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Welcome to the JSSW special issue on disability. When it was first announced that there would be a special issue dedicated to the programs and policies of people with disabilities, we knew it was an important topic, but we didn’t know what to anticipate regarding the number of submissions. Your interest and the number of submissions far exceeded our expectations—as well as the available space in this Journal to include all the thoughtful and well-researched manuscripts we received. We selected those articles that reflected the most cogent and contemporary issues facing program administrators, policymakers, and people with disabilities.

With this in mind, the first article in this special issue, “Dreams Deferred: Disability Definitions, Data, Models, and Perspectives,” sets the stage for contemporary discourse regarding disability. Several unique definitions of disability are presented verbatim from the source. The reader may be inclined to conclude that either everybody can be termed ‘disabled,’ or the definitions are so exclusionary the it would be difficult to identify any truly disabled person. It is this paradox that has thus far kept the disability community from becoming the once hoped for civil rights powerhouse. The disability community,
for the most part, remains fragmented and parochialized according to disability type. Common denominators, however, have united the fractions—primarily concerning access to transportation and voting precinct accessibility. It appears that wherever an issue is of concern to a broader population (and therefore, lobbying strength), special interests are set aside in pursuit of a common goal. In recent years, this has meant alignment with the older adult population which is represented by the powerful numbers and active voices behind the American Association of Retired Persons (AARP). The failure to speak as a unified voice has, unfortunately, led somewhat to the dilution of the Independent Living movement which had a strong start with one individual, Ed Roberts, and other like-minded people with disabilities in Berkeley, California in the 1970s.

Other articles in this issue revolve around very topical subjects in the disability community. “Dimensions of Loss from Mental Illness,” by Amy Baker, Nicholas Procter, and Tony Gibbons, provides insight into the psychosocial impact of a psychiatric illness, while “Connecting Youth and Communities: Customized Career Planning for Youth with Psychiatric Disabilities,” by Kim Brown, addresses a very important and proactive approach to a critical problem in the expanding recovery movement among consumers with mental illness and their supporters.

Two of the articles, “Influences on Job Retention Among Homeless Persons with Substance Abuse or Psychiatric Disabilities” by Russell K. Schutt and Norman C. Hursh, and “E-Therapy as a Means for Addressing Barriers to Substance Use Disorder Treatment for Persons Who Are Deaf” by Dennis Moore, Debra Guthmann, Nikki Rogers, Susan Fraker, and Jared Embree, deal with one of the newer classifications of disability under the Americans with Disabilities Act (ADA)—substance abuse disorders. Substance abuse as a stand-alone disability can be difficult to address both on the micro and macro levels. In combination with a disadvantage (such as homelessness) or a disability, there is ample evidence to indicate a need to understand the synergistic relationship between substance abuse and other variables so that effective and targeted treatment programs and policies can be developed.
A very timely article by Alexa Smith-Osborne, "Does the GI Bill Support Educational Attainment for Veterans with Disabilities? Implications for Current Veterans in Resuming Civilian Life," addresses a pressing issue for soldiers who return home and choose to begin vocational training and educational programs. The challenges are many for returning soldiers who must identify areas of support for successful readjustment to civilian life. Does the GI Bill fulfill its promise of education for our thousands of heroes who are returning home to America in the middle of one of the darkest economic times in our nation’s history?

Sandra T. Azar and Kristin N. Read’s manuscript, "Parental Cognitive Disabilities and Child Protection Services: The Need for Human Capacity Building," touches upon one of the most sensitive issues confronting people with disabilities: the ability to be an effective parent. And finally, we have included the article "Reaching Beyond the “Moron”: Eugenic Control and Secondary Disability Groups," by Gerald V. O’Brien and Meghan E. Bundy, that brings us nearly full circle to the very root of living with a disability—eugenics. As our society becomes more skilled at deciphering genetic codes and developing the technological systems to communicate that information to sources other than the individual (i.e.—insurance companies), eugenics and the birthright of an infant known to carry a disability have become fundamental bioethical debates both in and out of disability circles. How “Independent” can life be for a person with a disability if the option of selection and birth includes extinguishing perceived undesirable characteristics?

Imagine how most dreams of people with disabilities could be advanced and not deferred, if the commonalities between the disability groups could rise above the dissonant descriptions of disability held by policymakers, and if the debate over eugenics could be resolved at the individual level, rather than at the policy level. Perhaps a stronger civil rights movement would emerge, spurring inclusion rather than exclusion.

To advance the promotion of a just and inclusive society for people with disabilities will require a tenacity that has been exhibited in previous civil rights reforms in America. The struggles against oppression and stigma will be, and have been, exhaustive and irregular. The choice, however, is clear.
Perseverance must prevail to avoid the potential dichotomy and anomie reflected in the poem "Harlem" by great Harlem Renaissance poet Langston Hughes, whose writing articulates with a stinging lucidity the results of questioning the fight, or surrendering. Victory for a fully inclusive society can be near...if we do not succumb to deferring the dream.

*Harlem*

What happens to a dream deferred?

Does it dry up  
Like a raisin in the sun?  
Or fester like a sore—  
And then run?  
Does it stink like rotten meat?  
Or crust and sugar over—  
like a syrupy sweet?

Maybe it just sags  
like a heavy load.

*Or does it explode?*

References

When Ed Roberts, who had polio, forged new ground for people with disabilities by developing the first Center for Independent Living in 1972, the stage was set for people with disabilities and advocates to join together in a new civil rights movement. 'Invisible' no more, the disability community started what was expected to be a stratospheric leap into community inclusion. There was substantial hope held in the anticipated impact of the passage of the Americans with Disabilities Act (ADA) in 1990 (P.L. 101-336, 104 statute 327). For millions of Americans, it appeared that the ADA would provide avenues for increased economic parity and workforce participation. Unfortunately, almost 20 years later, people with disabilities have not made the much anticipated strides in employment; and attitudinal barriers continue to lock people with disabilities into a separate and unequal subpopulation.

People with disabilities are the nation's largest minority group, and the only one that any person can join at any time. If you do not currently have a disability, you have about a 20% chance of becoming disabled at some point during your work life (U.S. Department of Labor, 2009). Baby Boomers may, at last, force seismic environmental and attitudinal shifts toward inclusion as the number of people with disabilities in the United States increases to approximately 50 million (Steinmetz, 2002).

Estimating the number of people who live with a disability is difficult. The lack of one standardized definition of
"disability" results in a variable count that ranges from 35 million (The Institute of Medicine, 2007), to 43 million (the figure used during the ADA preparation), to over 120 million, if a loose estimate of those with any chronic or disabling condition are counted (Shapiro, 1993). The 2000 U.S. Census statistic, 53 million, is widely held to be the assumed marker regarding the population estimates of disability. The United States Census reports that 53 million people live with one or more chronic conditions that adversely affect their activity level.

There are dozens of laws and statutes that contain their own interpretation of "disability." Here are five key definitions that have been used to estimate the population of people who have a disability. The text that defines disability is verbatim from the notated source.

**Americans with Disability Act:**

the term 'disability' means, with respect to an individual:
1. a physical or mental impairment that substantially limits one or more of the major life activities of such individual;
2. a record of such an impairment;
3. being regarded as having such an impairment.

(Americans with Disabilities Act, 2008)

The ADA also attempts to define the term "qualified individual with a disability" as: an individual with a disability who, with or without reasonable accommodation can perform the essential functions of the employment position that such individual holds or desires. The determination of what functions are essential is the employer's responsibility and is usually found in written job, or position, descriptions. The four primary titles in the ADA legislation address telecommunications, transportation, architectural barriers, and access to public community venues.

(CESSI, 2003)

**United States Census:**

the structure of the census survey classifies disability in three domains: communication, physical, or mental.
1. People 15 and older were identified as having a disability in a *communication* domain if they met any of these criteria: (a) had difficulty seeing, hearing, or speaking; (b) were blind or deaf; or (c) identified on or more related conditions as the cause of a reported activity limitation (blindness or vision problem, deafness of hearing problem, or speech disorder).

2. People 15 and older were identified as having a disability in a *physical* domain if they met any of the following criteria: (a) used a wheelchair, cane, crutches, or walker; (b) had difficulty with one or more functional activities (i.e.—walking a quarter of a mile, climbing a flight of stairs, lifting a ten pound bag of groceries, grasping objects, getting in or out of bed); or (c) identified one or more related conditions as the cause of a reported activity limitation (arthritis or rheumatism; back or spine problems; broken bone or fracture; cancer; cerebral palsy; diabetes; epilepsy; head or spinal cord injury; heart trouble or hardening of arteries; hernia or rupture; high blood pressure; kidney problems; lung or respiratory problems; missing legs, arms, feet, hands, or fingers; paralysis; stiffness or deformity of legs, arms, feet, or hands; stomach/digestive problems; stroke; thyroid problems; or tumor, cyst, or growth).

3. People 15 and older were identified as having a disability in a *mental* domain if they met any of the following criteria: (a) had one or more specified conditions (a learning disability, mental retardation or another developmental disability, Alzheimer's disease, or some type of mental or emotional condition); (b) had any other mental or emotional condition that seriously interfered with everyday activities (frequently depressed or anxious, trouble getting along with others, trouble concentrating, or trouble coping with day-to-day stress); (c) had difficulty managing money/bills; or (d) identified one or more related conditions as the cause of a reported activity limitation (attention deficit hyperactivity disorder; autism; learning disability; mental or emotional problems; mental retardation; or senility, dementia, or Alzheimer's).
A note that follows the reported definitions of ‘disability’ in the three domains identified by the United States Census broadens the definition even more: "Limitations that have no clear placement in any domain were not included." (Steinmetz, 2002)

Centers for Disease Control (2002)
Disability is defined as an individual having "limitations in physical or mental function, caused by one or more health conditions, in carrying out socially defined tasks and roles that individuals generally are expected to be able to do." (Centers for Disease Control, 2009)

Social Security Administration
Social Security pays benefits only for total disability. "Disability" as defined by the Social Security Administration, uses a strict definition:
1. You cannot do work that you did before;
2. We decide that you cannot adjust to other work because of your medical conditions; and
3. Your disability has lasted or is expected to last for at least one year or to result in death. (Social Security Administration, 2009)

Individuals with Disabilities Education Act (IDEA)
This Act specifically addresses the education of infants and children with disabilities. As defined by IDEA, the term "child with a disability" means a child: "with mental retardation, hearing impairments (including deafness), speech or language impairments, visual impairments (including blindness), serious emotional disturbance, orthopedic impairments, autism, traumatic brain injury, other health impairments, or specific learning disabilities; and who, by reason thereof, needs special education and related services. (Knoblauch & Sorenson, 1998)

Rehabilitation Act of 1973
Considered the referent for many pieces of disability legislation, the Rehabilitation Act specifically addresses employment, training, and rights and advocacy provisions with a focus on individuals with
the most severe disabilities. (U.S. Equal Opportunity
Employment Commission, 2009)

World Health Organization (International Classification of
Functioning (ICF), Disability and Health)

The World Health Organization’s definition and
interpretation of disability is also widely used, and
distinguishes body functions and body structures as
markers in its definition. Impairment in bodily structure
or function is defined as “...involving an anomaly,
defect, loss or other significant deviation from certain
generally accepted population standards, which may
fluctuate over time.” (World Health Organization,
2009a)

The ICF is comprised of nine general areas of
functioning, in addition to a list of cognitive/mental
disorders:
1. Learning and applying knowledge
2. General tasks and demands
3. Communication
4. Mobility
5. Self-care
6. Domestic life
7. Interpersonal interactions and relationships
8. Major life areas
9. Community, social and civic life

The ICF also acknowledges the multidimensionality
of disability and integrates several models that offer
differing conceptualizations of disability. (World Health
Organization, 2009b)

The parameters of disability have continued to change, as
has the types of service programs offered. A condition (such as
a limb amputation) was an immediate presumption of disabil-
ity. Currently, the technology behind prosthetics has restored
most of the functional ability of people with amputations, thus
excluding them from how ‘disability’ is defined. The contem-
porary perspective from which the definition of ‘disability
‘has emerged balances functional, physical, and mental issues
with the degree to which an individual can participate in the
community and with others without blockage from environmental restrictions (i.e. lack of curb cuts for wheelchairs, inaccessible older buildings and churches, no braille menus available in restaurants, etc.).

