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Connecting Youth and Communities: Customized Career Planning for Youth with Psychiatric Disabilities

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Young people with psychiatric disabilities are significantly over-represented in the juvenile justice system, tend to be employed sporadically if at all, and frequently have negative connections within and to their communities. Recent research conducted in Montana with youth who have developmental and/or physical disabilities demonstrates the effectiveness of using a customized career planning model to increase linkages to resources and access to community-based employment. Side benefits include improved self-esteem and positive community connections. The customization model holds promise as a way to reduce the risk factors young people with psychiatric disabilities face and increase the resiliency factors that can assist them to achieve healthy long-term outcomes. The author describes the model as it has been applied in Montana, explores additional considerations when working with youth diagnosed with psychiatric disabilities, provides an example of the model in action, and makes recommendations for further areas of research and inquiry.

Key words: youth; transition; psychiatric disabilities; community; customized employment

Young people with psychiatric disabilities are significantly over-represented in the juvenile corrections system (Teplin, Abram, McClelland, Dulcan, & Mericle, 2002; Quinn, Rutherford, Leone, Osher & Poirier, 2005), tend to be employed sporadically if at all, and frequently have negative connections within and to their communities. Since 2001, the Rural Journal of Sociology & Social Welfare, December 2009, Volume XXXVI, Number 4

Institute Transition Projects at the University of Montana has been developing and field testing the Individualized Career Planning Model to address the poor post-school outcomes of youth with significant developmental and/or physical disabilities (Condon & Callahan, 2008). [Model development was supported by two U.S. Department of Education grants, which funded WISER—Work Incentives and Alternative Resource Development for Student Employment, #H324M000089; and Linkages to Employment, #H324M020140.] The model increases linkages to resources and access to community-based employment. Side benefits include improved self-esteem and positive community connections. The Individualized Career Planning Model holds promise as a way to reduce the risk factors young people with psychiatric disabilities face and increase the resiliency factors that can assist them to achieve healthy long-term outcomes.

Background

Various studies report the incidence of serious emotional and behavioral disorders in United States children ages 4-17 years as ranging from 4% to 13% (Burns et al., 1995; Colpe, 2000; Costello et al., 2003; Simpson, Scott, Henderson, & Manderscheid, 2002). According to the 2001 Report on Mental Health from the Office of the U.S. Surgeon General, one in ten children in the U.S. suffers from some sort of mental health problem, with depression and attention deficit hyperactivity disorder being the most common diagnoses. As many as one in every 33 children and one in eight adolescents may be suffering from depression, and a majority are not receiving treatment for their illness. More than 60% of children with serious mental health needs don't graduate from high school, and those who stay in school are more likely to face disciplinary actions and other negative consequences due to their behaviors (Wagner et al., 2003). At least 20% of youth in the juvenile justice system suffer from severe mental illness; the number can be as high as 70% if adolescents who have been committed for substance abuse are included (U.S. Office of the Surgeon General, 2001). In 2001, the U.S. Department of Education funded the National Longitudinal Transition Study-2 (NLTS2), which included a

sample of more than 11,000 youth ages 13 through 16 receiving special education services. Over a nine-year period, data are being collected, analyzed and reported. The NLTS2 2006 report found that 44% of the youth with emotional disturbances left school without finishing, the highest drop-out rate of any disability category (Wagner, Newman, Cameto, Levine, & Garza, 2006).

Once these youth reach adulthood, the numbers are equally discouraging—people with long-term psychiatric disabilities have the highest joblessness rate (current and historical estimates range from 50-90%) of any of the disability groups (Anthony, Buell, Shannatt, & Althoff, 1972; Anthony, Cohen, & Danley, 1988; Anthony, Cohen, & Vitalo, 1978; Anthony & Jansen, 1984; Bullis, 1997; MacDonald-Wilson, Revell, Nguyen, & Peterson, 1991), lowest participation in postsecondary training and education programs (only one in five youth with emotional disturbance followed through the NLTS2 study reported any involvement in postsecondary education) [Wagner et al., 2006], and the highest likelihood of remaining dependent on public assistance programs following high school of all groups of young adults. Sweeney (2000) reports that one-fourth to one-third of current Temporary Assistance to Needy Families (TANF) recipients has a serious mental health problem and approximately one-fifth of those who have left TANF and are not working also have mental impairments.

