be a bit more extensive, such as costs for paid mentoring (e.g., GROW), costs for training, and some transportation costs. The self-help model presents a very open door to the participant or potential participant. There is no required cost no need for a payor, and open trial without commitment. The maximal mutuality and the lack of titles and payments may be advantageous to the helper-helpee relationship.

Facilitating attendance and involvement in self-help groups may be difficult as many professionals and non-professionals are wary of them. Self-help groups need an appropriate model, and trained facilitators willing to follow/ enforce that model, in order to be effective. Without this self-help groups sometimes become settings where misinformation is spread, despite all good intentions. Self-help groups are limited in what they can do. They are not set up to provide vocational assessments, one-on-one counseling, job development, job coaching, assistive technology, or any of the other things job seekers with disabilities need during preparation and action. Also, they do not provide the economic and material supports that people with disabilities need for successful employment.

Peer-operated Services

Peer-operated services (POS) are offered by organizations that are managed and directed by people in recovery who are *paid* to serve their peers (Swarbrick, Schmidt, & Gill, 2009). These services are considered either an alternative or a complement to services offered by the traditional social service system. By definition, peer-operated means that people with disabilities constitute the majority of the governing board or advisory group that decides policies and procedures. Using one US standard for POS, more than 51 percent of the board officers should be self-identified as people who are current or past recipients of the public service delivery system. In the mental health service delivery system, examples may include drop-in centers or self-help centers, peer-operated housing and employment programs, and education and financial services programs. Collaborative Support Programs of New Jersey (CSP-NJ) is an example (Swarbrick, 2009a). CSP-NJ developed a Peer Employment Support (PES) model delivered by and for peers (persons living with psychiatric disabilities) in collaboration with the Department of Psychiatric Rehabilitation and Counseling Professions at the University of Medicine and Dentistry of New Jersey, School of Health Related Professions (Swarbrick, Bates, & Roberts, 2009). The PES model is based on research and field experience in the areas of supported employment, self help, and peer support. PES was designed to address ambivalence and increase opportunities for individuals living with a psychiatric disability to establish, pursue, and achieve employment and/or educational goals.

Peer-operated services can also operate outside of direct service provision, as we see with peer-operated program evaluation agencies and peer-operated technical assistance centers. ILCs are generally a type of peer operated or peer partnership which expertise in the areas of benefits advisement and systems advocacy, and self-advocacy groups in advocating for services and supporting individuals to self-advocate.

In New York State, all Independent Living Centers are consumer controlled, that is, more than fifty percent of their boards of directors are composed of individuals with disabilities. In a large number of all 43 Independent Living Centers in New York a majority of administrators and staff are also individuals with disabilities.

An example of a peer operated service or project described in our interviews is “Our Own Experience as Teachers” of SANYS. Self-advocates with developmental disabilities receive support from the AmeriCorps program to conduct awareness-building and training activities with a variety of audiences. Self-advocates present on topics such as their own personal stories, self-advocacy skills, Stop the “R” word, and emergency preparedness. While this program does not have a direct goal of promoting employment among individuals with developmental disabilities, this program improves the self-advocacy skills of AmeriCorps participants, supports their professional development, and increase awareness among providers and community members about the potential of individuals with developmental disabilities.

The Mental Health Peer Connection Job Club- Western NY Independent Living is another example of a peer operated service. It is a program for people with serious mental illness. There are three components to the job club. 1) Assisting recipients overcoming their barriers to employment. 2) Educating mental health recipients on the impact a working wage will have on benefits such as SSDI and SSI. 3) Rapid employment placement by peers who do job searches in the Erie County Community. All providers are also individuals with psychiatric disabilities who provide peer counseling, advocacy, independent living skills, technical assistance, and information and referral. Job club includes peer counseling and a peer support group held weekly. This peer support group is also attended by peer advocates and peers with benefits training in order to ensure that participants can obtain more technical information/problem-solving if necessary. The Vocational Peers share their experience. All paid peers have very similar experiences to those who are being served. Staff is culturally diverse to meet the needs of the poorest people in the communities served.

Peer operated services can offer the full continuum of employment-related services which could be offered by any provider agency, including the ability to take many forms of payment, including *Tickets to Work*. Programs using this model have the added credibility to service recipients brought by having staff and leadership with lived experience. This should be conducive to developing and maintaining a culture which helps dispel the backlog of negative experiences some service recipients have had. A limitation of the peer operated services model is that they are not available everywhere, therefore may require funding to develop and time to grow to strength and credibility systemic effort to create

credibility. Also, being peer-operated is no guarantee that the service uses current best practices. For example, clubhouses often cling to transitional employment and some ILCs have sheltered work, etc.

Peer Partnership (initiative)

Peer partnerships (also referred to as initiatives) take many forms, ranging from peers who volunteer in support roles, to those who are paid to provide support to service recipients within the traditional social service system. Peers are like any other person who wishes to contribute, but they bring the unique perspective of having the personal experience of a living effectively with a disability. Generally persons living with disabilities are involved in the program or service generally in a volunteer role. Professionals assume a lead in the control of the agency operations.

An example of a peer partnerships described in our interviews is “Keep on Track” of the Mental Health Association in Rochester, NY. With the support of a peer provider with benefits training, this group assists individuals who have returned to the workforce to report their wages correctly to the Social Security Administration and estimate how their monthly income will impact their social security benefits. This program also offers participants with practical support to complete the waging reporting process, such as access to computers, fax, copying machines, and filing of important or confidential documents. One of the challenges of this program has been to keep a large number of participants engaged and motivated.

Another example of a peer partnership is the Monthly Employment Lunches at St. Joseph’s Hospital Health Center (Syracuse, NY). This lunch-time meeting is open to anyone thinking about working, looking for employment, or working. Participants are encouraged to share about their experiences and challenges, strategies, and resources to overcome those challenges, employment leads, among other topics.

A positive aspect of peer partnerships is that the peer presence on governing bodies should help agencies develop or maintain a focus on recipient needs and credibility among recipients. However at the same time, the peer presence on governing bodies creates a risk of low retention in board roles, unless resources are allocated of mentoring, transportation, etc. as needed. It also creates a risk of non-representative peer presence, and of relegation of peers to an advisory board or community board status, rather than a governing board. Self-help groups under a professional-run agency umbrella should have all of the capacity and credibility of a peer-run self-help group. The partnership can add resources and clientele and provides a natural continuum and compliment of services and supports. Peer-run programs and peer volunteers provide added services at provider agencies add capacity, credibility, and empathy. However, there is some concern that seeking work from people without paying them can be a message of devaluing service recipients to current and potential clients and to the larger community.

People with Disabilities as Employees

There are two broad types of roles: 1) peer designated or specialist positions, and 2) traditional social service roles. There may be peer designated titles such as peer specialist, peer counselor, or peer advocate or people may occupy a more traditional social service position/title, such as nurse, case manager, vocational counselor, rehabilitation counselor, or social worker—they just also happen to be a person living with a disability. Direct service employment positions designed exclusively for peers have been established which acknowledge and develop the person in recovery's unique perspective and how it applies to the helping relationship. Both of the aforementioned position types have the benefit of increasing employment of people living with disabilities, and sending the message to the larger community that this is an agency or program which values the employment of people with disabilities. Those two benefits are also offered by a third role, non-service-related positions for people with disabilities in disability and related service organizations. This can include traditionally "in house" jobs such as personnel directors, bookkeepers, and cooks, as well as roles more likely to be contracted out such as plumbers, gardeners, wheelchair mechanics, and information technology specialists. Some organizations do adopt policies and practices which makes them self-accountable to minimize employment of and contracting with people without disabilities by their organization.

An example of the first role described of people with disabilities as employees that we came across in our interviews were the peer specialists at St. Joseph's Hospital Health Center New Connections Clubhouse. This organization holds regular advocacy meetings to define the role of the peer specialist. These meetings currently provide one-on-one support, and also facilitate peer support amongst others by scheduling group discussions around hope building and advice. Future plans include some peer specialists accompanying people while they do environmental exploring to check out prospective job sites, travel training, benefits and economics advisement, and help with housing issues. We also are encouraging alternative and complimentary approaches to recovery. The emphasis of future peer role development will focus on person centered planning approaches and development of community connections.