The measurement of 'disability' is hampered by primarily two obstacles: (1) the process of measuring a complex, multidimensional concept in a survey format is difficult, and (2) the constantly evolving concept of disability requires survey professionals to continuously develop new measurement approaches to adapt to the newest definitions of disability (Steinmetz, 2002).

In the past, people with disabilities were subsidized through federal and/or state entitlement programs, and the focus was on “fixing” the individuals through medical interventions. Today’s Independent Living movement addresses not just the physical aspect of disability, but rather stresses the barriers to inclusion in the social environment that prevent full participation (Marinelli & Dell Orto, 1999). Thus, programs and services have been substantially modified to reflect the examination of, and the removal of barriers in the workplace. Accessibility issues still remain in the social environment, however. “Visitability” is one such concern. Visitability refers to the ability a person with a disability has to visit friends’ homes, or places that are not required by law to be barrier-free.

It is easy to extrapolate from just the five definitions here why ADA lawsuits clog the justice system with people who claim disability discrimination, principally in the workplace. The word ‘disability’ lacks a clear, standardized meaning and has become so bloated in scope that most Americans can, with little effort, stretch a criterion to fit his or her particular situation. Have cynicism and skepticism regarding the disability status of a person, given the host of cumbersome definitions, affected the attitudes and perceptions of people without disabilities toward people with disabilities?

A landmark national survey of 1,000 randomly selected Americans with disabilities was conducted in 2004 by the National Organization on Disability and the Harris Poll organization to gauge attitudes toward, and the socioeconomic status of, people with disabilities. They defined ‘disabled’:
1. if he or she had a physical disability, a seeing, hearing, or speech impairment, and emotional or mental disability, or a learning disability.
2. if he or she had a disability or health problem that prevented them from participating fully in work, school, or other activities.
3. if he or she considered himself or herself disabled, or said that other people would consider him or her disabled. (National Organization on Disability, 2004)

The results demonstrated that people with disabilities still have pervasive disadvantages over people without disabilities, despite the Americans with Disabilities Act, though slight gains were reported with individuals having a "strong sense of common identity" with other people with disabilities, and a decrease in claims of discrimination in employment. Other significant findings:

- Only 35% of people with disabilities reported being employed full or part time, compared to 78% of those who do not have a disability. Recent studies indicate that it costs a business less than $300 to accommodate a worker with a disability.
- Three times as many people with disabilities live in poverty with annual household incomes below $15,000 (26 percent versus 9 percent).
- People with disabilities remain twice as likely to drop out of high school (21 percent versus 10 percent).
- Life satisfaction for people with disabilities also lags: only 34 percent said they are very satisfied compared to 61 percent of those without disabilities.
- People with severe disabilities have much greater disadvantages across all measured areas.
- Regarding health and well-being, 50 percent of the people with disabilities are worried about not being able to care for themselves or being a burden to their families, compared to 25 percent of other Americans. (National Organization on Disability, 2004)

Additionally, of those with disabilities of working age who are not working, 72% say that they would prefer to work (Texas School for the Blind and Visually Impaired, 1998). Identified
barriers to inclusion are transportation, inability to access friends' or relatives' homes, and the fear of losing health insurance and Federal-State disability benefits.

Attitudinal barriers play a central role in employability and socialization and, unfortunately, have not changed appreciably. The "spread" effect was identified by Dembo et al. in 1975 and has been the foundation of much research on attitudes toward people with disabilities. "Spread" refers to the overgeneralization of a disability into other or all aspects and attributes of a person, thereby making inferences about their intelligence, attractiveness, employability, etc. (Olkin, 1999; Wright, 1983). For example, forming the impression of a person in a wheelchair as being less intelligent, or stereotyping a woman with visible cerebral palsy as a less effective parent are examples of the 'spread effect.'

Olkin (1999, p. 62) identified factors that influence individuals' attitudes towards people with disabilities (PWD):

- **Perceiver characteristics**—Previous contact with PWD (amount and type of contact), information about the disability, general prejudice, authoritarianism.
- **PWD characteristics**—Social skills and attractiveness, comfort with own disability, perceived intelligence, demographics (gender, age, ethnicity, socioeconomic status).
- **Characteristics of the disability**—Disability type and severity, stigma of specific diagnosis, perceived contagion or heritability.
- **Characteristics of the milieu**—Social context and group norms, purpose and consequences of interaction. Whether interaction is observed, value of diversity in organization.
- **Social context**—Mass media, ad campaigns, 'charity' drive portrayals of PWD, availability of role models with a disability, news reports on disability, value of diversity in society.

Olkin (1999) further states that there are some disabilities that remain more stigmatized than others, and there is "... a remarkably stable hierarchy of acceptability of various physical disabilities" (p. 72). Individuals with sensory disabilities (hearing loss, blindness) have the most difficult time securing
employment and in breaking down barriers of discrimination in the social environment. People with highly disfiguring and visible disabilities (i.e. burn survivors) also remain less likely to be integrated in the workplace and socially.

A similar concept was expressed by renowned rehabilitation researchers Szmanski and Trueba (1995). They refer to the process of marginalization as "castification," a concept introduced in anthropology. Castification is fundamentally an institutionalized way of exploiting one social group (ethnic, racial, low-income, or other minority group), thus reducing this group to the status of a lower caste that cannot enjoy the same rights and obligations possessed by the other groups (in Marinelli & Dell Orto, 1999, p. 198).

If disability is viewed from a minority group perspective, people with disabilities are affected by the same oppression and discriminatory practices as other minority groups. Given the high number of individuals in the population who have a disability, conceptualization of people with a disability as a true "minority" group is often disputed. One helpful framework proposed by Stroman (1999) characterizes four criteria necessary for a group to be classified as having minority status. The minority group:

1. Is identifiable either in terms of appearance or behavior;
2. Experiences less access to power so that fewer resources, influence, and control are afforded to it;
3. Experiences discriminatory treatment, often evidenced by segregation and stereotyping; and
4. Sees itself as a separate group.

This framework, while helpful from a civil rights perspective, excludes a large number of people who have invisible disabilities. In fact, 'disability' is often attributed socially solely on the physical characteristics of an individual, or on assistive technology or ambulatory aids that the person uses.

Various models have been proposed by Hahn (1985, in Dell Orto, p. 196) to understand disability. The medical model defines disability in terms of functional impairments. The person with a disability is viewed as an entity to be fixed, or cured by 'experts.' The medical model is the most
dismembering of all the models but, unfortunately, remains a very strong, very stigmatizing perspective on disability.

Hahn’s second model, the economic perspective emphasizes the vocational and employability problems of people with disabilities. Individuals with disabilities are viewed as less than full participants in the market economy.

The third model, the socio-political model, is the only model that does not depend on the intervention of professionals to address, or treat, the disability. The socio-political model is at the core of the independent living philosophy. In this model, disability is a product of a person’s interactions with the environment. The environment is seen as the “disabling” obstacle, not the individual; examples include attitudes toward people with disabilities, architectural barriers, and inaccessible homes and services. Professionals act in a consultancy role, and treatment goal setting is individualized and driven, when possible, by the client. It is unfortunate that health care providers and to a large extent, insurance companies in the United States, will only support services to people with disabilities as long as ‘expert’ professionals direct the rehabilitation/service process.

Conclusion

The independent living movement of the 1970s, the passage of the Americans with Disabilities Act in 1990, and the sheer numbers (no matter which definition is applied) of persons with disabilities hold the potential for people with disabilities to amass a critical force to be reckoned with politically and socially. Unfortunately, the fragmentation of the various disability groups and the parochialism that exist makes advocating as a single voice difficult—thus diluting the power of the population of people with disabilities.

Part of the problem lies with the lack of a common definition of disability. If people with disabilities cannot agree on the parameters of the construct, it is unlikely that others will develop one standardized definition. And, until a collective agenda for social and environmental change is universally set, people with disabilities will remain fractionalized.
References


Dimensions of Loss from Mental Illness

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This review explores the nature, scope and consequences of loss resulting from mental illness. Losses are described within four key themes: self and identity, work and employment opportunities, relationships, and future-oriented losses. In reflecting upon review findings, several assumptions about loss are illuminated. Findings are situated within the cornerstones of recent mental health reform, specifically a recovery-oriented approach and social inclusion. Particular attention is directed towards notions of risk and responsibility and tensions in realizing the impact of loss within an individualized recovery framework. Implications and recommendations for policy and practice are highlighted.

Key words: loss, mental illness, recovery, risk

Loss is central to many areas of healthcare, ranging from perinatal loss (Callister, 2006; Franche & Mikail, 1999) to weight loss (Chaston, Dixon, & O'Brien, 2007), to that affecting people with HIV/AIDS (Yang & Kleinman, 2008). In much of the healthcare literature, loss is intimately connected with the concepts of grief, mourning and bereavement, with grief often portrayed as the characteristic response to a loss (Appelo, Slooff, Woonings, Carson & Louwerens, 1993; Engel, 1961; Morrison, 1997). What constitutes appropriate responses to loss and grieving has been widely debated. At one end of the spectrum, authors suggest that loss and grief are
perceived and experienced in personal ways (Lendrum & Syme, 1992; Morrison, 1997; Rothaupt & Becker, 2007) and according to factors such as culture (Weston, Martin, & Anderson, 1998), level of development, support systems and the success or failure of past experiences and present attitudes (Morrison, 1997). In contrast, there have been many attempts to categorize grief into specific stages or phases, with several authors contending grief to be the necessary reaction and prerequisite for healing and recovering from a loss (Appelo et al., 1993; Lafond, 1994). Such recipes for grieving may be unhelpful as they tell us how people ought to experience loss (Weston et al., 1998), when grief may not necessarily be experienced (Repper & Perkins, 2003; Stein, Dworsky, Phillips, & Hunt, 2005). Inherent to these discussions about loss and grief is an intense preoccupation with the individual, a manifestation of individualism in modern Western society. At this point, it is important to note that this review reflects a modern, Western perspective, as this holds important implications in respect to concepts such as self (MacIntyre, 1990) and approaches to healthcare (Conrad, 2005; Giddens, 2009).