More than 46% of the two million adults in the United States with at least one episode of homelessness self-identify as having a mental health problem (President's New Freedom Commission on Mental Health, 2003). The U.S. Department of Justice reports that 16% of the population in prison or jail has a mental illness and inmates with mental illness in prison were 2.5 times as likely to have been homeless in the year preceding their arrest than inmates without a mental illness (Ditton, 1999). The NLTS2 2006 found that of the young adults with emotional disturbances, more than three-fourths had been stopped by police other than for a traffic violation, 58% had been arrested at least once, and 43% had been on probation or parole. One-third of the youth had not found a way to become engaged in their community after leaving school (Wagner et al., 2006). This despite the fact that research suggests there is

no correlation between a mental health diagnosis and an individual's ability to live independently and be employed in the community (Anthony, Cohen, & Farkas, 1990).

A 1999 report by the Office of Inspector General for the U.S. Department of Health and Human Services linked the poor employment outcomes for youth with disabilities to factors such as the lack of transition planning, employment preparation, services and linkages. Report authors also noted that youth with mental or developmental disabilities face additional challenges. Components of "best practice" (for schools, families, and service providers) for transition planning and curriculum have been summarized as follows: vocational assessment; supported employment services; employability and social skills training; parent involvement in transition planning; transition-focused Individualized Education Plans; community-based instruction and curriculum; instruction in integrated settings; and inter-agency coordination (Kohler, DeStephano, Wermuth, Grayson, & McGinty, 1994; National Alliance for Secondary Education and Transition, 2005). Additional evidence-based best practices for students with mental health needs include person-centered planning (a process in which a group of trusted people focus on an individual, helping her to articulate and plan to achieve her life vision); follow-along supports (ongoing or "as needed" assistance available after formal service provision has ended) and integrated employment and treatment services (to allow for coordination of clinical and employment-related services and supports that will help an individual be successful on the job site) [Belcher & Ephross, 1989; Becker & Drake, 1993, 2003; Becker, Torrey, Toscano, Wyzik, & Fox, 1998; Bond, Drake, Becker, & Mueser, 1999; Becker & Bond, 2002; Marrone, 2005].

Although there is a growing body of knowledge about strategies that are effective in helping youth with disabilities prepare for adulthood, post-school outcome data suggest the strategies are not being employed in an inclusive, coordinated, community-centered manner. Educators, mental health professionals, service providers, families, and the students themselves are searching for "best practice tool kits" they can use to help young people achieve successful transitions.

The Individualized Career Planning Model

Beginning in 2001, a longitudinal customized model of career planning (known as the Individualized Career Planning Model) was developed in Montana with the support of U.S. Department of Education Model Demonstration funds. The model targeted students who experienced developmental and/or physical disabilities that created barriers to employment (Condon & Callahan, 2008).

“Customized employment means individualizing the employment relationship between employees and employers in ways that meet the needs of both” (Callahan, 2002). Work experiences and jobs are created, carved or negotiated for the individual student based upon their needs, strengths and interests. For students with a significant impact of disability, customizing an experience or employment setting increases the opportunities for their participation and maximizes their competent performance (Condon & Callahan, 2008). In order for the job developer to successfully negotiate responsibilities, working conditions, support strategies and accommodations, the relevant impacts of an individual’s disability (that is, how it affects the job seeker in the workplace and what supports will allow the individual to function most competently) should be disclosed.