In the field of psychiatric rehabilitation, there is a growing body of evidence regarding the effectiveness of conventional services provided by practitioners living with a disability when compared to employees who do not have a disability. Multiple studies have demonstrated that peers provide equally effective services when compared to non-peer providers (Schmidt, Gill, Solomon, & Pratt, 2008). Some studies have examined peers as employees and found that there have been positive impacts on peer providers themselves (McGill & Patterson, 1990; Sherman & Porter 1991).

Similar to the role of peers in the other models, peers as employees can only enhance regular provider agency services through credibility and empathy. Furthermore, peer employees in specialized roles, such as navigator, recovery coach, and job coach should result in enhanced capacity, credibility, and empathy. Also as with peer partnerships, peers and employees creates risks of salary disparity and role disparity which need to be managed carefully.

Table 1 provides a description of peer support models including pros cons and examples in general and those found in New York. Appendix III - Peer Support Practices Found in New York, includes a more thorough listing of the peer delivered examples which informants reported to be available in New York.

Table 1- Types of Peer Support Models

MODEL: SELF-HELP		
Pros	Cons	Examples
<ol style="list-style-type: none"> 1. Mutuality should be maximal, without titles and payment getting in the way of the helper-helpee relationship. 2. Systemic costs can be minimal. May be as little as a donation of space, or may be a bit more extensive, such as <ul style="list-style-type: none"> • Costs for paid mentoring (e.g., GROW) • Costs for training • Some transportation costs 3. Presents a very open door to the participant/potential participant. No required cost. No need for a payor. Open trial without commitment. 4. An ideal model for people contemplating action towards employment or education 5. Can serve as a niche for people contemplating work or a source of social, instrumental and practical support for people with disabilities seeking to maintain employment. 	<ol style="list-style-type: none"> 1. Some professionals and non-professionals do not automatically trust self-help, so awareness and willingness to attend is far from automatic. 2. Self-help groups need an appropriate model, and trained facilitators willing to follow/enforce that model, in order to be effective. 3. Despite all good intentions, self-help groups sometimes become settings where misinformation is spread. 4. Absent economic supports, self-help groups may lack things which some people with disabilities may need, like: <ul style="list-style-type: none"> • Transportation • Sign language interpreters • Materials in Braille 5. Self help groups are limited in what they can do. They are not set up to provide vocational assessments, one-on-one counseling, job development, job coaching, assistive technology, or any of the other things job seekers with disabilities need during preparation and action. 	<ol style="list-style-type: none"> 1. Thousands of self-help groups meet in our states every month, including mental health groups (like <i>Recovery International</i>), addiction groups (like <i>Alcoholics Anonymous, Dual Recovery Anonymous</i>), specialized bereavement groups (like <i>The Compassionate Friends</i>), and support groups for people dealing with various kinds of disabilities. 2. Self-Advocacy Groups in New York State, <i>which support individuals with developmental disabilities</i> 3. New Jersey's <i>Peer Employment Support</i> groups are an example of self-help groups focused on employment. 4. Cross Disability Peer Support Group on Employment (<i>e.g., Independent Living Center of the Hudson Valley, Inc.</i>)

MODEL: PEER OPERATED SERVICES

Pros	Cons	Examples
<p>Can offer the full continuum of employment-related services which could be offered by any provider agency, including the ability to take many forms of payment, including <i>Tickets to Work</i>.</p> <p>Have the added credibility to service recipients brought by having staff and leadership with lived experience.</p> <ol style="list-style-type: none"> Should be able to develop/maintain a culture which helps dispel the backlog of negative experiences some service recipients have had. 	<ol style="list-style-type: none"> Are not available everywhere, therefore may require <ul style="list-style-type: none"> funding to develop time to grow to strength and credibility systemic effort to create credibility. Being peer-operated is no guarantee that the service uses current best practices. Clubhouses often cling to transitional employment. Some ILCs have sheltered work, etc. 	<ol style="list-style-type: none"> Peer-run service agencies like <i>Collaborative Support Programs-NJ</i> Social Clubs Peer-managed mental health clubhouses Independent Living Centers in New York State. Many local affiliates of <i>Mental Health America</i>. Our Own Experiences as Teachers of <i>SANYS</i> The Job Club of <i>Mental Health Peer Connection- WNYIL</i>. <i>We Can Work/We Can Save Campaign/NYAPRS</i>. Peer Bridger Program of <i>NYAPRS</i>.

MODEL: PEER PARTNERSHIPS

Pros	Cons	Examples
<p><u>Peer presence on agency governing bodies</u></p> <p>Should help agencies develop/maintain a focus on recipient needs and credibility among recipients.</p> <p><u>Self-help groups under a professional-run agency umbrella:</u></p> <ol style="list-style-type: none"> 1. Should have all of the capacity and credibility of a peer-run self-help group. 2. Added access to resources and clientele. 3. Natural continuum and complement of service/support <p><u>Peer Volunteers providing added services at provider agencies</u></p> <ol style="list-style-type: none"> 1. Volunteers add capacity. 2. Peer volunteers add credibility and empathy. <p><u>Peer-run program in a provider agency, such as drop-in centers/resource centers:</u></p> <p>Should result in adding capacity, credibility, and empathy to the agency continuum.</p>	<p><u>Peer presence on agency governing bodies</u></p> <p>Creates risks of:</p> <ol style="list-style-type: none"> 1. Low retention in board roles, unless resources are allocated of mentoring, transportation, etc. as needed. 2. Non-representative peer presence. 3. Relegation of peers to an advisory board or community board status, rather than a governing board. <p><u>Peer Volunteers providing added services at provider agencies</u></p> <p>Seeking work from people without paying them can be a message of devaluing service recipients to current and potential clients and to the larger community.</p>	<ol style="list-style-type: none"> 1. Employment Peer Panel of <i>MHA Rochester.</i> 2. “Keep on Track” of <i>MHA Rochester.</i> 3. Monthly Employment Lunches of <i>St. Joseph’s Hospital Health Center.</i> 4. “Grapevines” Retail Training Club of <i>Clearview/Potpourri Social Club.</i> 5. Friends of Independence Tours of <i>Independent Living Center of Newburgh</i>

MODEL: PEERS AS PROVIDERS

Pros	Cons	Examples
<p>Can only enhance regular provider agency services through credibility and empathy.</p> <p>Peer employees in specialized roles, such as navigator, recovery coach, job coach, etc. should result in enhanced capacity, credibility and empathy.</p>	<p>Creates risks of salary disparity, role disparity, etc. which need to be managed carefully.</p>	<p>Peer Employment Specialists</p>

Value, Benefits and Roles of Peer Support

Key informants provided their perspectives regarding what they believe is the advantages, and values that peer providers with disabilities can offer. These advantages may be associated with the bonding function of social capital. Several participants shared that having been through the “lived experience,” gives providers with disabilities an advantage in gaining trust: “I have been disclosing that I am a consumer. There is a trusting relationship that is developed. It seems to be most successful when people share life experiences.” Trust seems to facilitate engagement as reported by the following excerpt “(Being peers,) clients are more engaged and less fearful. They see us as equals.” Another participant commented that peers are in a unique position to engage and encourage those who are not yet thinking about work. Some participants felt that because of the shared experience, peer providers may be better at bringing the “human element” to the service, helping the client feel less like a subject or a number in a quota.

Key informants also provided their perspective regarding the key areas, benefits and unique roles that peer providers with disabilities can offer. These include:

- a) role modeling and hope building
- b) emotional support
- c) being able to share valuable information and being able to assist with systems navigation and advocacy, and
- d) facilitating social capital building

Informants described how peers provide role modeling and hope building when providing employment support. Several indicated that having the “lived experience” offers credibility. The following responses illustrate this statement: “It’s important to get advice on overcoming barriers, but also valuable to see that it’s been done.” As examples of success, providers with disabilities are inspirational as well as credible. “When you see people with disabilities working, you think you can work too.” Similarly, a participant noted that the peer relationship between provider and person served can encourage a work ethic and positive attitude. One participant commented that these elements: “the trust, credibility, engagement, and acceptance are valuable to encourage a person with disabilities to ‘take the next step’ towards employment.” Also, “A supplemental advantage of being a peer is that they can relate and share their own experiences related to empowerment and hope building.”