Authors agree that people who have a mental illness experience a profound degree of loss (Baxter & Diehl, 1997; Johansson & Lundman, 2002; Lafond, 1994; Macias & Rodican, 1997; Perese & Perese, 2003; Repper & Perkins, 2003) and in many instances, these losses extend to families, communities and societies. For example, globally, across both genders and the socio-economic spectrum, depression is the leading cause of years lost to disability (World Health Organization, 2008). Yet this statistic fails to reflect the many losses people with mental illness experience due to widespread stigma and social exclusion. These social problems often result in shame, despair and ostracism, affect areas of daily living such as housing, employment and social opportunities (Carr & Haplin, 2002) and are cited by mental health consumers as a reason for not seeking help (Groom, Hickie, & Davenport, 2003; Hayward & Bright, 1997). Yet to date, no comprehensive review of loss resulting from mental illness exists. In addition, the types and consequences of losses have not been clearly articulated within the literature. This review addresses several key questions: What is the nature, scope and consequences of losses experienced
due to mental illness? And why is the concept of loss relevant to recovery and the flourishing of human beings affected by mental illness? By the term recovery, the authors refer to the approach underpinning current mental health policy and practice. Perhaps the most well-known definition of recovery is provided by Anthony (1993, p. 15): "a deeply personal, unique process of changing one's attitudes, values, feelings, goals, skills and/or roles. It is a way of living a satisfying, hopeful, and contributing life even with limitations caused by the illness." Following a review of relevant literature, arising themes, sub-themes and their practical application will be considered. Analysis will be guided by theoretical work of Anthony Giddens (1991, 1999, 2002, 2009), highlighting social theory that emphasizes phenomena which in our everyday lives we acknowledge as primary features of human action. This will involve looking beyond assumptions surrounding the phenomenon of loss which are taken for granted.

The following search strategy informed this review. Nine databases were searched including: MEDLINE, Allied and Complementary Medicine (AMED), Academic Search Premier, CINAHL, PsycARTICLES, PsycINFO, Psychology and Behavioral Sciences Collection, Scopus and Health Source: Nursing/Academic Edition. Search terms included 'mental disorder' OR 'mental illness' OR 'psych$' OR 'schizophrenia' AND 'loss' OR 'lost' OR 'lose' OR 'grief'. Abstracts were assessed for applicability as were reference lists of selected articles to obtain further literature. Limitations imposed included peer-reviewed papers written in English in the past 15 years, with the exception of core informative pieces. The review was limited to adults/adolescents and excluded children. Papers were excluded if: (a) factors other than mental illness or related factors, such as treatment or stigma, resulted in loss, for example, the death of a significant other; and (b) mental illness was not the primary diagnosis of participants.

Variation between and within the quantitative and qualitative paradigms of the studies included in this review cannot be captured in a single set of quality criteria. As selected quantitative studies used statistics as a form of descriptive narrative, papers were not rejected based on quality appraisal scoring; rather, quality was gauged by the level of rich description and
insight into the phenomenon under study. This same approach was taken when appraising other non-research publications and reports that held particular relevance and contributed further understanding to the topic of interest. There is controversy surrounding the viability of combining findings of research studies that use different methods (Barbour, 1998). We take the view that while there may be multiple explanations of phenomena, they ultimately relate to a common underlying reality (Mays, Pope, & Popay, 2005) and therefore can promote a broader understanding of a research topic. Quantitative studies were included for their capacity to reveal dimensions of loss, while the researchers sought to augment these findings using richer, descriptive accounts from a number of qualitative studies and analytical papers. Thus, thematic analysis was chosen for its ability to identify and bring together the main, recurrent or most important issues or themes to emerge from the combined research literature (Mays et al., 2005). Synthesis was carried out in several stages. First, each study was independently reviewed and findings were summarized in point form, classifying key themes and categories. These were discussed with two fellow researchers with the view to explore similarities and differences within the topic area, as well as divergent viewpoints. Studies were not grouped by inclusion criteria (i.e. studies that provided insight into the experience of loss versus those that described or evaluated the extent of loss) as a considerable amount of overlap was identified across the selected studies and conceptual papers. Findings were then grouped according to similar themes and sub-themes.

This review begins by exploring the term "loss" within the field of mental health and everyday language used to depict mental illness. The nature, scope and consequences of losses that occur due to the presence of mental illness will then be presented. Finally, review findings will be situated within the contexts of recovery and social inclusion, with particular attention to the concepts of risk and trust, highlighting implications for both mental health practice and the wider society.
Loss Arising from Mental Illness

The notion of loss is central to many everyday expressions, though typically disrespectful terms, used to portray mental health problems within Western society: for example, 'He's losing it,' 'She's lost the plot,' 'He's lost his marbles,' 'She's losing her mind,' and 'He's losing control.' In a study of how mental illness was portrayed in children's television in which the 59 of 128 episodes viewed contained one or more references to mental illness, 'losing your mind' was the third most common term depicting mental illness and all references to mental illness had a central implication that the character was losing control (Wilson, Nairn, Coverdale, & Panapa, 2000). The concept of loss manifests within other derogatory phrases used to describe people with mental health issues, including 'a screw loose,' 'gone in the head,' 'a can short of a six-pack,' and 'gone insane.' An Australian poet and mental health consumer, Sandy Jeffs, explored sayings which denote madness in her poem entitled *A Thesaurus of Madness* (Jeffs, 1998). Many of these sayings encompass loss, such as "suffers from loss of reason," "a camel short of a caravan," "a brick short of a load," and "a sandwich short of a picnic." Other terms which have been used to depict people with a mental illness include "lost souls" (Fitzpatrick, 2007) and being treated as a "lost cause" (Lewiston, 2007).

Loss is also central to many official criteria for mental disorders; for example, several features that characterize major depressive disorder include the loss of interest or pleasure, loss of appetite and loss of libido (American Psychiatric Association [APA], 2000). Negative symptoms of schizophrenia, including affective flattening, alogia and avolition reflect a loss of normal functions (APA, 2000) and positive symptoms produce a loss of usual cognitive functioning and a capacity to orient oneself to both external and internal reality (Wittmann & Keshavan, 2007). As with depression, anhedonia is also common in schizophrenia (APA, 2000). Other examples of losses that characterize mental disorders include the loss of sleep during manic episodes in bipolar disorder, fear of abandonment—a potential loss—in borderline personality disorder (APA, 2000) and weight loss and amenorrhea in anorexia nervosa (Lee, 1995).
Loss of role performance, including prospects for the future, is also an important diagnostic feature of many disorders (Appelo et al., 1993). In addition, it has been argued that in the case of schizophrenia, much behavior indicative of this disorder is incorrectly interpreted as psychopathological or as a lack of motivation, instead of being an ordinary reaction to the many losses arising from schizophrenia (Appelo et al., 1993). There is also a large body of work examining significant loss as a possible aetiological factor in mental illness, however, this topic is outside the boundaries of the current review.

Loss from mental illness has been conceptualized broadly as a pervasive sense of “something missing” (Vellenga & Christenson, 1994) and as more nebulous and stigmatized than loss arising from physical disorders (Baxter & Diehl, 1998). The losses arising due to mental illness will now be considered in four key areas: self and identity, work and employment opportunities, relationships, and future-oriented losses. However, it should be noted that in many instances, losses encompass several categories and therefore, the following categories are not mutually exclusive.

Loss of Self and Identity

Loss of self or identity as a result of mental illness has been articulated in a range of ways including being stripped of one’s identity (Jeffs & Pepper, 2005; Joseph-Kinzelman, Taynor, Rubin, Ossa, & Risner, 1994), shattering the core sense of self (Young & Ensing, 1999), the dispossessment of selfhood (Letendre, 1997) and no longer knowing who one is (Macias & Rodican, 1997). Sandy Jeffs describes the intense nature and consequences of this type of loss:

With the onset of mental illness, one is often stripped of one’s identity and left with a sense of failure and distress. One feels like a shell; a being of no substance; one who walks in the shadows of others and casts none of one’s own; a victim of the spooks and phantoms that pervade one’s mind. (Jeffs & Pepper, 2005, p. 92)

Various metaphors have been used to illustrate this loss experience. In a study exploring the impact of bipolar
disorder on the development of self and identity, one participant’s experience of losing the things that help to define their sense of self was symbolized as a reed floating in the wind (Inder et al., 2008). In a different study which explored everyday occupations before and after diagnosis in focus groups with four young men who had schizophrenia, loss of self was portrayed in the analogy of a computer crashing that needed to be rebooted (Gould, DeSouza, & Rebeiro-Gruhl, 2005). Another participant described that his psychological map had been taken away, stating, “If you don’t have a map, you don’t know where you are or where you’re going...You could be lost.” (Gould et al., 2005, p. 470). Gould and colleagues’ study was titled “And then I Lost that Life” to highlight the losses experienced due to schizophrenia.

Loss of former self was one of four categories generated within the Personal Loss from Mental Illness (PLMI) scale, a brief measure assessing loss from mental illness (Stein et al., 2005). This category included three items that reflected changes in self perceptions due to mental illness (Stein et al., 2005). Loss of identity also emerged as the central theme of the mental illness experience for participants in an ethnographic study which used photovoice as a methodology (Fleming, Mahoney, Carlson, & Engelbretson, 2009). In this study, identity loss was described as the culmination of the effects of suffering and stigma, however, findings are limited by the fact that data were generated from an artistic interpretation of participants’ experiences, rather than from participants themselves, and it is unclear whether measures such as member checking occurred (Fleming et al., 2009). Loss of a previous life or self was also described elsewhere in the literature (Browne, Hemsley, & St. John, 2008; Davies, 2001; Lim, Nathan, O’Brien-Malone, & Williams, 2004) and the loss of a ‘normal life’ for people with schizophrenia has been described by family members as one of the most devastating aspects of this disorder (Stein & Wemmerus, 2001). Loss of time was discussed in relation to losing youth (Bassett, Lloyd & Bassett, 2001), periods whilst unwell (Browne et al., 2008; Lim et al., 2004; Robertson & Lyons, 2003) and due to a lengthy diagnosis (Joseph-Kinzelman et al., 1994).

A recent study examining all first-person accounts (n=45) over several years from two well-known psychiatric journals
yielded five themes, the most prominent of which was a loss of self (Wisdom, Bruce, Saedi, Weis, & Green, 2008). For many, this resulted in the loss of a previously held identity, yet for others it involved removing the good parts of the person or specific identity roles, such as being a parent (Wisdom et al., 2008). The authors also noted that the majority of passages describing a loss of self were devoid of hope and associated with a focus on symptoms and illness rather than recovery or strengths. In other studies, identity loss was connected to the experience of insubstantiality (Inder et al., 2008) and one person’s experience of identity loss was connected to self-loathing and feeling that others detested him (Macias & Rodican, 1997).

Other losses related to self and identity included dignity, respect and self-esteem. Loss of control over one’s life experienced whilst hospitalized was perceived to lead to a loss of dignity (Joseph-Kinzelman et al., 1994; Letendre, 1997; Nilsson, Nåden, & Lindström, 2008). Findings from a study exploring patients’ experience of involuntary psychiatric care suggest that the feeling of decreased human dignity arose from a perceived loss or lack of respect from others, described broadly as a violation of integrity (Johansson & Lundman, 2002). Elsewhere in the literature (Yang & Kleinman, 2008), loss of moral status was discussed as having major implications for people with stigmatized conditions such as schizophrenia, including a ‘social death.’ Loss of self-esteem was described by a group of young men who experienced employment issues following psychosis (Bassett et al., 2001) and lost self-esteem was also reported as a consequence of losing control over one’s life due to hospitalization (Letendre, 1997). Similarly, a loss of self-confidence was identified by a group of men with serious mental illness (Noh, 2004) and in reference to feelings of helplessness, hopelessness and a view of being defective (Lim et al., 2004). Lost confidence was also perceived to result from the combined stigma of having a mental illness and receiving a pension (Browne et al., 2008). Further, people who had experienced psychosis described losing confidence in others due to impaired judgment (Koivisto, Jahonen, & Vaisanen, 2003).