The Individualized Career Planning Model emphasizes the following:

- The goal is paid, community-based employment or self-employment for each job seeker regardless of the severity of his or her disability. This is accomplished through customized transition planning, work experiences, and employment opportunities, all driven by the individual’s interests, support needs, strengths and contributions.
- Alternative resources that increase consumer and family choice and control over services (e.g., Social Security work incentives), are incorporated into transition planning.
- Linkages between agencies such as Vocational Rehabilitation, Developmental Disabilities, Workforce Investment and the schools are developed to promote the collaborative funding of employment and transition activities for each student. (Condon & Callahan, 2008)

The model is built on two assumptions. First, employment is a right that everyone should have the opportunity to exercise. Through work, we not only gain access to economic resources, we nurture self-esteem, social connections and a sense of belonging. Second, all individuals, regardless of the nature or severity of their disability, can be successfully employed in the community. Everyone has talents to share and contributions to make—with proper supports, these talents and contributions can be translated into workplace success. The Individualized Career Planning Model components allow practitioners (teachers, family members, service providers, etc.) to identify and capture the strengths, interests, contributions, and support needs of an individual, and then to use that information to negotiate a customized job in the community. Following are descriptions of the model components.

Discovery. The process of Discovery answers the questions, “Who is this individual? What are her strengths, skills, interests, preferences, and contributions with respect to employment? What supports are necessary for him to exhibit his best performance? What factors motivate her to work? What are the conditions that must be met for his employment to be successful? What job tasks could she perform for an employer?” Discovery is primarily accomplished through intentionally spending time with the job seeker in familiar and unfamiliar settings and through conversations with the job seeker and others who know him or her well (Condon & Callahan, 2008). It should be a collaborative process, with information from a variety of settings and sources ultimately completing a comprehensive, whole-life, strengths-based picture of the individual.

Vocational Profile. Discovery information is captured, summarized and documented in a written format called the Vocational Profile (Callahan & Nisbet, 1997). The Profile is a compilation organized into three sections: demographics, which includes the individual’s connections to the community through relatives, friends, social groups, and their neighborhood, as well as a map of their daily routines to help identify strengths, interests and support needs; description, which is composed of objective written “pictures” of the individual’s performance in a variety of settings and at a variety of tasks, always from a strengths-based perspective; and summary,

in which trends from the previous two sections are summarized to be used for employment planning. Once the job seeker and his family (if applicable) have given their approval, the Vocational Profile is shared with members of the customized employment planning team and is used to guide the selection or creation of school and community-based jobs.

Customized Planning Meeting. The Customized Planning Meeting is a structured group process that guides future job development activities. Planning Meeting participants are determined and invited by the job seeker and may include friends, family members, teachers, employers, counselors, case managers, faith community leaders—anyone who knows the individual well and is willing to play an active role in helping to create customized employment. Outcomes of the meeting consist of: the terms of negotiation for a job in which the individual can succeed; a summary of contributions the person can bring to an employer; a list of specific tasks the individual can perform; and a list of specific employers in the community whose businesses might match the person's conditions for employment, value the person's contributions, and have a need for the specific tasks the person can complete (Condon & Callahan, 2008).

Representational Portfolio. The Representational Portfolio is a marketing tool job developers can use to represent job seekers to employers. It is a pictorial and narrative representation of the individual—their contributions and capabilities, as well as the particular job tasks they can perform (Condon & Callahan, 2008). Essentially the information gleaned during Discovery, captured in the Vocational Profile, and summarized at the Customized Planning Meeting is translated into a marketing presentation. The Portfolio is divided into two sections. The first section introduces the concept of customized employment, explaining how customization can create a “win-win” situation in which the job seeker's strengths and talents are matched to the business's needs. The second section of the Portfolio introduces the individual job seeker, using pictures and text to graphically describe his interests, contributions, and successful support strategies, as well as the specific job tasks he can perform. These tasks become the building blocks of a customized job (Condon & Callahan, 2008).