Emotional support was frequently mentioned as a role of peer providers. The bonding that occurs between peers sets a foundation for emotional support which is evidently valuable to people with disabilities when seeking employment. In the meetings and interviews, fear and anxiety were emphasized as barriers to employment. One ILC provider listed emotional support and validation as one of the most valuable aspects of peer support. “It’s

so important to know you're not alone." Another informant shared that the peer relationship can help build coping skills.

Another advantage of peer providers as reported by informants is *informational support*. The peer provider's acquired knowledge of systems navigation and available resources that comes with the lived experience can be shared with a peer they are assisting/serving. A participant from one of the mental health agencies spoke of one of his co-workers who has a disability and "goes above and beyond what is expected to ensure that he is not overpaying and gets the maximum from his benefits." Having his own well-being at stake, this provider has learned strong techniques and strategies to work the system which he can now share with his clients. Providers who have been through the lived experience are also in a legitimate position to give their experiences related to managing their disability and employment, issues such as disclosure.

Providers with disabilities are also at an advantage to serve the bridging function of social capital needs for employment. Interview responses indicated that the peer relationship and the shared experiences and frustrations can ease the feeling of isolation, demonstrating to the client that they are not alone in their struggles. As one peer provider shared: "It's so important to know you're not alone." Also, several participants asserted that peer providers may be more likely to have *networking connections* that would be valuable for employment. Exemplifying the value of social networking, a self-advocate commented: "Each person has their own experience, but all together we can have a network to help share information."

While many participants acknowledged the value of social capital and its importance for employment, few initiatives or strategies were mentioned for "bridging" individuals to organizations, community members and social networks outside of the disability community. An independent living center highlighted their "Friends for Independence" community awareness and networking strategy. This program has the main purpose of creating bridges between individuals with disabilities and the community at large through education of and networking with community-based organizations, financial institutions, and employers. Banks, schools, community providers, and human resource staff, among other groups, participate in an informational and networking gathering on different disability-related topics, including personal stories of people with disabilities. In the opinion of the administrators of this Independent Living Center, the program has had significant success at engaging organizations and institutions not part of the "disability" system through newspaper advertisements and "word of mouth" strategies. Thus, this program contributes to individuals with disabilities achieving employment and community integration by increasing awareness about the contribution and potential role of people with disabilities in the community and expanding their social connections.

Nevertheless, a participant from a mental health agency noted a barrier to programming aimed at improving social capital. This interviewee indicated that there are no funding streams to support services that focus on building social capital. It may be worthwhile for

fundors, policy makers, administrators, and advocates to examine how existing services can enhance social capital or how new programs can be developed and funded.

Peer support can be a vehicle for solidarity and mobilization towards employment. Along these lines, peers can have a role in advocacy and education for changing attitudes and perspectives of the greater community which may serve as barriers to social networking and social as well as economic integration of people with disabilities. For example, several participants noted that people with disabilities can have the role of educating providers about the capabilities of people with disabilities and arguing the "business case". As one participant stated, "Only people with disabilities can show all the roles we can fill" –to change the image of what people with disabilities are capable of. This may happen by peers disclosing their disabilities to employers, and appears to fit a much broader definition of peer support.

Recommendations

Building a Peer Support Model: Principles, Roles and Competencies

The following are *principles, roles and competencies* for a peer employment support model based on data gathered through interviews and meetings in NYC and Albany.

Guiding Principles: Peer Employment Support Service (PESS)

Cross-disability: The separation of different disability groups (e.g., physical disabilities vs. psychiatric vs. developmental) has responded at least in part to the fragmented services that support individuals with disabilities. Efforts to expand and strengthen peer support must consider a cross-disability framework. Many individuals have multiple disabilities, and have ended up in a particular system as a result of bureaucratic reasons (e.g., someone determining that they "belonged" more in the mental health than developmental disabilities system). Many of the existing systems do not serve well people whose disabilities cross neat categories. Also, the interaction between people with multiple disabilities has the potential of creating identification with the inspiring experiences of overcoming challenges and not identifying with a particular disability. PESS should be able to serve the full spectrum of disabilities. PESSs recognize that while some services vary based on the disability of the person served, and may require specialized personnel or assets; many issues are common across disabilities. There should be a heightened awareness of diversity **and** commonality among people with disabilities; people with different disabilities but many of the same struggles- can share skills and resources, can be inspiring. The common bond is the shared experience of seeking and maintaining employment. Believe that work is possible and no one is unemployable.

Diversity: There is a great of experience and knowledge accumulated through decades of providing general peer support, and peer support with the goal of employment, across all disability groups. Different organizations and disability groups have explored diverse strategies and methods to providing peer support (e.g., peer-mentoring, job clubs, certified peer specialists, self-advocacy groups). A cross-disability effort ought to recognize and

build upon the wealth of experience and information and seek ways to integrate multiple strategies that can together create a more comprehensive and effective approach.

Role Modeling: Peer supporters serve as role models for other people with disabilities who are seeking or maintaining employment. Many members of the peer support or recovery advocacy community have been working for a long time. Role modeling is a key aspect of peer support. Peer supporters can be both provocative and challenging, and therefore help people to think about employment, career goals, self advocacy, etc. Role modeling can be explicit by assuring employment opportunities for people with disabilities throughout the organization. Any hiring of people without disabilities, or contracting for services to a company that is not owned and operated by people with disabilities must be clearly justified by the inability to get the needed skill, credential, or service within the disability community. Purchasing and contracting should make maximal effort to use vendors who are demonstrably friendly to people with disabilities.

Complements Professional/Clinical Supports: Peer support and professional/clinical services should complement each other. Supports provided by individuals that have the lived experience of overcoming disability have a unique and distinct role. Some people may need rehabilitative services such as habilitation services, benefits advisement, occupational therapy, and vocational counseling) which are unlikely to be initially available from a PESS. People who need the services of physicians, therapists, etc. to deal with the medical aspects of their disability will probably find the need to get these services outside of peer support.

Individualized and Strengths-Based: Individuals with disabilities who will provide peer support/services must receive support to determine the most effective role they can assume (e.g., panelist, group facilitator, systems advocacy, job coach), and a person-centered plan to develop the necessary competencies/training process to be successful at fulfilling such role(s). Disability should not be viewed as disabling.

Person-centered: PESS services are aimed at the employment outcome desired by the person served. This means that decent effort can be invested in helping people establish preferences and desires, but that the desires of anybody other than the person served should have minimal impact on the services delivered. Programs recognize that people have varying desires in terms of full-time employment and leaving public benefits versus working and maintaining benefits. Benefits counseling is always available.

Accessibility: Services should be accessible to all residents regardless of economics, and not make SSA or VESID funding and eligibility a prerequisite for services. This also means serving

- people who might be ineligible for various Government funding due to rejection of treatment, criminal convictions, etc.
- people in jails/prisons, institutional or developmental centers, and closed rehabilitation programs

- transition-age youth.

Integrated Competitive Employment is the Goal: PESSs should make integrated competitive employment (including self-employment) in the community the primary objective. This is not to say that schooling, volunteer work, or unpaid internships might not be “stops along the way” for some people served.

Supportive of Challenges of Getting and Keeping a Job: The experience of losing a job is extremely traumatic for any individual. For individuals with disabilities who may not be afforded with many opportunities in life to demonstrate our potential, this can be particularly traumatic. A large number of people with disabilities who are currently unemployed and/or have limited hope about their ability to achieve employment are individuals who lost a job have not been supported to try again, and/ or have become paralyzed by that experience of loss. PESS welcome people who are at any point of getting, keeping, leaving, or mourning a job. Any PESS services which have the potential to have waiting lists will offer “expedited re-entry,” so that someone who has lost a job, or could use some services to prevent job loss or plan job change, does not need to wait.