Other concepts related to the loss of self included freedom, choice, control and independence. Loss of freedom was discussed mainly in reference to being hospitalized (Davies, 2001;
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Dipple, Smith, Andrews, & Evans, 2002; Pereira, Furegato, & Pereira, 2005) and due to limited autonomy experienced whilst in involuntary care (Davies, 2001; Johansson & Lundman, 2002). One participant perceived that an absence of freedom in this environment perpetuated a range of losses, including justice, speech and attention (Pereira et al., 2005). More broadly, Anthony (1993) speaks of the loss of rights and equal opportunities that may occur following the label of mental illness. In a study with women who had puerperal psychosis, loss was one of three themes, comprising a loss of control in the areas of self, decision-making and treatment (Robertson & Lyons, 2003). For participants who had experienced psychosis, loss of control over one's self was reported to result in feelings such as causing harm to others or oneself and being controlled by outside powers, which in turn culminated in reactions such as insecurity, exhaustion, guilt and sleeplessness (Koivisto et al., 2003). Participants in another study expressed loss of control in bodily terms, related to medication side-effects such as foaming at the mouth, slurred speech or contortion of facial muscles, and loss re-emerged in stories of forced abortions, body-searches and restraint whilst in hospital (Davies, 2001). The loss of control associated with hospitalization or treatment procedures led to strong feelings of being trapped and anguish (Letendre, 1997) and further contributed to a loss of self or identity (Joseph-Kinzelman et al., 1994; Letendre, 1997). Another loss related to freedom was the loss of belongings such as clothes and money during admission to hospital (Joseph-Kinzelman et al., 1994) as well as other possessions outside of hospital (Lewiston, 2007). Furthermore, for some people who had spent long periods of time in hospital, a loss of community, asylum and safe place were experienced at the point of leaving hospital (Davies, 2001). In a study exploring consumers' insights into the recovery process, loss of control and independence were specifically connected to the initial stages of acknowledging the illness and seeking help (Young & Ensing, 1999).

**Loss of health and abilities.** Loss of health-related quality of life was studied in a large population survey in Finland, using two instruments which enabled comparisons of severity across different conditions (Saarni et al., 2007). Results showed that
people with typically chronic disorders, including dysthymia, generalized anxiety disorder, agoraphobia and social phobia, experienced the largest losses in health-related quality of life, however some conditions, including bipolar disorder and schizophrenia, were not included in this study (Saarni et al., 2007). Of note, results for people with dysthymia and generalized anxiety disorder were comparable to those reported by people 20 years older with conditions that considerably decreased health-related quality of life, such as Parkinson’s disease and heart failure (Saarni et al., 2007). Loss of health has also been reported due to treatment and medication effects. For some consumers, treatments have resulted in losses in the areas of motivation (Bassett et al., 2001), energy (Bassett et al., 2001; Nilsson et al., 2008), weight (Nilsson et al., 2008), bone density (Perese & Perese, 2003), normal sexual and reproductive functioning (Chernomas, Clarke & Chisholm, 2000; Perese & Perese, 2003) as well as a sense of health generally (Dipple et al., 2002). Several participants who experienced a loss of energy connected this with their medications’ effect on thought processes, describing a fear of “chemical lobotomy” (Nilsson et al., 2008). In a study exploring the everyday experience of being a patient in a psychiatric hospital, participants reported medications caused a loss of “ability to do things,” memory and concentration (Letendre, 1997). Loss of concentration was also noted as a consequence of bipolar disorder (Inder et al., 2008). Participants in another study described the difficulties associated with losing memory, ability to learn new things and access previously obtained knowledge and these created a sense of insecurity and impediments to an active life (Erdner, Magnusson, Nyström, & Lützén, 2005).

Also identified within the literature were the loss of abilities (Bassett et al., 2001; Fisher & Mitchell, 1998), including the ability to focus (Gould et al., 2005) and cognitive and emotional abilities (Wittmann & Keshavan, 2007). Participants in one study felt they had lost the ‘privilege’ of experiencing normal emotions as a result of puerperal psychosis (Robertson & Lyons, 2003). Other people with a mental illness spoke of lost abilities to undertake multiple roles and tasks simultaneously following the onset of their illness (Lim et al., 2004). The loss of roles (Browne & Courtney, 2007; Corring &
Cook, 2007) and routines were described as being a part of the
burden of having a mental illness. Roles and routines also com-
prised one of four categories of loss in the PLMI scale (Stein et
al., 2005).

**Loss of work and employment opportunities.** Losses in the area
of work encompassed a number of factors, including the loss
of previous work (Inder et al., 2008; Nilsson et al., 2008; Stang,
Frank, Yood, Wells, & Burch, 2007), employment opportunities
(Bassett et al., 2001; Vellenga & Christenson, 1994) and earn-
ings (Kessler et al., 2008; Marcotte & Wilcox-Gök, 2003; O’Neill
& Bertollo, 1998). It is likely that this area has received greater
research attention than other kinds of loss however, due to
the massive economic implications for society. For example, a
recent study estimated serious mental illness to be associated
with a loss of $193.2 billion in personal earnings across the total
U.S. population during 2002 (Kessler et al., 2008). There is a
vast body of knowledge reporting on productivity loss due to
mental disorders and predominantly data are collected using
self-report methods. Productivity loss resulting from mental
illness covers a range of circumstances including absentee-
ism (Acarturk et al., 2009; Hoffman, Dukes, & Wittchen, 2008;
Stang et al., 2007), presenteeism and work-cutback (Stang et al.,
2007) as well as lost productivity from low rates of workforce
participation (O’Neill & Bertollo, 1998; Lindström, Eberhard,
Neovius, & Levander, 2007) and premature mortality (Insel,
2008). Due to the extensive range of measurement tools used,
mental disorders studied, and factors such as geographical
variability and inflation, it is difficult to make comparisons
across studies. However, core issues pertaining to loss in this
area have been summarized below.

Losses experienced due to the costs of treating mental dis-
orders are experienced on both a societal and an individual
level. Unlike many other medical disorders, losses to society
in the form of healthcare costs are derived from indirect
rather than direct costs, such as public income support pay-
ments and the effect of reduced educational attainment (Insel,
2008). Productivity losses for participants with social phobia
accounted for approximately 95% of total costs of this disor-
der, which equated to more than four times the total cost for
a person without a mental disorder (Acarturk et al., 2009).
Furthermore, this study was based on self-report and did not include the impact of presenteeism, both factors likely to result in underestimation (Acarturk et al., 2009). In a study examining the direct and indirect costs for patients with schizophrenia (n = 225), productivity losses accounted for approximately 43% of the total costs which included medical costs, care and living costs (Lindström et al., 2007). Of a cohort of 59 patients with bipolar disorder, approximately half reported missing at least one week of work during the past month and 41% reported fearing the loss of their current job due to their emotional state (Stang et al., 2007). Additionally, almost half (47%) felt their performance was ‘sometimes to all of the time’ lower than that of their peers and 17% cited their disability as the reason for unemployment (Stang et al., 2007). However, as this study was conducted with patients from a psychiatric clinic that was part of a large managed care organization, findings are not generalizable, as they do not represent those who do not have access to such care (Stang et al., 2007). In another study which included 1502 participants, people with mental health problems (n=358) reported the second highest number of job losses, behind musculoskeletal disorders (n=468), yet again, it is necessary to question the generalizability of these results, as this study was conducted with men from rural areas only (Solomon, Poole, Palmer, & Coggon, 2007).

Consumer accounts of losses in the area of work revealed some of the possible reasons for losing employment and the meaning and consequences of such loss (Bassett et al., 2001; Davies, 2001; Inder et al., 2008; Lewiston, 2007; Lim et al., 2004; Macias & Rodican, 1997; Nilsson et al., 2008). The inability to create consistency due to bipolar disorder was perceived to lead to disruption and discontinuation in education, employment and career development (Inder et al., 2008). In another study exploring psychosocial issues with people with bipolar disorder, participants connected a loss of work with lost status, both educational and financial (Lim et al., 2004). Another person described how he had lost responsibility after losing a job (Macias & Rodican, 1997). Other losses stem from the loss of work, creating a fierce cycle that may involve a loss of income, decreased self-esteem and motivation in job-seeking (Bassett et al., 2001). Loss of vocational opportunities was one of several themes in
two studies about men who had psychiatric disorders (Bassett et al., 2001; Vellenga & Christenson, 1994). Studies with women who had a severe mental illness revealed similar findings with regard to loss of employment opportunities, vocational potential or related factors (Chernomas et al., 2000; Hochman, Fritz, & Lewine, 2005; Pereira et al., 2005). The desire to work is evident in many participants' narratives (Pereira et al., 2005), but the risk of potential loss, of losing either a job or financial benefits, were also of considerable concern, as illustrated by one participant who stated, "I want to try and find a job, but I'm scared...that I'm going to get sick and I'm going to lose my job, and I'm going to have no money and how am I going to get back on welfare?" (Chernomas et al., 2000, p. 1518).

Loss of Relationships

It is widely reported that people with mental illness experience severe disruptions and losses in relationships (Fisher & Mitchell, 1998; Kulkarni, 1997; Lim et al., 2004; Pereira et al., 2005; Stein et al., 2005), ranging from relationships with family (Chernomas et al., 2000; Lim et al., 2004) to social contact with colleagues (Nilsson et al., 2008). Compared with people without a mental illness, people with mental illnesses experience a higher rate of divorce (Kessler, Walters, & Forthofer, 1998; Overbeek, Vollebergh, Engels, & Meeus, 2003; Butterworth & Rodgers, 2008). Findings from a study conducted over a decade ago (Kessler et al., 1998) estimated that in the U.S., approximately 23 million years of marriage among men and 48 million years of marriage among women were lost due to divorce associated with prior psychiatric disorder. In addition, there is a large body of work emerging about loneliness and social isolation for people who have a mental illness (Browne et al., 2008; Elisha, Castle, & Hocking, 2006; McCrea & Spravka, 2008; Nilsson et al., 2008). Loss has been described in terms of a lack of fellowship and relief (Nilsson et al., 2008), lost trust in others (Koivisto et al., 2003) and the loss of place in a social milieu (Wittmann & Keshavan, 2007). One factor perceived to lead to a loss of support from others was frequent changes in living arrangements, which created barriers to adequate support for some participants (Chernomas, Clarke, & Marchinko, 2008). However, Corrigan (2003) points to a range
of factors leading to lost social opportunities for people with a mental illness, ranging from biological effects to societal stigma.