Negotiate a Job or Design a Business. Using the Representational Portfolio, the job developer begins marketing the job seeker to businesses identified during the Customized Planning Meeting. (Job developers may be funded through Vocational Rehabilitation, Tribal Vocational Rehabilitation, Workforce Investment Act, Mental Health, Developmental Disabilities, etc., or they may be friends, family members, case managers, school teachers, paraeducators, or others acting on the job seeker's behalf.) The negotiation between what the applicant needs and can contribute and what the employer needs leads to a custom-tailored job developed or customized on behalf of the individual (Condon & Callahan, 2008). For example, the local police department may have piles of accident photos needing to be scanned into computer files, but no staff available or assigned to do the scanning. A job developer could negotiate a part-time position for a job seeker who has an interest in police work and the ability to scan and organize materials into the computer.

Plan for Ongoing Supports. It is essential that planning for ongoing supports takes place prior to the individual beginning employment. Such issues as job coaching, follow-along services, personal care requirements, etc. must be addressed up-front to help ensure success in the workplace (Condon & Callahan, 2008). This should be a coordinated activity between the new employee, job developer, family members (if applicable), supervisor, co-workers (if appropriate), case manager, mental health professional, physician, and other professionals as needed.

Social Security Benefits Analysis and Referral to Resources. The other major component of the Individualized Career Planning Model is the incorporation of Social Security benefits analysis and referral to other resources into the planning process. The fear of losing essential financial and health care benefits paralyzes many individuals with disabilities from trying to enter the workplace. Discussions of the impact of wages on benefits, explanations of Social Security work incentives—such as the Plan for Achieving Self Support, or PASS, which allows eligible beneficiaries to set aside earnings toward a vocational goal—and linkages to appropriate community resources can help potential job seekers overcome this fear.

The Individualized Career Planning Model strategies have been successfully implemented with many Montana youth and adults who had been labeled “too disabled to work” (Condon & Callahan, 2008). These outcomes are well-documented in Rural Institute publications (Condon, 2002; Condon & Pescheck, 2002; Condon, Brown, & Jurica, 2005; Condon, Moses, Brown, & Jurica, 2003; Condon, Moses, Brown, & Jurica, 2004; Griffin & Hammis, 2003; Griffin et al., 1999). Students receive increased paid work experience and are connected to adult agencies prior to high school exit, which has historically been positively correlated with success in employment post-graduation and a smoother transition from schools to adult services (Luecking, 1997). In addition, students and their families report increased linkages to the community and enhanced student self-esteem as a result of their experiences with the Individualized Career Planning Model.

When the four-year Linkages to Employment project (which demonstrated utilizing the Individualized Career Planning Model with transition-age students who had a significant impact of disability) ended in 2006, Rural Institute staff conducted a “Where Are They Now?” survey of former project participants. Of those who responded to the survey, 67% had graduated from high school, 25% were still in school, and 8% had dropped out. While the participants were in school, 33% had at least one unpaid school-based work experience, 17% had at least one paid school-based work experience, 50% had at least one unpaid community-based work experience, 25% had at least one paid community-based work experience, 58% had at least one paid community-based job and 7% had at least one volunteer experience. At graduation, 44% held a community-based job (one student was self-employed). In terms of enhanced connections to community resources, 75% of survey respondents reported they were currently working with other agencies (e.g., Developmental Disabilities, Community Rehabilitation Providers, Vocational Rehabilitation, Mental Health, WIA); 75% were receiving Supplemental Security Income (SSI) benefits (one SSI recipient had an approved PASS plan to save toward a vocational goal); and 100% reported engagement in at least one regular community activity (employment, recreation/leisure, and/or volunteerism) [Brown & Condon, 2006].

The Model and Youth with Psychiatric Disabilities

President Bush's New Freedom Commission on Mental Health's 2003 report, "Achieving the Promise," states that for an individual with a psychiatric disability, working in one's community is central to recovery and should be a major goal of the mental health system. Too often, however, employment is viewed as a post-treatment consideration rather than an integral part of recovery. By using the Individualized Career Planning Model to access customized work experiences and employment, youth with psychiatric disabilities can reap the benefits of a well-coordinated process that incorporates many of the identified "best practice" transition strategies.