Maintain an Advocacy Agenda focused on Community Change: PESSs recognize the stigma and public prejudices associated with disabilities and make maximum effort to help dispel these. PESSs recognize that helping people join the integrated workforce, and participate in their communities in other ways, play an important role in reducing communal prejudice and stigma. PESSs reject the notion that people with disabilities are primarily suited to secondary labor market employment.

Collaboration: We consider it important to collaborate with other supports identified by the person receiving services. This may include family, friends, residential or other treatment providers, Government funders, schools, and employers/potential employers. PESSs recognize that collaboration between employment service and treatment service can maximize outcomes for many people, and do so with the person’s permission. In all cases (especially when someone other than the person served has decision making authority, such as a guardian), we advocate for the person being served.

No Wrong Door: PESSs recognize that many people have been frustrated by the complexity of getting employment help, and follow a no-wrong-door approach to the maximum extent possible. This can include:

- advertising, informational briefings, and support groups in the community so that people can find their way to a peer employment support service,
- working with existing service providers (employment, disability, treatment) so that people who get services as those settings can become aware of the PESS, and
- ensuring that people served are helped to use other services, not just sent to the service.

Access to On-Going Flexible Supports. We recognize that people's needs change over time. Services should be time-unlimited, and also allow people who have left services due to not having an interest in employment, having obtained stable employment, experiencing institutional stays, etc. rapid re-entry to active service. PESSs recognize that fragmented services over time are a frustration for many people. PESSs will be organized so a person has a primary person the work with who will help him or her during intake, active service delivery, and follow-up (*continuity*).

Holistic Approach: We recognize that employment is not an isolated segment of a person's life. Efforts should be focused on helping a person to access the resources (transportation, education, etc.) they need to achieve and maintain employment, and also to help a person maximize their desired outcomes in terms of physical health, housing, community and family integration, etc. PESSs should also recognize that people receiving services often have a backlog of negative experiences regarding employment, social control, and stigma, and may have experienced actual trauma as a result of these. Services are delivered in a way that respects the negative experiences people have had. We also recognize that a key skill people who move out of poverty need is financial competence.

Roles: Peer Employment Support Service (PESS)

The findings of this project suggest that PESS can support individuals in the process of obtaining and maintaining employment through multiple roles:

a) Role modeling and hope building: Peer facilitators are uniquely positioned to build hope among other individuals with disabilities about their potential to achieve employment and career aspirations. Peer facilitators can do so through role modeling, i.e., by showing by example that it is possible for a person with disabilities to work. When appropriate, peer facilitators can also utilize their own stories of employment success and motivate individuals with disabilities to become aware about the ways in which their own narratives (the stories we tell ourselves) "get in the way" of taking at chance at work. Part of this role is assisting individuals to explore their employment, self-employment and/or career aspirations through conversations and/or exercises that foster discovery.

b) Providing emotional support: Peer facilitators also have a key role in sharing experiences and frustrations as well as coping methods that may help individuals to overcome anxieties related to the pursuit of work and/or job performance. One of the ways in which peer facilitators can be most helpful is by strengthening the "bonding" social capital of individuals, such as by letting individuals supported know they are not alone and that others have navigated through similar waters.

c) Providing information and assisting with systems navigation and advocacy: A key role stated by many informants was that of a *general navigator, liaison, and prime contact* (the Albany focus group identified the need both for navigation assistance and for a primary contact with continuity). This role would also include maintaining contact and collaboration as requested by the person with the person's

other support services. Here are some of the concrete tasks that peer facilitators can be helpful with:

- Sharing information about resources and opportunities that assisting individuals exploring work options and discovering preferences
- Building awareness about work incentives available for people with disabilities to transition to work
- Assisting individuals in finding and using academic and non-academic training to meet their career goals.
- Assisting individuals to access transportation, programs that provide train about the use public transit, and support to get vehicle modifications associated with employment goals.
- Being an advocate for and with (encouraging the person to become a self advocate, and help others articulate their employment pathway, so they can establish an identity as worker.)
- Advocating for and with a person with VESID and other entities to get financial and other supports.
- Connecting people to people and resources outside of the specific service agency
- Liaison to colleges or other settings.

d) Facilitating social capital building: Peer facilitators can support individuals to expand their social networks in order to have stronger access to information, resources, employment/volunteering connections and leads, ongoing support to maintain employment, and opportunities for professional advancement. Peer facilitators can do so by connecting people to more diverse faith and non-faith based social networks (e.g., churches, community centers, Lions Club, Rotary Club) or simply by introducing them to individuals in the community who may have common interests or goals.

Peer facilitators can fulfill these roles in one-on-one and group settings with varying levels of formality. For instance, peer facilitators can meet individuals supported in their homes and community settings (e.g., via phone, coffee houses, parks). They can also leading peer employment support groups with a myriad of goals, such as helping people with disabilities consider employment/education choices, make needed changes to secure and maintain employment, provide emotional support, or offer strategies to expand social capital.

Roles of Peers as Providers

Peer as providers can also fulfill multiple professional roles. The unique value of peer providers is the ability to merge technical information and skills with the personal lived experience thus services and supports providing. Some of the areas in which peer providers can be helpful are:

- Benefits advisement: Fear of losing benefits and not being able to self-support is one of the main reasons why people with disabilities do not attempt employment. Benefits advisement is one of the roles that peer providers have assumed. Peer providers who offer benefits advisement not only bring their technical expertise and training about work incentives, but also their own personal experience of utilizing those resources and, most importantly, navigating a complex system.
- Job development, either as a result of a specific person's employment goals and needs or in a job development team.
- Specific assistance in the pre-employment (job search and interview), employment (visible or invisible coaching), and job termination phases.
- Administrative and support roles, such as program evaluation.

Competencies: Peer Employment Support Service (PESS)

People with disabilities providing support to other individuals with disabilities can do so through multiple roles (as described above). This requires that individuals providing support/provider develop some general competencies and also specific competencies according to the more specific role that they may take. For instance, it is important that all people with disabilities sharing their personal experience as part of the provision of support are capable of reflecting about their personal story and communicating it in ways that build hope and inspire in others. Also, it may be important for all individuals promoting employment to have some basic knowledge of work incentives and/or the organizations that can provide specialized advice. However, only those providing case-specific benefits advisement need to be competent in benefits counseling.

Recognition and Utilization of Personal Strengths and Abilities: Individuals with disabilities who will provide peer support/services must be able to recognize their assets and limitations to determine the most effective role they can assume (e.g., panelist, group facilitator, systems advocacy), and have a person-centered plan to develop the necessary competencies/training process to be successful at fulfilling such role(s).

Knowing Responsibilities and Setting Boundaries: When providing peer support, individuals must be clear on what their roles are. Individuals must be able to recognize where to draw the line between helping and enabling.

Sharing Personal Stories of Employment Success: To fill the role of hope-building and narrative change when providing peer support for employment it is helpful for the peer to use examples of their own success and experience. This requires the peer to be comfortable

with their disability and to be aware of how their own experiences may apply and inspire. When sharing personal stories, individuals must recognize that their own experiences and situations may not be exactly the same as the person they are sharing with (e.g., if they had a bad experience with an organization, not everyone may have negative interactions with that organization). **Not exactly sure how to word this section.**

Working knowledge of community resources: It is helpful if individuals providing peer employment support are aware of the resources available in their communities. Providers/facilitators do not have to be experts or have information in all areas, but it is essential that they can offer information about who/where individuals supported can obtain specialized or more details information.

Competencies for Peers as Professionals

People with disabilities often provide peer support in professional positions. A valuable competency for this scenario is to be able to weave personal experience with technical knowledge. Having been through the lived experience, people may be fit for a professional position of assisting others with disabilities in employment. However, individuals with disabilities who become providers need to have the same technical competencies/expertise as non-disabled individuals necessary to fulfill the expectations of the role. For example, an individual with the peer experience who takes the role of a job coach ought to have the training necessary for job coaching.