**Loss of friendships and intimate relationships.** Lost friendships were also commonly encountered by people with a mental illness in the studies reviewed (Chernomas et al., 2000; Chernomas, et al., 2008; Lewis, 2004; Nilsson et al., 2008; Parker, 2001). The loss of friends was connected to lost employment or education opportunities (Chernomas et al., 2008; Macias & Rodican, 1997) as well as lost energy and lack of mutuality (Nilsson et al., 2008). Some consumers perceived that lost friends did not understand their illness, which in turn created difficulties in relating with and connecting to the world around them (Chernomas et al., 2000). One person described the risk of disclosing illness and her choice not to, in the hope of preserving friendships (Parker, 2001). Lost friendships were experienced as particularly difficult for people who already had limited supports (Chernomas et al., 2008). Lost relationships with partners or spouses was also evident in several narratives (Dipple et al., 2002; Inder et al., 2008; Lim et al., 2004; Nilsson et al., 2008) and the loss of a sexual self was considered particularly challenging for people who had spent considerable time in hospital (Davies, 2001).

**Loss of family.** Lost relationships with family members due to the impact of mental illness was highlighted in several studies (Chernomas et al., 2000; Fox, 1999; Lim et al., 2004) and this was sometimes expressed in terms of abandonment (Young & Ensing, 1999; Pereira et al., 2005). Overwhelmingly however, the literature describing lost relationships with family focused upon children. Loss of relationships with children for women who have a mental illness is estimated to be high (Miller, 1997). For example, in one study, the percentage of mothers with serious mental illness who experienced custody loss was more than four times that of mothers without such disorders (Park, Solomon, & Mandell, 2006). The importance of custody issues for people with a mental illness, and women in particular, is reflected in many consumer accounts within the literature in the area of motherhood (Bassett, Lampe, & Lloyd, 1999; Dipple et al., 2002; Fox, 1999; Savvidou, Bozikas, Hatzigeleki, & Karavatos, 2003) but notably also within studies that did not
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specifically aim to explore parenting issues (Chernomas et al., 2000; Joseph-Kinzelman et al., 1994; Lewiston, 2007; Lyon & Parker, 2003; Pereira et al., 2005). Custody loss or losing contact with children was the greatest fear of mothers in one study which sought to understand the parenting experiences of 42 women with a mental illness (Nicholson, Sweeney, & Geller, 1998). In a study examining reasons for custody loss with 82 women who had a persistent, severe mental illness, approximately one third of the women (35%) cited their psychiatric condition as the central factor leading to the loss of custody of their children (Hollingsworth, 2004). Yet in another study, none of the mothers with a chronic mental illness who had lost custody of their children attributed this loss to psychiatric problems, however, the sample size was much smaller (n=10) (Sands, 1995).

The loss of relationships with children due to mental illness is not confined to custody loss. As Nicholson and colleagues (1998) point out, losing a child may occur through voluntary placements whilst a parent or carer is in hospital, through involuntary removal because of assumed, suspected or documented abuse or neglect or as a consequence of divorce. Furthermore, the loss of relationships with children and loss of motherhood may be experienced temporarily, such as during the postnatal period if a mother experiences puerperal psychosis (Robertson & Lyons, 2003). Yet although many postnatal mental illnesses are short-lived, consequences of a sense of lost motherhood and not being able to fulfil mothering duties may lead to intense feelings of guilt and inadequacy (Robertson & Lyons, 2003). Separation from children may also be prolonged during periods when mothers with a mental illness are unwell, resulting in the fear of custody loss (Schen, 2005). There are also reports from parents with a mental illness of ‘diagnoses being used against them’ by spouses and child welfare workers, leading to custody loss (Ackerson, 2003). Worry of this potential loss may contribute to a mother’s decompensation, non-compliance with treatment (Nicholson et al., 1998) or result in reluctance to seek healthcare (Ackerson, 2003; Miller, 1997), assistance with parenting skills (Bassett et al., 1999; Sands, 1995) or childcare (Kulkarni, 1997).

Even when children are returned to the care of parents
following temporary removal, mothers may worry of recurring loss and be aware that their behavior will be constantly monitored (Nicholson et al., 1998). Findings from a study exploring whether parents treated in public mental health services perceived they might lose child custody or visitation if they were not adherent to treatment showed almost 20% (n=36, 19%) perceived this to be the case, with the most prevalent sources of pressure being family (42%), followed by social services (28%) [Busch & Redlich, 2007]. Fear of losing custody was one of eight themes in a study exploring parenting roles for mothers with a mental illness, and this issue permeated all focus group discussions (Bassett et al., 1999).

**Future-oriented Losses**

Several future-oriented losses have already been considered, including the loss of future employment opportunities and the fear of potential custody loss. Loss of future was the final of four categories of loss included in the PLMI scale (Stein et al., 2005) which included items such as hope and plans for the future. It has been suggested that cumulative losses from mental illness may result in a loss of hope for the future (Lewis, 2004) or loss of a viable future (Wittmann & Keshavan, 2007). Fear of potential losses, including the loss of supports and resources, were evident in personal narratives about the experience of schizophrenia (Hochman et al., 2005; Parker, 2001) and because of the early onset of schizophrenia, this illness may take the form of lost potential, the loss of whom the person would have been were it not for the illness (Hochman et al., 2005). Lost opportunities (Noh, 2004), possibilities (Davies, 2001), goals (Deegan, 1996) and dreams (Corring & Cook, 2007; Davies, 2001; Deegan, 1996; Gould et al., 2005) appeared within many narratives about living with a mental illness. A lost sense of future is also noted to be closely connected to, and impact upon, flourishing in the present time (Deegan, 1996).

**Discussion**

This review reveals the enormous range and consequences of losses that occur due to mental illness. One striking finding was the number of qualitative studies in which loss was
reported as a theme but where the research did not specifically set out to explore this issue. These included studies exploring the mental illness experience generally (Davies, 2001; Fleming et al., 2009; Gould et al., 2005; Vellenga & Christenson, 1994; Wisdom et al., 2008), barriers to employment for men with a mental illness (Bassett et al., 2001), gender-related concerns (Lyon & Parker, 2003) and parenting experiences for women with a mental illness (Bassett et al., 1999; Robertson & Lyons, 2003). As we delve deeper into the nature and scope of loss associated with mental illness, the binding element of these circumstances is the way in which they relate to the self-identity of an individual, the logic of which has been examined by Giddens (1991). All human beings continuously monitor the circumstances of their activities as a feature of what they do, and such monitoring has discursive features, albeit limited in some situations. This has been explored by Giddens as a feature of social reflexivity whereby individual action is bound to social processes and circumstances.

Loss is often described as 'personal loss' (D'Andrea & Daniels, 1992; Harvey & Miller, 1998; Stein et al., 2005) yet so often, this epithet fails to accurately portray the nature of the loss experienced. Repeatedly within the literature, what is described as a 'personal loss' affects or is influenced by others, where 'others' may refer to an individual, group or society. This is easily apparent when a relationship is lost, as it is likely that this loss will impact on another person. However, a loss of employment will affect others, whether it is family members or more broadly the societal impact of unemployment. Similarly, many of the losses in the 'self or identity' section in this review are also influenced by others. For example, dignity or respect only exist, and are subsequently described, in reference to others, as are rights and freedom. Hence, many of the losses reviewed here are essentially social in nature and need to be considered in this light. It is recommended that clinicians and future researchers in this area avoid using expressions such as 'personal loss' and instead, adopt phrases that more accurately reflect the social nature of loss, such as 'interpersonal loss.'

It could be argued that our use of the category 'loss of self and identity' does not suitably capture the social nature of these losses. However, we remain mindful that though we are influenced by social contexts, we still possess and create our own
individuality (Giddens, 2009). Furthermore, losses were predominantly described in terms of being a loss to an individual, also captured in terms such as 'personal loss' and the assumed relationship between loss and grief, as previously noted. This emphasis upon the individual is a reflection of the individual model of disability and overarching individualism that dominates within Western societies (Giddens, 2009). More broadly, these observations can be understood within the structural phenomenon of individualization (Beck, 2007; Beck & Beck-Gernsheim, 2002), in which people are increasingly forced to construct their own life situations and biographies, in contrast to development through traditional cultural and social institutions. This process, imposed upon the individual by modern institutions, also shifts the opportunities and risks associated with making decisions onto individuals (Beck, 2007), which has important implications for people who have a mental illness as well as mental health reform in Western societies. These issues shall be considered in more detail shortly.

Although a range of losses have been highlighted to result from mental illness, effort to assess loss (Piper, Ogrodniczuk, Azim, & Weideman, 2001) and support people in this context is often lacking (Lafond, 1994). Several reasons for overlooking this topic have been offered. First, the impact of mental illness is not readily recognized as a loss or as a subject for grieving and thus generates an additional problem for people affected by mental illness, of grieving a loss when it is not recognized as a loss by society (Lafond, 1994). In addition, people who have sustained extensive loss may be threatening, 'as they reflect our own fears, and remind us of our own vulnerability,' which may result in a need to create distance from the person (Myhrvold, 2006, p. 125). Both potential explanations are largely concerned with micro considerations and it has been argued that social work may be better served by conceptualizing interventions in ways that more explicitly incorporate both micro and macro concerns (Wheeler-Brooks, 2009).

Turning to possible macro concerns, we live in a risk society (Beck, 1992; Giddens, 2002) that emphasizes managing risks and generates a diversity of possible futures (Giddens, 1999). Risk is closely connected with the concepts of security,
safety, responsibility and the aspiration to control, particularly with respect to controlling the future (Giddens, 1999). Giddens (1999) also notes that risk has several sides, one referring to the chance of avoiding an unwanted outcome and the other being an energizing quality, such as in financial markets. Risk plays a major role in policies and approaches within mental health care, although largely with the aim of assessing and managing risk (Kemshall, 2002; Pilgrim, 2008). In light of this and the intensity of emotions often experienced from loss, individuals and systems which support people with a mental illness, including families, health professionals and mental health policy, may avoid the topic of loss to avert possible risks. Yet by ignoring the subject of loss, people with a mental illness are denied the opportunity to disclose and share experiences of loss and engage in potentially cathartic responses. In turn, this may perpetuate stigma and social exclusion, by further marginalizing and disenfranchising people with a mental illness.

Risk is also closely bound to the concept of trust (Eriksson & Hummelvoll, 2008), a relationship which is of special interest within the field of mental health. In this review, issues of risk and trust governed decisions as to whether people with a mental illness disclosed their illness (Parker, 2001) or sought work (Chernomas et al., 2000). Mental health consumers also need to have trust in systems of care. Individual responsibility, empowerment and hope are cornerstones of a recovery orientation. For people with a mental illness, a great deal of self-trust and self-confidence will be crucial if the recovery approach is to be realized in its entirety. Exploring loss and its consequences may be considered a risky approach, yet this is crucial to rehabilitation (Lunt, 2001) and recovery in mental health (Davidson, O’Connell, Tondora, Styron, & Kangas, 2006; Deegan, 1996). On this point, Davidson and colleagues make an important distinction that it is peoples’ access to opportunities for taking risks that needs to be increased, not risks to providers or communities.

Stigma, social exclusion and social isolation and how these social problems impact upon the lives of people with a mental illness permeated throughout this review, including the meaning and consequences attributed to lost relationships,
the loss of dignity, respect, confidence and employment opportunities. Related to this, it is notable that the majority of losses reported were intangible, such as relationships, sense of freedom and opportunities. Exceptions to this observation were items such as personal belongings and physical elements, such as weight and bone density. At a therapeutic level, it is important that health professionals working with people who have a mental illness are mindful of the many losses that may impact upon clients in their journey of recovery (Chernomas et al., 2000; Gould et al., 2005) and the role that such loss and grief may play in perpetuating mental illness (Dipple et al., 2002). People who have a mental illness may need assistance in addressing losses (Bassett et al., 2001) and grieving lost opportunities (Wisdom et al., 2008) and this may take the form of acknowledging clients’ experiences of loss and fears about potential losses (McCrea & Spravka, 2008), grief counselling and stress management (Chernomas et al., 2008). However, it is important to note that within the literature, the concept of loss appears to have been taken for granted, for example, that grief must take place following a loss in order for recovery (Lafond, 1994) or reintegration within society to occur (Appelo et al., 1993). In challenging this assumption, it is recommended that this topic not be approached so prescriptively, but rather according to the needs of people affected by loss.