Youth with mental health-related disabilities often have very different needs when compared to students with other types of disabilities; the model allows services to be custom-tailored to meet those unique needs. For example, mental illness tends to be episodic and symptoms variable, necessitating flexible and ongoing supports rather than a constant level of intervention (Randall & Buys, 2006). Emotions, the ability to interpret other people's behavior and react appropriately, and interpersonal relationships are often impacted. Decision making can be poor, and stamina and endurance limited. Psychiatric medications result in a variety of side effects, sometimes significant enough that young people stop taking their prescriptions altogether. Stress may trigger or exacerbate symptoms. Individuals may be reluctant to disclose their disability for fear of stigma and discrimination (Virginia Commonwealth University, 2004). Family members and mental health professionals may erect fear-induced barriers to employment (Rapp, Shera, & Kisthardt, 1993).

Too often, because of the "invisible" nature of their disabilities, these young people are labeled "lazy" or "behavior problems" at school, at home, and in the community, and the need for accommodations may go unrecognized. The few connections they typically have are often of a negative nature (e.g., involvement with Youth Probation or Family Services). As they are isolated from other disability groups and from their communities and as they are subjected to low expectations for success from those around them, people with mental

illness may experience a deterioration in their condition and functioning that has less to do with their illness than it does with how they are treated (Harding, Zubin, & Strauss, 1987; Marrone & Golowka, 1999).

Unemployment, the common post-school outcome for young adults with psychiatric disabilities, can exacerbate the stigma of mental illness, increase symptomology, lead to social isolation, and trap individuals in poverty (Herman, 2006). Conversely, employment enhances social standing; may decrease symptoms through structure, routine and regular productive activity; creates connections – social networks, natural support systems, friendships and intimacies; and, with proper benefits planning, increases available household income (Marrone & Golowka, 1999).

The Individualized Career Planning Model offers a person-centered approach to employment that accentuates an individual's strengths and markets these to community employers. Relationships are built; connections are created. Models comprised of elements similar to those found in Individualized Career Planning have demonstrated effectiveness with this population. The entrepreneurial job development approach used in Australia with people who have schizophrenia, for example, found that potentially long-term relationships with employers could be developed using an approach that emphasized a match between employee assets and employer needs (Randall & Buys, 2006).

Customization allows the job developer to negotiate with employers on behalf of a job seeker. Areas around which support or negotiation may be necessary and examples of customization which could be considered include: cyclical performance—a flexible schedule will allow the employee to take time off when symptoms are severe; decision making—a designated co-worker might assist with decisions as needed; concentration and focus—negotiating a private work area with minimal noise and distractions could improve the employee's ability to focus; stamina and endurance—the employee might be more successful with a shortened work schedule and the ability to take frequent breaks; interpersonal contacts and relationships—co-workers can serve as peer mentors to model appropriate workplace interactions; medication side effects—a

crisis plan can be developed and shared with the supervisor so she knows about potentially serious side effects and what to do if the employee starts exhibiting/experiencing them; delusions, hallucinations, unusual behaviors, movements or mannerisms—a break room can be designated as a “safe space” where the employee can go when she is experiencing hallucinations, delusions, etc.; hygiene—negotiate a work setting, such as telecommuting from home, where hygiene won’t be an issue; and physical restlessness—build time into the work day for several vigorous walks outside (Ford, 1995). Taking these areas into account, the job developer and employer may customize the job seeker’s work schedule, job duties, workplace policies, and/or the employment environment (Mancuso, 1993).

Although disability disclosure is a sensitive issue for individuals with mental health diagnoses, an up-front discussion with the employer about the impact of one’s disability as it pertains to employment is essential in order to negotiate key elements of the customized job.

The Model in Action

Tom (not his real name) lived in a small, rural Montana community. The manifestations of his disability included “black and white” thinking, rigid adherence to rules, and awkwardness in social situations. Tom was ostracized by his high school peers. They considered him a “rat” because when he worked at the school store and caught other students stealing candy, he reported the theft instead of ignoring it as was the practice with the teenage employees. Classmates also found his speech patterns and mannerisms strange. Tom’s reputation spread to community employers. When he applied for a job at the local grocery store, he was turned down without an interview.