When acting as professionals, peer employment support personnel might be individuals with additional training in one of the following areas:

- a. Vocational assessments
- b. Self employment
- c. Job development (with possible subspecialists in education, healthcare, human service, etc.)
- d. Adult education and technical schools
- e. Computer skills and distance learning
- f. ADA rights
- g. Benefits advisement
- h. Transportation
- i. Specific needs, accommodations, and assistive technology – all disabilities
- j. Specific needs, accommodations, and assistive technology for people with hearing impairments. This person would need to be competent in ASL.

- k. Specific needs, accommodations, and assistive technology for people with visual impairments. This person would need to be competent in Braille.
- l. Specific needs, accommodations, and assistive technology for people with brain injury and developmental disabilities
- m. Specific needs, accommodations, and assistive technology for people with psychiatric disabilities
- n. Spanish speaking Program assessment and evaluation
- o. Program marketing
- p. Funder relationships

Recommendations for policy-makers, providers and advocates

The recommendations of this report are aimed at the following stakeholders:

1. state administrators and policy makers, to seek funding, establish and enforce regulations, etc.
2. cross-disability providers and disability specific providers, to identify ways in which to adapt recommendations to their own agencies and programs,
3. systems advocates, to compel the system to make needed changes, and advocate for services and encourage individuals with disabilities to utilize peer support, consistent with the findings of this report.

State administrators and policy makers:

Create opportunities for inter-agency integrated funding (e.g., VESID, OMH, OMRDD) of peer employment and self-employment support initiatives that allow peer providers to support individuals across disabilities independent of the primary source of funding. This would help overcome the silo-like funding structure and increase the effectiveness of resources available as it is more cost-effective to fund cross-disability peer support activities than in silos.

Create opportunities for synergy between the activities of peer employment support services and DOL-Disability Program Navigators (DPNs). The DPN program was developed to create and/or strengthen the connections between employment supports for people with disabilities to help individuals navigate a complex workforce system. Peer employment support can complement the work of DPNs by providing direct “on the ground” navigation.

Demonstrate the effectiveness of a peer employment support service in helping individuals overcome the fragmentation of services by providing individuals with continuity of services and not letting them “fall through the cracks” of the system. This could be done by supporting a few communities to strengthen their peer employment support activities and fostering the interagency collaboration and cooperation.

OMH, OMRDD, DOH, and VESID ought to provide existing programs with mandates and incentives to help people with disabilities expand their social capital.

Cross-disability providers and disability specific providers:

1. Ensure that social capital/social networks is an area of assessment and service planning for all individuals with disabilities (i.e., all people must be afforded the opportunity to identify their networks of support and connections and strategies to expand their social capital)
2. Provide opportunities for people served to access peer employment support across all phases of services (e.g., engagement/first contact, discovery/planning, service delivery, progress review). This would ensure that peer support is provided to facilitate effective engagement, meaningful planning, quality services, etc.
3. Develop strategies to enhance the ability of peer support activities to improve the social capital of people with disabilities towards employment and self-employment (e.g., networking activities with the community at large).

Systems Advocates/grassroots disability organizations:

Establish a cross-disability advisory committee for a cross-disability peer employment support campaign. The purpose of this advisory committee will be to guide the development of strategies and tools to be made available to people with disabilities providing peer employment support services, and serve as a cross-disability advocacy force.

Support peer-operated programs to access the Social Security Administration's Ticket to Work (TTW) funding. This funding stream is an untapped resource that can cover a myriad of peer support services aimed at helping individuals obtain and maintain competitive employment, which could complement funding received from state programs. Statewide organizations (e.g., NYAPRS, NYAIL) could assist to develop networks of peer provider programs to minimize the administrative costs involved in TTW reimbursements, access to training and consultation infrastructure.

Build collaboration with the goal of establishing a cross-disability grassroots employment campaign modeled after the "We Can Work" campaign that brings together all statewide peer-operated organizations, such as NYAIL, NYAPRS, SANYS, etc.

Next Steps

1. Convene a cross-disability advisory committee to flesh out a peer employment support model, designed to be an efficacious (i.e., efficient *and* effective) way to improve the proportion of New Yorkers with disabilities who become and remain employed. The key elements of this model have been described in this report. This peer support model could be implemented in either of two contexts: (1) as a limited service designed to provide support and mentoring, offer information and navigation support, and foster social networks, as a complement to more traditional VR services (in a self-help model or a peer-operated program); or (2) as a full disability employment service, known as a Peer Employment

Support Service (PESS). The latter could cover not only aspects specific to peer support in its “pure” form (e.g., role modeling, emotional support) but also specialized services delivered by individuals with disabilities (e.g., job development, benefits advisement).

2. Develop tools for peer employment support facilitators/providers. One of these tools can include a Peer Facilitator Guide describing the principles, roles, and competencies involved in providing effective peer employment support. Another tool can entail a web-based peer support resource modeled after the one developed by Columbia University’s Workplace Center (and maintained by the Empowerment Center), or other media such as Facebook.
3. Pursue funding stream to conduct a demonstration project to assess the effectiveness of peer employment support in helping individuals navigate the complex and fragmented system of employment and self-employment services. This demonstration could entail supporting a few communities to strengthen their peer employment and self-employment support activities and fostering the interagency collaboration and cooperation, and thus ensure that individuals receiving services from multiple systems are effectively referred and counter-referred.
4. Disseminate the findings of this report through media that effectively addresses the priorities and concerns for state administrators, systems advocates, providers, and people with disabilities; and in ways that provide these multiple stakeholder groups with clear suggestions and actions steps.

Suggested Next Steps – Work Plan Summary

Strategy	Actions	Outputs (and time required)	Responsible
Convene cross-disability advisory committee to flesh out PES model	<ul style="list-style-type: none"> • Follow up with 60 + peer providers and advocates who participated in this project • Reach out to grassroots disability organizations not involved in the first phase (e.g., Empire State Association for the Deaf) • Identify advocates willing to commit to participate in the advisory committee • Convene peer advocates to present results of this projects, and to serve as a kick off meeting for advisory committee 	<ul style="list-style-type: none"> • Letters of invitation sent out to all peer providers and advocates identified (1-2mos.) • Advisory committee’s first meeting (2-3 mos.) • Advisory committee’s kick off meeting and presentation of project results (3-4 mos.) 	NYAPRS NYAIL SASNYS Other grassroots organizations TBI
Develop peer employment support tools/resources	<ul style="list-style-type: none"> • Advisory committee to decide which tool/resources will be created as cornerstones for the peer employment support model • Advisory committee to outline content • Identify group capable of developing tool • Advisory committee to oversee development of tool/resources 	<ul style="list-style-type: none"> • First tool/resource for cross-disability peer employment support is developed (6-9 mos.) 	NYAPRS NYAIL SASNYS
Secure funding and support for demonstration project	<ul style="list-style-type: none"> • Approach MIG and other funding sources to • Identify 3-4 sites across NYS and disability groups to implement demonstration project 	<ul style="list-style-type: none"> • Funding (3-6mos.) • Work plan for demonstration finalized (3-6 mos.) 	
Disseminate findings	<ul style="list-style-type: none"> • Develop three briefs on peer employment support for (1) state administrators; (2) providers; (3) advocates and people with disabilities 	Briefs on Peer Employment Support published (3-6mos.)	MIG NYAPRS

REFERENCES AND RESOURCES

American Community Survey (2008). Retrieved on January 4, 2010 from www.euro.who.int/DOCUMENT/E81384.pdf

Bakker, A., Demerouti, E., Shuffler, W. E., & Xanthopoulou, D., (2009). Work engagement and financial returns: A diary study on the role of job and personal resources. *Journal of Occupational & Organizational Psychology*, 82(1), 183-200. Retrieved from Academic Search Complete database.

Bertrand M & Mullainathan S (2003). Are Emily and Greg More Employable than Lakisha and Jamal? A Field Experiment on Labor Market Discrimination. Poverty Action Lab Paper No. 3 (January). Retrieved on January 2, 2010, from www.povertyactionlab.org/papers/3_Mullainathan_Market_Discrimination.pdf.