Many of the losses encompass several of the categories developed for this review; for example, the loss of employment opportunities may be categorized as a future-oriented loss. Loss has multiple dimensions and is therefore difficult to categorize. Furthermore, in many instances, losses precipitate from one another, resulting in a messy tangle of losses that is complex to discuss. The four core categories summarizing losses in this review reflect the volume of literature apparent in each of these areas, and should be approached with caution. For example, the areas of work and relationships for people with mental illness may have received greater research attention than others. Another example is the literature about loss of custody for parents with a mental illness, which was overwhelmingly focused on mothers’ experience of custody loss, with loss of custody amongst fathers with a mental illness
rarely encountered in this search. This review is limited by the search terms used to obtain papers. Words such as ‘reduction,’ ‘diminished’ and ‘decreased’ and consequences of losses, for example ‘loneliness,’ ‘divorce,’ and ‘suicide,’ which imply losses in areas such as relationships and future, were not used as search terms for this review. The review was also restricted to works written in English, most of which were delivered from a modern, Western perspective. These observations and overall review findings underline the need for further research in the area of loss from mental illness, with particular consideration to how other cultures perceive this topic and the impact of loss on recovery.

The vast array of losses that result from mental illness and the impact of such loss described in this review are important contributions to inform future mental health policy and practice. Pertinent to this task, particularly in light of the individualized recovery approach, will be to consider the largely social nature of loss and how this influences matters such as risk and responsibility. These observations point to the urgency in increasing opportunities for social inclusion and social capital for people with a mental illness. Further, it is important to ensure that people with a mental illness are included in the planning and evaluation of future mental health services and policy. Finally, crucial to realising a recovery vision that supports self-determination and empowerment, opportunities need to be made available within a supportive environment to assist people to explore loss, take risks and grow beyond the presence of mental illness.

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References


Influences on Job Retention Among Homeless Persons with Substance Abuse or Psychiatric Disabilities

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Job retention is an important psychosocial rehabilitation goal, but one that is not often achieved. We investigate facilitators of and barriers to employment retention among homeless individuals with psychiatric and substance abuse diagnoses who were re-interviewed eight or more years after participating in a traditional vocational rehabilitation program. Most program graduates who maintained employment had secured social support from a variety of sources; personal motivation was also a critical element in job retention and compensated in some cases for an absence of social support. Both the availability of social support contacts and personal motivation influenced likelihood of maintaining sobriety. Physical health problems prevented continued employment for several individuals despite social support and desire to work, while receipt of disability benefits seemed to reduce work motivation.

Key words: vocational rehabilitation; homelessness; social support; mental illness; substance abuse

Securing and maintaining employment are important goals in psychosocial rehabilitation programs, but they are neither
often nor readily achieved. Between one-tenth and one-third of individuals with severe and persistent psychiatric disabilities are competitively employed at any given time; the fraction employed falls in the lower end of that range for persons who are also homeless and/or who abuse substances (Gold, Meisler, DuRoss, & Bailey, 2004; Rosenheck, Leslie, Keefe, McEvoy, Swartz, Perkins, et al., 2006; Wells & Williams, 2003). When compared to other homeless individuals, those with substance abuse disorders are less likely to have worked and they are likely to have worked fewer months in the last year and to have experienced longer periods of unemployment since their last job (Burt, Aron, & Lee, 1999; Wells & Williams, 2003). In a national study, the 20 percent of homeless persons who were working had only temporary jobs or received insufficient pay to maintain housing (Burt et al., 1999).

A growing body of research identifies predictors of the ability to secure employment among persons experiencing psychiatric or substance abuse disabilities or homelessness. Few, however, have focused on the factors involved in retaining jobs once they are secured. This scholarly lacuna results in part from the program evaluation focus of much employment rehabilitation research: securing a job is a successful program outcome, but maintaining a job is influenced by post-program factors that are harder to identify and outside of the program's control. Investigation of employment retention also requires maintaining contact with participants over a longer follow-up period, thus imposing additional burdens on research design. Yet such challenges must be overcome in order to fill this critical gap in scholarly understanding of individual behavior and program effectiveness in the world beyond the workshop.

The National Health Interview Survey on Disability (NHIS-D) identified the employment rate for individuals with any diagnosed mental disorder as 44% (McAlpine & Warner, 2001), while estimates for those with severe and persistent psychiatric disabilities range from 10% to 30% (Wewiorski & Fabian, 2004). Rates of competitive employment for homeless persons with severe mental illness have been estimated at between 7 and 21% (Pickett-Schenk, Cook, Grey, Banghart, Rosenheck & Randolph, 2002; Rog, Holupka, Brito, Storm, Hopper, Roy, et al., 1998; Rosenheck et al., 2006; Shern et al., 1997) and as only
slightly higher for homeless persons with substance abuse disorders (Wells and Williams, 2003; see also Rog & Holupka, 1999).

When asked, 42% of homeless persons identify finding employment as a primary need and 24% note lack of employment as a key reason for their homelessness (Burt et al., 1999). Almost three-quarters of persons with psychiatric disabilities aspire to satisfying employment (Center for Mental Health Services, 2003; Cook, Pickett-Schenk, Grey, Banghart, Rosenheck, & Randolph, 2001; Shaheen, Williams, & Dennis, 2003; Trutko, Barnow, Kessler-Beck, & Rothstein, 1997) and rehabilitation experts identify employment as a critical element in reducing homelessness among persons with severe mental illness and improving their quality of life (Bianco & Shaheen, 1998; Ratcliff, Shillito, & Poppe, 1996; Pickett-Schenk et al., 2002).

In spite of this high level of interest in employment, traditional vocational rehabilitation programs that seek to prepare mental health clients for work have had, at best, limited success (Bond, Becker, Drake, & Volger, 1999). Rates of placement in competitive (paid) work were only 17% and 29% in two traditional vocational rehabilitation programs reviewed by Twamley, Padin, Bayne, Narvaez, Williams, and Jeste (2005), while Bond (2004) found an average competitive employment rate of 19% in nine studies, and Crowther, Marshall, Bond and Huxley's (2001) meta-analysis indicated an average competitive employment rate of only 12% one year after the program experience. By contrast, in one recent review of nine studies, supported employment programs that emphasize rapid job placement and as-needed continuous support—termed the "Individual Placement and Support" (IPS) model—have yielded much higher rates of placement in competitive jobs, from 32% to 78% (Bond, Becker, Drake, & Volger, 1997), with a mean of 56% competitively employed for at least one day during follow-up periods up to two years (Bond, 2004).

Yet securing employment does not itself eliminate employment-related difficulties: jobs that are obtained often involve very low pay, no benefits, temporary positions and menial work (Becker, Whitley, Bailey, & Drake, 2007; Burt et al., 1999; Wells & Williams, 2003). Moreover, the rate of competitive
employment tends to decline after one or two years in an IPS program, resulting in long-term employment rates that are similar to traditional vocational training programs (Becker, Drake, Bond, Xie, Dain, & Harrison, 1998; Bond et al., 1997; see also Dorio & Marine, 2004; Zuvekas & Hill, 2001; Drake, McHugo, Bebous, Becker, Harris, Bond, et al., 1999). Job acquisition does not mean job retention (Lehman, Goldberg, Dixon, McNary, Postrado, Hackman et al., 2002).

Most efforts to predict employment outcomes among persons with psychiatric or substance abuse disorders have focused primary attention on employment acquisition, have used preexisting individual characteristics as predictors, and have explained little of the variance in outcomes (Collins, Mowbray & Bybee, 2000; Wewiorski & Fabian, 2004). The few studies of job retention after successful job acquisition indicate that service provision is more important than individual characteristics or level of functioning (e.g., Clark, Xie, Becker & Drake, 1998). The likelihood of job retention increases with the intensity of support provided (Becker, Xie, McHugo, Halliday, & Martinez, 2006; Collins et al., 2000), with the availability of supportive clinicians (Quimby, Drake, Becker, 2001), and with the provision of ongoing, integrated social support rather than simply clinical services (Becker et al., 2006; Dorio & Marine, 2004; McKay, Johnsen, & Stein, 2005). Using retrospective interviews with consumers who had been placed in jobs through an IPS program at least eight years earlier, Becker et al. (2007) also found that ongoing support from employment specialists improved retention, while the likelihood of job retention was reduced for those working full-time rather than part-time and for those experiencing severe psychiatric symptoms. By contrast, sociodemographic characteristics do not appear to be associated with the likelihood of job retention (Becker et al., 2007).

However, these limited findings of beneficial social support effects have been called into question after Leff, Cook, Gold, Toprac, Blyler, Goldberg et al.'s (2005) meta-analysis of data for 1,340 participants collected at seven sites of the Employment Intervention Demonstration Program (EIDP). Receipt of on-site counseling, support and problem solving was associated with job retention—but this relationship was due to
individuals who retained their jobs and then received more support, not to a higher rate of job retention after receiving job support.

Work motivation and its components have not been examined in research on employment outcomes among homeless persons, but research on persons with substance abuse disorders has identified self-efficacy, self-direction and self-belief as important motivational factors affecting behaviors ranging from drug abuse to job acquisition and retention (Miller, 1996; Roessler, 1998). Numerous trials have established the efficacy of motivational interviewing—a form of counseling “for eliciting behavior change by helping clients to explore and resolve ambivalence”—for substance abuse treatment retention and other outcomes (Miller & Rollnick, 1991; Miller & Rollnick, 2002; Miller, Yahne, Moyers, Martinez, & Pirritano, 2004; Rollnick & Miller, 1995). Ongoing interpersonal interaction can also change motivation (Bien, Miller, & Boroughs, 1993).

We examine in this article the factors affecting job retention among former participants in a community rehabilitation program (CRP) for homeless persons with psychiatric or substance abuse disabilities. We focus primary attention on the role of social support, including support from service personnel (Becker et al., 2006; Becker et al., 2007; Cook, Lehman & Drake, 2005) and the influence of motivation in job retention (Roessler, 1998). Our sample includes both participants who were still working one or more years after program participation and participants who were no longer working. Through analysis of responses in intensive interviews, we are able to compare the characteristics and orientations of participants who retained jobs with those who lost them. We were also able to elicit and examine the participants’ perspectives on the reasons that they were able or unable to retain their jobs. Although our approach is similar to Becker et al.’s (2007) recent study of an Individual Placement and Support (IPS) program, we focus instead on alumni of an employment and vocational rehabilitation program dedicated to homeless people with disabilities who began with a sheltered workshop experience.
Methods

As little is known about the experiences of homeless individuals with disabilities who are transitioning from chronic unemployment to sustained employment, an exploratory qualitative research approach was used (Denzin & Lincoln, 2005). Semi-structured interviews allowed participants to describe their lived experiences and their perceptions during the process of recovery and reintegration into their communities. We used grounded theory methodology (Charmaz, 2006; Strauss & Corbin, 1998) to analyze our data so as to develop a theoretical understanding of the concepts and issues related to job retention, social connections and processes, and disability.