Tom’s school chose to participate in a federally funded project through which Rural Institute staff mentored school personnel to implement the Individualized Career Planning Model. With his special education teacher taking the lead, Tom partnered with his occupational therapist, school psychologist and a Rural Institute staff person to complete Discovery, write

a Vocational Profile, conduct a Customized Planning Meeting, and create a Representational Portfolio. Because of what the team learned about Tom through Discovery, the very same grocery store where he had been denied a job emerged as the top priority for job development—the work environment met the conditions he needed to have in place, the business owner would value his contributions, the job resonated with an interest he had in retail, and the store might have need of the tasks he knew how to perform, such as stocking shelves and straightening merchandise.

Customized employment typically involves representation of a job seeker by a job developer—this allows for negotiation between the job developer and the employer. In Tom’s case, his teacher and the psychologist used his Representational Portfolio to represent him to the grocery store owner. They knew the business employed numerous teens and experienced substantial losses due to theft. In marketing Tom, they emphasized his honesty and total compliance with rules. They assured the employer that if Tom ever saw anything untoward in the store, he would immediately report it. The employer offered Tom a job at 20 hours per week. Tom’s job developers negotiated a position description for him that eliminated several of the tasks a “courtesy clerk” would typically be assigned, such as bagging groceries, a duty which would require Tom to converse with customers—something he was not yet comfortable doing.

Through his customized job, Tom not only gained valuable experience and a paycheck, he started to change his community reputation, build informal support networks through his co-workers, and feel immensely more self-confident and self-efficacious.

Recommendations for Further Research

In order to establish it as an evidence-based practice, randomized trials of the Individualized Career Planning Model should be performed. Although anecdotal evidence strongly supports the model as an effective employment strategy for individuals with disabilities, its acceptance would be more rapid and widespread if quantifiable, statistically valid data

reflecting the model's effectiveness existed. In addition, measurable self-esteem and community connection outcomes should be developed and included in the model research.

Once the evidence base is in place, a fidelity scale should be developed. Fidelity scales are "instruments for measuring implementation of a program practice" (Bond et al., 2002, p. 239). As an example, the Supported Employment Fidelity Scale was developed to measure program fidelity to seven supported employment principles: consumer choice—people who want to participate are not excluded; employment efforts are integrated with treatment; competitive employment is the goal; rapid job search is offered; continuous follow-along supports are in place for as long as needed or wanted; consumer preferences drive the process; and benefits counseling is provided (Bond, 2004). When a program claims to be using a supported employment approach, its processes and services can be measured against the fidelity scale. Programs with high fidelity to the supported employment principles should have outcomes comparable to other high fidelity programs; a low fidelity rating might help explain poor program outcomes, and would point to problems with supported employment implementation rather than with supported employment itself. A similar scale created and validated for the principles of the Individualized Career Planning Model would allow researchers to examine the model's effectiveness in different program sites and hypothesize as to whether or not observed outcomes were in any way correlated with fidelity (or the lack thereof) to model principles.

Conclusion

Mental health treatment systems are chronically underfunded in most states, and both financial and physical barriers to receiving services exist. In order to achieve universal access for people with disabilities with the goal of full participation, as stressed in the New Freedom Initiative, it is critical to continue to develop, implement, evaluate and disseminate information about community-based approaches to long-term planning and coordination between school personnel, students, families, business people, and adult service agencies. It

is only through this approach that the likelihood of positive, meaningful outcomes that reflect student and family interests, preferences, and needs will be realized. It is essential to improve collaborative efforts and maximize the utilization of all innovative and alternative resources to ensure that healthy community connections are built while students are still in school, and are not disrupted for students with psychiatric disabilities as they exit school. The Individualized Career Planning Model offers an option for connecting youth and their communities in meaningful, mutually beneficial ways.

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