Bjelland, M. J., Erickson, W. A., Lee, C. G. (2008, November 8). *Disability Statistics from the American Community Survey (ACS)*. Ithaca, NY: Cornell University Rehabilitation Research and Training Center on Disability Demographics and Statistics (StatsRRTC). Retrieved December 28, 2009 from www.disabilitystatistics.org.

Carter, E. W., Hughes, C., Guth, C. B., & Copeland, S. R. (2005). Factors influencing social interaction among high school students with intellectual disabilities and their general education peers. *American Journal of Mental Retardation*; Sep;110(5) :366-77.

Condeluci, A., Ledbetter, M., Ortman, G., Fromknecht, J., & DeFries, M. (2008). Social Capital: A View from the Field. *Journal of Vocational Rehabilitation*, 29 133–139

Davidson, L., Chinman, M., Kloos, B., Weingarten, R., Stayner, D., & Tebes, J. K. (1999). Peer support among individuals with severe mental illness: A review of the evidence. *Clinical Psychology: Science and Practice*, 6, 165-187.

Department of Health and Human Services. (2006). *National Consensus Statement on Mental Health Recovery*. Rockville, MD: Substance Abuse and Mental Health Services Administration, U.S. Department of Health and Human Services.

Doughty, C., & Tse, S. (2005). The effectiveness of service user-run or service user-led mental health services for people with mental illness: A systematic review. 2005; A Mental Health Commission Report; Mental Health Commission, Wellington, New Zealand.

Fleischer, D. (2001). *The Disability Rights Movement*. Philadelphia: Temple University Press.

Fremstad, S (2009). Half in Ten: Why Taking Disability into Account is Essential to Reducing Income Poverty and Expanding Economic Inclusion. Paper published by the Center for Economic and Policy Research, Washington, DC.

Granovetter, M. 1974. *Getting a Job*. Chicago.

Haring, T., & Breen, C. (1992). A peer-mediated social network intervention to enhance the social integration of persons with moderate and severe disabilities. *Journal of Applied Analysis*, 25, 319-333.

Knox, M. & Parmenter, T. R. (1993). Social networks and support mechanisms for people with mild intellectual disability in competitive employment. *International Journal of Rehabilitation Research*; 16(1):1-12.

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- Lippold, T. & Burns, J. (1999) Social support and intellectual disabilities: a comparison between social networks of adults with intellectual disability and those with physical disability. *Journal of Intellectual Disability Research*; May;53(5):463-73.
- Mead, S., & MacNeil C., (2006). Peer support: What makes it unique? *International Journal of Psychosocial Rehabilitation*, 10 (2), 29-37.
- McGill, C. W., & Patterson, C. J. (1990). Former patients as peer counselors on locked inpatient units. *Hospital and Community Psychiatry*, 41, 1017-1019.
- Mowbray, C. T., & Moxley, D. P. (1997). A framework for organizing consumer roles as providers of psychiatric rehabilitation. In Mowbray, C. T., Moxley, D. P., Jasper, C. A. & Howell, L. L. (Eds.), *Consumers as Providers in Psychiatric Rehabilitation* (pp. 35-44). Columbia, MD: International Association of Psychosocial Rehabilitation Services.
- National Organization on Disability (NOD), *2004 NOD/Harris Survey of Americans with Disabilities (2004)*.
www.nod.org/index.cfm?fuseaction=Feature.showFeature&FeatureID=1422 (accessed 1.8.10)
- Parris, A.N., & Granger, T. (2008). The power and relativity of Social Capital. *Journal of Vocational Rehabilitation*, 29, 165–171
- Pelka, F. (1997). *ABC-CLIO Companion to the Disability Rights Movement*. Santa Barbara, California: ABC-CLIO, Inc.
- Potts, B., (2005). Disability and employment: considering the importance of social capital. *Journal of Rehabilitation*, 71 (3), 20-25.
- President's New Freedom Commission (2003). *Achieving the promise: Transforming mental health care in America. Final report*. (DHHS Publication No. SMA-033832.) Rockville, MD: Substance Abuse and Mental Health Services Administration.
- Putnam, R., (2000). *Bowling Alone: The Collapse and Revival of American Community*. Simon & Schuster Paperbacks. New York.
- Schmidt, L. T., Gill, K., Solomon, P., & Pratt, C. (2008). Comparison of service outcomes of case management teams with and without a consumer provider. *American Journal of Psychiatric Rehabilitation*, 77, 310-329.
- Schaefer-McDaniel, N. J. (2004). "Conceptualizing Social Capital among Young People: Toward a New Theory." *Children, Youth and Environments* 14(1): 140-150.
- Sherman, P.S., & Porter, R. (1991). Mental health consumers as case management aides. *Hospital and Community Psychiatry*, 42, 494-498.
- Siisiäinen, M. (2000), Two Concepts of Social Capital: Bourdieu vs. Putnam, Paper presented at ISTR Fourth International Conference The Third Sector: For What and for Whom? Trinity College, Dublin, Ireland, July 5-8.
- Solomon, P. (2004). Peer support / peer provided services: Underlying process, benefits and critical ingredients. *Psychiatric Rehabilitation Journal*, 27(4), 392-401.
- Solomon, P., & Draine, J. (2001). The state of knowledge of the effectiveness of consumer provided services. *Psychiatric Rehabilitation Journal*, 25(1), 20-27.
- Swarbrick, M. (2009a). Collaborative support programs of New Jersey. *Occupational Therapy in Mental Health*, (25), 224-238.

Swarbrick, M. (2009b). Designing a study to examine peer-operated self-help centers. *Occupational Therapy in Mental Health*, (25), 252-299.

Swarbrick, M., Bates, F., & Roberts, M. (2009). Peer employment support: A model created through collaboration between a peer-operated service and university. *Occupational Therapy in Mental Health*, (25), 325-334.

Swarbrick, M., Schmidt, L., & Gill, K. (2009). *Persons in Recovery as Providers: The Wisdom of Experience*. United States Psychiatric Rehabilitation Association.

Wilkinson, R., & Marmot, M. (2003). *Social determinants of health: the solid facts, 2nd edition*. World Health Organization Regional Office for Europe.

Wojciechowska, A, Walczewski, K., & Cechnicki A (2001). Correlations between some features of social networks and treatment outcome in patients with schizophrenia three years after initial hospitalization. *Psychiatria Polska; Jan-Feb;35(1):21-32*.

Zippay, A (2001). The Role of Social Capital in Reclaiming Human Capital: A Longitudinal Study of Occupational Mobility among Displaced Steelworkers. *Journal of Sociology & Social Welfare* 28, no. 4: 99-119. Academic Search Complete, EBSCOhost accessed December 11, 2009.

APPENDIX I - Participating Programs and Organizations

New York Association on Independent Living - NYAIL (n=2)

Independent Living Centers (n=23)

- Independent Living (Newburgh) (11)
- Western New York Independent Living Project (Buffalo)
- Harlem Independent Living (2)
- Bronx Independent Living Services
- Independent Living Center of the Hudson Valley (Troy) (2)
- Finger Lakes Independent Center (Ithaca)
- Catskill Center for Independence (Oneonta) (2)
- New York City Center for Independent Living (Manhattan)
- Taconic Resources for Independence (Poughkeepsie)
- Southern Tier Independence Center (Binghamton)

Self-Advocacy Association of NYS and DD providers (n=18)

- SANYS - Board of Directors (12)
- SANYS - Regional Coordinators (3)
- SANYS - Special Projects Assistant – Policy Advocacy
- SANYS- Self-advocate
- ADD (Long Island)

New York Association of Psychiatric Rehabilitation Services (n= 2)

Mental Health Association of NYS (n=1)

Mental health programs (n=19)

- Baltic Street (NYC) (4)
- Community Access & Howie The Harp (NYC) (2)
- Clearview & Potpourri social club (Albany) (2)
- Fountain House (NYC) (2)
- Mental Health Association in Columbia-Greene (Hudson) (2)
- Mental Health Association in Rochester (2)
- MHEP Peer Networking Group – NYC (NYC)
- Liberty House (Glens Falls)
- Mental Health Peer Connection – WNYIL (Buffalo)
- NYAPRS Peer Bridger Program
- Saint Joseph's Hospital (Syracuse)

APPENDIX II - Interview Guide

Introduction

Thank you very much for participating in this project. This interview is part of a project sponsored by the New York State Medicaid Infrastructure Grant. The purpose of this project is to learn about the services and supports that people with disabilities provide to other people with disabilities in the area of employment. We are not looking for your personal experience, but rather your perceptions of these services. The information you give us today will help us write a report to the State about the services that people with disabilities provide and could provide to improve their employment outcomes.