All participants were recruited from a community rehabilitation program (CRP) that provided specific employment and vocational rehabilitation services to homeless persons with disabilities. Participants were referred to the program by shelters and homeless programs in an urban area. The referring agency screened the participant for diagnosis (usually mental illness or substance abuse) and confirmed that the individual had been clean and sober for a minimum of three months. Subjects received employment and vocational rehabilitation services ranging from rapid employment placement, vocational training, assistance with a resume and job applications, job interview practice, internet job search, and employer networking. Case managers also assisted the participant, as necessary, in identifying employer contacts and networking within the community. An employment placement specialist networked with employers and coordinated interviews. After participants obtained employment, the case manager coordinated other homeless service resources such as housing, medical/rehabilitation treatment, criminal justice services, or transportation. Follow-up services continued for 90 days and ranged from periodic telephone contact to more intense monitoring of medical treatment and social/housing/leisure activity development.

In contrast to the IPS-model programs that have been the focus of much recent research (Becker et al., 2006; Lehman et al., 2002), this employment and vocational program accepted referrals from shelter and community homeless programs and provided services within a traditional community
Job Retention among Homeless Persons

rehabilitation program in which participants received employment experience and training in a sheltered workshop prior to competitive job placement. Also, the employment goal was full-time competitive employment, although an individual could start with or change to fewer than full-time hours based on individual factors or preferred job availability. Since our focus is on long-term job retention, we do not think that this different starting point raises issues different from those investigated in Becker et al.’s (2007) long-term follow-up of job retention among IPS participants.

We used a maximum variation sampling strategy (Miles & Huberman, 1994) to allow us to capture the diverse experiences of individual participants, as well as to identify common issues relating to job acquisition and job retention. Individuals were recruited from one to five years after post-program placement in competitive jobs. Twenty-three participants demonstrated sustained competitive employment and 12 obtained employment but did not sustain employment. Sustained competitive employment was defined as more than 90 days of employment, with no more than two periods of unemployment of no more than one week each, earning at least minimum wage for a minimum of 20 hours per week.

Homeless individuals have a wide range of disabilities, but the most common disabilities are mental illness and chronic substance abuse. We focused only on those with psychiatric and/or substance abuse disabilities. We stratified the sample based on disability type, gender and minority status and selected cases so as to achieve equal numbers of men and women, of white and African-American respondents, and a proportion of substance abusers and mentally ill clients that was equivalent to our population of program graduates. We selected 23 individuals who had sustained employment and 12 subjects who had obtained employment but were unable to retain their job. None of those invited to participate in an interview refused. All had histories of substance abuse and had been clean and sober at the time of job placement, or had a history of psychiatric illness, as defined by the referring agency and documented in the individual’s agency record.

Using this sampling strategy, we aimed to identify common patterns and experiences that cut across different types of
cases (Denzin & Lincoln, 2005). We developed a semi-structured face-to-face interview protocol incorporating input from homeless people with disabilities and information gathered during two preliminary focus groups. The interview schedule requested information about sociodemographic characteristics, prior program participation, and employment history, and then asked open-ended questions about health, program experience, social relations, service supports, work experience, and work-related attitudes. Levels of social support were summarized using an index comprised of answers to questions about support received from friends, family, support personnel and coworkers. Each question was scored on a five-point scale ranging from "very negative" to "very positive." Substance abuse status was coded as "solid" (also used for those who did not have a substance abuse history), "in recovery," or "not in recovery."

The interview protocol was piloted with individuals who were homeless and had a disability and who had acquired employment through the agency. We then interviewed 35 participants who had acquired employment through the community rehabilitation agency over the previous five years. The interviews ranged in length from one to two hours and were conducted by trained interviewers from Boston University's Sargent College of Rehabilitation Sciences. Boston University's IRB approved all research procedures.

Each interview was tape-recorded and transcribed. The resulting text files were entered into a qualitative data analysis program, NVivo, by a trained research assistant. Initial codes were based on the interview questions but were elaborated through an inductive process, with the co-investigators reviewing each code and the associated text.

Our analysis begins with a description of the sample. We then compare cases with positive and negative work outcomes, focusing on comments about social supports and motivation and noting consistencies and inconsistencies in these comments.
Results

The detailed information about employment outcomes obtained in the interviews modified our a priori classification of one case, so that 11 cases in our obtained sample had negative employment outcomes (two of which had begun with a positive work outcome), while 24 cases had positive employment outcomes (one of which had begun with a negative work record). Graduates were working in jobs ranging from janitorial, warehouse, food services and housekeeping work to receptionist, clerk, line worker, health aide and counselor, with the majority in “blue collar service” occupations. The average tenure in their last job was 1.2 years, while they had worked an average of 5.3 years in their last three jobs.

Eight of the 14 graduates with positive work outcomes had maintained their sobriety and developed multiple supportive social relations. Their comments often indicated pride in their sobriety:

Once I did get sober and I had some sobriety under my belt I started to get a life; you know, life happens.

[i]t was fun you know, cause I had found my body, you know and I didn’t haf’ta be somebody else all the time.

One successful graduate had been incarcerated while his son grew up and had been rejected by his family because of his drug use and difficult behaviors. After gaining his sobriety, he was able to reestablish positive relations with family members: “They respect me, they admire me.” He said of his father, who previously had banished him from the house, that he “was very, very proud of me.”

Successful graduates highlighted the value of relations with supportive staff. Case managers and other staff could provide both instrumental assistance and general encouragement. One graduate described a case manager who had helped with evaluating psychotropic medication needs and remarked that through a relationship with a therapist, he found that “somebody finally believed in me.” Another emphasized the
value of ongoing supportive ties with program staff:

REALLY important...[to be in touch with case managers after leaving the employment program.] You know, and it makes you feel good...and then again, too, I want THEM to know that I appreciate the work they did for me.

Another case manager advised her client how to dress for an interview and to develop a resume. The client said, "...[the case manager explained how to] gap the thirteen years I wasn't working when I was caught up in the grip of my disease." Yet another case manager stayed with a client through three days of detox, developed a trusting relationship, and subsequently walked the client through a job interview. "...if it wasn't for him, I don't know what I would have did." And another graduate described his "solid relationship" with his case manager, and remarked, "I don't know if I have the words to express how wonderful she was, I mean...."

The successful graduates also often emphasized the value of their ties with a spouse, supervisor, or friends. One was now living with his son and father, had a supportive landlord and a very supportive supervisor, and maintained a close relationship with his mother-in-law in spite of the termination of his relationship with his drug-using wife. Several mentioned their focus on maintaining friends with others who were "doing the right things" and on staying away from former substance-abusing contacts. Another took pride in demonstrating his accomplishments to his friends, in part as a way of acknowledging their help: "I wanted them to know, 'Okay, I'm showin' you that I DID want to do somethin'. You know, 'what you did is payin' off.' So I always would call 'em."

The 11 graduates with negative post-program employment outcomes reported sporadic work histories. In many cases, they also noted increasing difficulties in jobs before they left the labor market. One graduate who had stopped working reported problems with coworkers, problems with supervisors who didn't speak English, problems with literacy, and the appeal of receiving Social Security Income instead of working:

I just didn't like it; too hectic for me; got into a fight,
bored, didn’t get along with people, just couldn’t do it [write things down]; felt like that people were lookin’ at me [due to illiteracy].

Rather than being a source of support, friends, family and workplace contacts were sometimes seen as obstacles. One graduate “had to do the work of coworkers,” stated “nobody helps me,” and states that a boss was “a big jerk.” Reports of rejecting social opportunities and being out of touch with family members were common. One graduate would “constantly lock myself in the room and just stay in there and watch TV.” Another explained that “I’d rather do things my way.”

Uncontrolled substance abuse was also common: “And then I had picked up, and I didn’t get any better…but I did it anyway…. It’s a shame when you KNOW you’re doin’ wrong and you do it anyway.”

The differences in substance abuse and social supports between those who retained their jobs and those who did not are summarized in Tables 1 and 2. Seventeen percent of those with negative work outcomes were not in recovery, compared to none of those with positive work outcomes. Furthermore, the average level of social support was significantly higher among those with positive work outcomes than among those with negative work outcomes. Alcoholics Anonymous was often cited as a source of peer support to maintain sobriety.

Table 1. Recovery Status by Sustained Employment

<table>
<thead>
<tr>
<th>Recovery Status</th>
<th>Sustained Employment</th>
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<tbody>
<tr>
<td></td>
<td>Not Sustained</td>
</tr>
<tr>
<td>Not in recovery</td>
<td>16.7%</td>
</tr>
<tr>
<td>In recovery</td>
<td>50.0</td>
</tr>
<tr>
<td>Solid*</td>
<td>33.3</td>
</tr>
<tr>
<td>Total</td>
<td>100.0%</td>
</tr>
<tr>
<td>N</td>
<td>(12)</td>
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</tbody>
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*Includes those who had not had a substance abuse problem.

t2=4.74, df=2, p=.093.
Stress was a common complaint among those who had lost their jobs. One graduate reported that on one job, things "got hectic" and he "ended up doing' everybody else's jobs." Another, who reported that she "loved" working and was given "employee of the month," ultimately resigned from her job due to the level of stress she experienced.

What seemed to distinguish two respondents who had managed to maintain positive work outcomes in spite of problems with sobriety and social supports was a high level of motivation to change. One graduate had "to change everything" by turning away from old substance-abusing friends and by seeking out coworkers in order to develop new friendships.

I mean, I had, I was... I had tunnel vision. I had tunnel vision. And I was gonna do this!... knew that I needed a good job...in order to have...to HAVE the pride. ...there's so many people out there that are just...they're just WAREHOUSED! ...if you're flippin' burgers at McDonald's and you're forty-seven years old, right? Where's your pride?

Another graduate linked his high level of motivation to vocational rehabilitation:

Thank God when I got here I had a desire to do whatever it took to stay sober.... When you first went there, nobody's gonna make you, you make out the list of what you want to do in your mind to go on. I wanted to get a job and get my own place. I pushed myself.

By contrast, low levels of motivation were expressed by several who had not maintained employment. "I, um...basically, I had no choice there...I HAD to get a job, because that was one of the rules of livin' at the house."

In another case, receipt of Social Security Income benefits diminished interest in working, despite the recognition that with a job, "[t]hat responsibility is...you enjoy that and...and that keeps you...that's one of the things that keeps you goin'."
Table 2. Social support by sustained employment

<table>
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<tr>
<th>Social Support Score</th>
<th>Not Sustained</th>
<th>Sustained</th>
</tr>
</thead>
<tbody>
<tr>
<td>$\bar{x}$ (s.d.)</td>
<td>3.28 (1.0)</td>
<td>3.87 (.66)</td>
</tr>
<tr>
<td>N</td>
<td>12</td>
<td>23</td>
</tr>
</tbody>
</table>

$t = -2.1$, d.f. = 33, $p = .043$

In every case of ongoing employment, one or more reliable sources of social support had been developed. However, some graduates who had established supportive relations with one or more contacts were still not able to maintain competitive employment. For some of these graduates, a negative experience with coworkers or a supervisor diminished the interest in seeking another job. For example, one graduate reported a poorly run job in a kitchen with a lot of pressure, poorly trained coworkers, and insufficient help. Repeated headaches, the need to take job time for medical appointments related to her rheumatoid arthritis, and diabetes compounded problems with a supervisor and led to her decision to resign.