We would like to encourage you to share your thoughts and opinions as honestly as possible. The findings and recommendations of this evaluation can make a difference in the services available for people with psychiatric disabilities in the future. We will not include in our report or any other document the names of the people who participated in the interviews or the names of agencies or programs unless we ask you for your permission. INSERT NAME (If there is someone assisting with notes taking) and I will take notes about this discussion.

Participating in this interview is absolutely voluntary, so please keep in mind that you can choose to stop this interview at any point. If your program funding or supports are related in any way to NYAPRS, the Office of Mental Health, VESID, or any state agency, be reassured that the services you provide will not be affected in any way whether or not you participate. State administrators or funders will be presented with general conclusions and will not be told about particular statements of any individual.

Before we start, do you have any questions?

Topics

Information about organization or program

- We understand that your agency ...(provides these services and supports)
 - Do you agree?
 - Are there any other services/supports that we did not mention?
 - More specifically, any other services/supports related to employment (e.g. job development, job coaching, advocacy, vocational rehabilitation and counseling)?
 - Are there any informal services/supports provided that you value which are not necessarily operationalized?
- In providing these services and support, with what other agencies, organizations, or providers does your agency collaborate with? And what is your relationship with them? (E.g. referrals, joint programs etc...)
 - More specifically, what other agencies, organizations or providers does your agency collaborate with that are not necessarily services for people with disabilities or services having to do with disabilities?

Information about peer-run services and peer support practices

- Of the services/supports we mentioned (under first bullet), which ones are provided by people with disabilities? And delivered exclusively by people with disabilities?
- What are the ways in which people with disabilities support one another to achieve employment?
 - In other words, what is their role in providing support for employment? Hope-building? Role modeling? Building social connections? Practical support (e.g., rides, filling out applications)?
- Through what means do people with disabilities support one another to achieve employment? In other words, how do they fulfill their role? One-on-one talks? Support groups?
 - Through what means do people with disabilities (positively) influence one another's perceptions of their own ability to achieve economic integration? (Use as probe if not already discussed)
 - What is the role of people with disabilities in helping one another to access further supports/services outside of the agency?
 - More specifically, what is the role of people with disabilities in helping one another to access supports/services outside the agency that are not necessarily services for people with disabilities? (Use if not already discussed)
- Of the roles that people with disabilities have as providers (e.g. hope building, connecting), which ones do you feel are the most valuable to those receiving the support?

Perceptions about employment and peer support needs

- What are all the services/supports that people with disabilities in your community need to successfully achieve employment?
 - More specifically, what are the types of employment supports people with disabilities need to be successful at achieving employment (e.g., employment connections, job development, job coaching)?
 - What are the types of clinical supports people with disabilities need to be successful at achieving employment?
 - What types of services/support do people with disabilities need to connect to other people and organizations outside of your agency to successfully achieve employment?
 - To successfully achieve successful employment, what types of services/supports do people with disabilities need to connect to people and organizations outside of your agency that that aren't disability services (wrap around supports)?
- In your opinion, what are the employment support needs of people with disabilities in your community that are not currently met by existing services/supports?
- Which of these needs can be best met by service providers with disabilities?
 - OR
- What are the support needs that people with disabilities can provide for one another?
 - Do you feel that these needs are being met?

Peer support model

- What are the types of support that people with disabilities can effectively provide for one another to achieve employment? Hope-building? Emotional? Social capital building? Networking? (e.g., introducing person to others, building relationships with community), Practical (e.g., rides, childcare)?
 - What types of services and supports can people with disabilities effectively provide for one another to connect with other people and organizations outside of the agency?
 - More specifically, what are the types of services/supports that people with disabilities can effectively provide for one another to connect with other people who are not disabled and other agencies and organizations that aren't disability services?
- What do you think can be done to enhance the supports that are available, and provide the supports that are not yet available?
- What are the competencies that people with disabilities who provide support to other people with disabilities need to have in order to be effective?

What types of tools and resources can improve the ability of people with disabilities to provide effective support to other people with disabilities?

APPENDIX III - Peer Support Practices Found in New York

Self-Help:

Cross-Disability Peer Support Group on Employment (Independent Living of the Hudson Valley): This peer support group was launched a few months ago with the purpose of creating a space for individuals with any type of disability to receive support in the process of obtaining employment (e.g. mutual encouragement, resume-building). While this group meets at the independent living center, the direction and agenda of its activities was determined by the group. At the time of the interview, this group was having difficulty in meeting on a regular basis and had decreased in number of attendees.

Cross-disability peer support groups (self-help): Multiple independent living centers described self-help groups. Some of these groups are run by individuals with disabilities, receiving support from the respective ILCs (for things such as meeting space) but are autonomous to determine their mission and ongoing programming. While these groups may have a general goal, employment is often an issue discussed in those groups. Some other support groups are facilitated by a staff person and in connection to other services provided by a program. For instance, a peer support group for people who are blind or visually handicapped hosted by the Independent Living of Newburgh. While the focus of this support group is on taking responsibility for personal wellness, employment is often a topic of discussion and mutual support.

Self-Advocacy Groups (SANYS): The Self-Advocacy Association of NYS is composed of over 200 self-advocacy groups across NYS, of which about 65 are located in NYC. These groups are very diverse in their focus, leadership and outreach, and have strong leadership and awareness about the key areas that affect the quality of life of people with developmental disabilities, such as housing, community inclusion, transportation, and employment supports. The strength of self-advocacy groups seems to be in their capacity to advocate for individuals to access services that can make a difference in their lives, and to collectively advocate for systemic/policy changes. Leaders and members of several self-advocacy groups discuss their concerns about, for instance, the overemphasis of the MRDD system on day habilitation programs and not on expanding employment supports and opportunities. Some other self-advocacy groups have a strong focus on issues that have an indirect but important impact on supporting the employment of members. For instance, an Albany area self-advocacy group has done extensive research about transportation resources and opportunities that could be expanded (e.g., vouchers, Capital District Transportation Authority-CDTA corporate “swiper” discount programs), and utilizing web-based resources to strengthen social networking and communication between peers and with other community members (e.g., Facebook).

Several self-advocacy groups in NYC are interested in leading a campaign that changes the perception of people with developmental disabilities as a burden to one that recognizes this community as a resource, contributors to local communities, and effective and loyal

employees. Considering these strengths, self-advocacy groups can serve as a key infrastructure for a campaign on employment as well as to disseminate information about resources and materials/resources developed under the Medicaid Infrastructure Grant.

Other Peer Support Groups: New York State is served by a variety of face-to-face peer support groups in mental health. Recovery International currently lists 69 groups in the state. 21 groups are listed by the Depression and Bipolar Support alliance. At least 20 other groups are available affiliated with NAMI Connection (or an earlier model known as NAMI CARE), Obsessive Compulsives Anonymous, and Schizophrenics Anonymous. While none of these associations follows a model where employment is the primary goal, it is “all but guaranteed” that any group session will include people seeking and getting support around resuming and completing educations, finding and keeping work, using vocational services and supports, and facing issues around benefits and employment trade-offs.

Peer operated services:

The Job Club (Mental Health Peer Connection- WNYIL): Mental Health Peer Connection's Job Club began in 2003. It is a program for people with serious mental illness. There are three components to the job club. 1) Assisting recipients overcoming their barriers to employment. 2) Educating mental health recipients on the impact a working wage will have on benefits such as SSDI and SSI. 3) Rapid employment placement by peers who do job searches in the Erie County Community.

Six staff members work in the Job Club. All providers are also individuals with psychiatric disabilities who provide peer counseling, advocacy, independent living skills, technical assistance, and information and referral. The Peer Counseling appears to be the most effective tool in assisting people with serious mental illness become employed. The Job Club has a zero exclusion policy, that is, if an individual indicates a desire to work, the program will support her/him to obtain employment as immediately as possible. Along with the services being provided, the program also provides financial resources for individuals to access interview/work clothes, work equipment, vocational classes, transportation, and personal grooming services as needed. The program also has six computer and phone stations that are specifically dedicated to the job club; used for job searches, applications, and resume writing.

An important component to this program is the Peer Support group held weekly for job club members. It is an open group. Issues of discussion include maintaining employment, keeping appointments and still working, getting a job, and spreading around possible job leads. The Peer Support group is non-traditional as it takes place in the evening and a homemade dinner is provided. This weekly peer support group has the goal of encouraging participants through the process of obtaining employment (e.g., discovery process/goal planning, job search, applications, preparing for/starting a job) and essential sharing of information to improve the likelihood of employment (e.g., job leads, connections, and general community resources).

This group is also attended by peer advocates and peers with benefits training in order to ensure that participants can obtain more technical information/problem-solving if necessary. The Vocational Peers share their experience. All paid peers have very similar experiences to those who are being served. Staff is culturally diverse to meet the needs of the poorest people in our community. On average this program serves 300 mental health recipients per year, with a 41% success rate (maintaining employment for three months or longer).

WE Can Work Forums/Workshops (WE Can Work Campaign/NYAPRS): Part of a statewide campaign on employment aimed at building the hope and social capital of individuals with psychiatric disabilities, these forums feature presentations of personal stories of recovery and employment success, as well as information about work incentives, rights, and resources available in local communities. Presenters are primarily individuals in mental health recovery, in partnership with professionals and/or community providers.

“Our Own Experiences as Teachers” (SANYS): Self-advocates with developmental disabilities receive support from the AmeriCorps program to conduct awareness-building and training activities with a variety of audiences. Self-advocates present on topics such as their own personal stories, self-advocacy skills, Stop the “R” word, and emergency preparedness. While this program does not have a direct goal of promoting employment among individuals with developmental disabilities, this program improves the self-advocacy skills of AmeriCorps participants, supports their professional development, and increase awareness among providers and community members about the potential of individuals with developmental disabilities.

“Making it Happen” (SANYS): This publication features the stories of several men and women with developmental disabilities. The main purpose of this printed material is to share with other individuals with developmental disabilities, providers, and the community at large stories of self-determination and success. Individuals featured have achieved self-determined goals after years of struggles, aided by the support of caring individuals and innovative programs, in areas such as integrated housing, personalized day programming, and meaningful employment.

Peer Mentoring: Several mental health programs and independent living centers implement peer mentoring as a strategy to improve skills among individuals supported in fairly practical areas such as travel training, resume building, interviewing skills, and others. For instance, Bronx Independent Living center has a strong mentoring program on interviewing skills. Through “mock” interviews participants are mentored on whether or not and how to disclose disability, how to emphasize qualifications (versus disability) and communicate the “business case” of why the person should be hired.

Peer Bridger Program (NYAPRS): The Peer Bridger Program facilitates the community integration of individuals from six psychiatric hospitals across NYS. Peer Bridgers provide peer support through one-on-one and group activities for several months before and after discharge. The goal of this program is to support individuals in developing connections

with community resources that can facilitate their social inclusion, and at the same time support their narrative change in order to decrease the likelihood of re-hospitalization. While the focus of the peer bridging is not specific to employment, its broad goal of promoting connections with community resources and expanding social networks set a foundation to support employment/career goals.

Social clubs: Social clubs are peer-run programs with the goal of promoting mutual support in an environment that supports the belief that mental health recovery is possible. While social clubs may not have a strong focus on employment, they can have a role in engaging individuals in start-up conversations about employment (e.g., have you thought of working? if you could work or go to school, what would you like to do? , what fears do you have about working?). For instance, the Potpourri Social Club (at ClearView Center) is often the first stage for individuals who may have been institutionalized for a significant period of time to start a discussion about employment and eventually get connected to skills programs within the same organization (e.g., computer training, GED classes, retail training program) or another provider. Often former members of the social club and graduates of the supported employment program come back to the social club and share their experiences of community and employment integration.

Peer Partnerships (initiatives):

Employment Peer Panel (MHA Rochester): Individuals with psychiatric disabilities share their personal stories of success in order to inspire other individuals, improve awareness about the importance of employment in the mental health recovery process, and educate the community at large. Panelists conduct presentation to a variety of audiences including probation departments, mental health programs, employers, insurers, and other community settings. With the support of a staff person trained in benefits, the peer panelists also engage participants in discussions about work incentives. This program has been in existence for about four years.

“Keep On Track” (MHA in Rochester): With the support of a peer provider with benefits training, this group assists individuals who have returned to the workforce to report their wages correctly to the Social Security Administration and estimate how their monthly income will impact their social security benefits. This program also offers participants with practical support to complete the waging reporting process, such as access to computers, fax, copying machines, and filing of important/confidential documents. One of the challenges of this program has been to keep a large number of participants engaged/motivated.

Monthly Employment Lunches (St. Joseph’s Hospital Health Center): This lunch-time meeting is open to anyone thinking about working, looking for employment, or working. Participants are encouraged to share about their experiences and challenges, strategies/resources to overcome those challenges, employment leads, among other topics.

“Grapevines” Retail Training Club (Clearview/Potpourri Social Club): This is a training program is designed to develop basic job and “soft” skills (e.g., attendance, teamwork, communication skills, interaction with the public, using cash registers). Many individuals who participate in this training program are members of the peer-run Potpourri Social Club, and eventually transition to the Clearview supported employment program. An average of 20 individuals currently participate in this training program. Peer support takes place informally among participants, and in interaction with the social club.

“Friends of Independence” Tour (Independent Living of Newburgh): This program has the main purpose of creating bridges between individuals with disabilities and the community at large through education of and networking with community-based organizations, financial institutions, and employers. Banks, schools, community providers, and human resource staff, among other groups, participate in an informational and networking gathering on different disability-related topics, including personal stories of people with disabilities. This program has had significant success at engaging organizations and institutions not part of the “disability” system through newspaper advertisements and “word of mouth” strategies. This program contributes to individuals with disabilities achieving employment and community integration by increasing awareness about the contribution and potential role of people with disabilities in the community and expanding their social connections.

Job Hunt Club (Independent Living of Newburgh): This support group is available to those looking for a job in tandem with the employment programs of the host agency. This club promotes mutual encouragement among peers through the process of looking for and applying for jobs.

Peers as Employees:

Peer Employment Specialists:

Multiple mental health programs have created paid positions with titles such as peer specialists and peer advocates. Often these peer providers take roles in employment/vocational activities (e.g., role modeling, travel training, environmental exploring, resume building, systems advocacy, and connecting with community resources). These individuals are often formally trained and/or certified. A few organizations provide formalized training programs leading to a certification as peer specialists. The “Howie the Harp” Advocacy and Training Center (Community Access) provides a nationally recognized training program in NYC. St Joseph’s Hospital Health Center (Syracuse) also offers a peer specialist training through the Mental Health Empowerment Project, Inc., and continuing relationship with MHEP is intended to provide ongoing training and support for peer, staff, and administration. Paid work will begin in 2010.

St. Joseph's Hospital Health Center New Connections Clubhouse holds regular advocacy meetings to define the role of the peer specialist. These meetings currently provide one-on-one support, and also facilitate peer support amongst others by scheduling group

discussions around hope building and advice. Future plans include some peer specialists accompanying people while they do environmental exploring to check out prospective job sites, travel training, benefits and economics advisement, and help with housing issues. We also are encouraging alternative and complimentary approaches to recovery. The emphasis of future peer role development will focus on person centered planning approaches and development of community connections.

www.NYMakesWorkPay.org

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