Two graduates had negative work outcomes despite having maintained their sobriety and having developed meaningful social supports. Health problems were employment barriers to continued employment in both cases.

I couldn’t hold a job for forty to forty-five hours a week, I know that. You know I...would like to do something maybe like twenty hours a week. ...I’m the type I want to get out, so hopefully, by next summer I’ll be doing something. You know, I, well, I like extra money.

Should I get off the disability permanently and try to work full time and know, at the same time, the last couple of years at um, and as I get older, it’s not any better [health problems], you know what I mean.

The likelihood of job retention and the level of social supports were generally similar for men and women, for black, Hispanic and white sample members, and for those identified
as having psychiatric disabilities. However, individuals whose comments indicated they were solidly in recovery from substance abuse tended to have more positive work-based social relations and were more likely to be working than those whose recovery from addiction was not so certain. In addition, half of black respondents described their relations with service staff in terms that were rated as “very good,” as compared to just one in seven white respondents.

Discussion

Our investigation of employment retention among graduates of a sheltered workshop program for homeless persons with disabilities adds new insights to the literature on job retention. Respondents described social support processes involving family, friends, coworkers, and Alcoholics' Anonymous peers as providing both critical incentives and important practical and emotional resources. Connections with professional staff were also critical in many cases, sometimes complementing natural social supports and sometimes compensating for their absence. Although the types of professional supports ranged from mental health counselors to job placement advisors, it appeared to be both the practical advice and the respect and esteem that an empathetic professional could provide regardless of their official job title that was critical to many graduates. Given these multiple sources of social support, focusing on just formal supports offered through a job support program or even any type of support offered only at work will inevitably underestimate the value of social support (Leff et al., 2005). In this result, we lend support to the understanding of the multifaceted and fungible nature of social support revealed in Laub and Sampson’s (2003) life course study, in Rogers, Anthony and Lyass’s (2004) analysis of perceived support among vocational rehabilitation clients, and in Arrigo and Takahashi’s (2006) identification of the value of community-building processes among former homeless decarcerated addicts living in an SRO (single room occupancy) residence.

Personal motivation, or “agency” (Laub & Sampson, 2003) was also a critical element in job retention and in some cases was sufficient to compensate for deficient social supports.
Several graduates described a reciprocal reinforcement process in which those who provided social support increased their personal motivation, which then fueled their desire to maintain that support and not let others down. In contrast, those with low levels of work motivation, whether due to a prior disinterest in work, health problems, or the receipt of SSI, were quick to resign from their jobs or to delay seeking new jobs when problems developed.

Maintenance of sobriety was intertwined with both social support processes and personal motivation. Several respondents emphasized the importance of their decision to stay away from former substance-abusing friends as a critical element in their successful post-program employment experience. In almost every instance of successful job maintenance among former substance abusers, the commitment to maintain sobriety went hand-in-hand with the commitment to maintain employment. Family, friends, and professional staff were just as important in reinforcing a commitment to maintain sobriety as they were for encouraging continued employment. Personal orientation and the presence of social support were inseparably linked with regard to their influences on individual behavior.

Because we used retrospective interviews to assess post-program experiences, we cannot adequately disentangle cause and effect in the relationships we have examined. We do not know if the type of month-by-month analysis that Leff et al. (2005) conducted with the EIDP data would call into question our respondents' assertions about the timing of support and job loss. However, our findings are consistent with most of the limited literature on employment retention among persons with disabilities as well as with the more general scholarship on the predictors of successful outcomes for persons with disabilities. Like Becker et al. (2007), we found that ongoing staff support was beneficial and that part-time rather than full-time employment could increase job retention by reducing stress and maintaining eligibility for financial benefits. We encourage further research using more rigorous longitudinal or experimental designs in order to conduct formal hypothesis tests. The greater benefit that African American respondents seemed to derive from their relations with service personnel should also be explored in job retention studies that have larger samples.
and more measures of potential mediating factors.

We also note the limitation of our sample to homeless persons with disabilities who were referred to a sheltered workshop program and who graduated from that program. We suspect that in a sample composed of individuals who were less accepting of services, the ratio of positive to negative employment outcomes would be much lower and that levels of social support and personal motivation would be considerably reduced. Although our purposive selection of cases of employment failure as well as success help somewhat to mitigate the consequences of our service-involved sample, it is also possible that predictors of employment retention would change with a different sample. On the other hand, the comparable rates of job loss among persons who have completed traditional rehabilitation programs, as in our sample, and those who have completed IPS programs suggest that there may be many similarities in the processes involved in job retention.

Conclusions

Consistent with prior investigations of long-term employment outcomes of formerly homeless persons with substance abuse and/or psychiatric disabilities, our research indicates that job retention is not easily achieved even after initial job placement. Although all participants in the program we studied had initially been placed in jobs, about half in our long-term follow up were no longer employed. Whether the starting point is an IPS-supported employment model or a sheltered workshop program like the one we studied, long-term outcomes seem to be similar.

What our research adds to previous investigations is further understanding of the factors that influence job retention after initial job placement. Our results suggest that the key to successful transition to long-term employment is long-term supports that are developed in a community context, not the initial employment method used. Whatever their starting point, what is critical for persons with histories of homelessness, mental illness and/or substance abuse is developing a package of supports while they are in a vocational rehabilitation program that they can continue to access after leaving the formal program. These supports can be garnered through
service staff, family and friends, or directly in the workplace, but they are critical for most individuals. Many persons may not easily develop such supports without active program assistance, and our findings suggest that this may be achieved more easily if there is a preliminary preparatory period prior to movement into community-based employment.

Our results also highlight the importance of three other factors in long-term job retention. Ongoing substance abuse treatment programs should be available in all vocationally-oriented rehabilitation programs in order to encourage maintenance of sobriety and therefore maximize the likelihood of job retention. The paradox of welfare benefits such as SSI should also be recognized in employment programs. While such benefits can be critical to survival for many persons suffering from disabilities, they also can serve as a disincentive to work. Transfer payment policies should be reexamined in order to ensure that persons with disabilities can work the number of hours they can manage and not suffer reduced income as a result. Further research should also test the value of motivational interviewing in order to overcome lack of motivation as a barrier to job retention.

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E-therapy as a Means for Addressing Barriers to Substance Use Disorder Treatment for Persons who are Deaf

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Persons who are deaf face a number of challenges with regard to vulnerability for substance use disorders. Moreover, accessible treatment for this condition can be difficult to establish and maintain. The Deaf community may be one of the most disenfranchised groups in America in regard to appropriate access to substance use disorder (SUD) prevention and treatment services. This article reviews findings related to substance use disorder and treatment for this condition among persons who are deaf. It also reviews a promising approach for addressing treatment needs via e-therapy, and it highlights the challenges and concerns regarding e-therapy for this population. E-therapy services demonstrate promise in reaching a larger and therefore more economically viable treatment population of deaf individuals while providing culturally appropriate and comprehensible recovery support options. Demographic and intermediate treatment outcome data are presented on a state-wide
program established to serve persons who are deaf in the mid-west.

Key words: deaf, substance use disorders, treatment, e-therapy, culturally appropriate

Research since the 1980s has indicated that persons who are deaf face a number of challenges with regard to alcoholism and/or drug abuse (Boros, 1981). The concerns focus on two factors: the risks for substance use disorders (SUD) are appreciable (Guthmann & Moore, 2007), and access to traditional SUD treatment is very limited. The Deaf community may be one of the most disenfranchised groups in America in regard to appropriate access to SUD prevention and treatment services. This article outlines the substance abuse risks and previous efforts to address this need. It also reviews a promising approach for addressing these needs via e-therapy, and highlights the challenges and concerns regarding e-therapy for this population.

Based on estimates taken from the National Health Interview Survey, the United States has an estimated 500,000 persons who are deaf and nearly double that number who "at best, can hear & understand words shouted at the better ear" (Holt, Hotto, & Cole, 1994; NCHS, 1994). This source, although dated, is likely a better determinant of the percentage of the Deaf population, as more recent nationally representative surveys group "deaf" with "hearing impaired," thereby artificially inflating the probable percentage of persons who are deaf (Mitchell, 2004). Severely and profoundly deaf individuals require accommodations beyond hearing aids in order to access their communities and workplaces. The numbers above are rough estimates, as people who are deaf do not use telephones, which is the standard method for obtaining census-based data.

Establishing an estimate on the number of persons who are deaf and experience SUD also is tenuous. The most methodologically rigorous study to date utilized a regional survey of substance use by deaf individuals by means of an interactive ASL-based kiosk in New York City and the upstate New York area. The researchers concluded that alcohol and drug use in this population is similar to patterns reported for the general
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population (Lipton & Goldstein, 1997). However, this survey was conducted in public places, such as libraries and deaf clubs. Some researchers contend that deaf individuals at greatest risk for SUD are those who are socially isolated and less connected with the Deaf or hearing communities, as well as being less fluent in ASL (Guthmann & Blozis, 2001). Therefore the actual percentage of deaf persons with SUD may be higher. This is reflected by the majority of articles on SUD among the Deaf, as it is generally assumed that SUD rates are higher than the general population.

A number of barriers exist when trying to provide substance abuse treatment services for deaf individuals (Heavyrunner, 1992; Guthmann, 1999; Titus, Schiller, & Guthmann, 2009). Concern about accessibility for the Deaf to SUD treatment programs have been repeatedly documented (Berman, 1990; Boros, 1980; Guthmann & Graham, 2004; Lane, 1985; Miller, 1990; Moore & Polsgrove, 1991). Contributing to problems linking with services, SUD treatment providers do not fully understand their responsibilities for serving the Deaf, or they encounter difficulty in paying for sign language interpreters. Researchers and advocates maintain that the majority of substance abuse treatment programs are not culturally or linguistically accessible (Ferreyra, Rousso, & deMiranda, 2002). Specifically, few programs have counselors who are deaf and/or fluent in ASL, or they do not use interpreters or technology to provide access (video phone, video relay, equipped with flashing alarms, etc.).

The specific barriers to SUD treatment for persons who are deaf include the following:

1. Deafness is a low incidence condition, and most SUD providers rarely receive referrals concerning deaf individuals. As such, they are generally unprepared to provide ready access to treatment. Historically, the array of treatment services available to hearing individuals has not been accessible for deaf people.

2. Deaf individuals, their families or professionals serving them may struggle for lengthy periods of time attempting to locate and access appropriate programming (Guthmann & Sandberg, 1998).

3. Specialized programming to meet the needs of deaf
individuals is costly due to the need for specially trained staff and/or interpreters, travel costs, and the depth and breadth of consumer needs. For example, aftercare and sobriety support needs are thought to be a greater need within the Deaf community (Waltzer, 1992).

4. Group therapy, the most common method for SUD treatment, is very difficult to comprehend for persons who are deaf, even when certified interpreters are present and the consumer is fluent in sign language. Concepts such as "sobriety" or "higher power" are largely absent from the Deaf lexicon (Guthmann & Sandberg, 1998), and language idioms do not translate (e.g., "Denial is not a river in Egypt" makes no sense for a culturally Deaf person). ASL is a separate and distinct language with its own set of rules and the syntax and grammar are totally different from spoken and written English. The average reading level of persons who are Deaf with a high school diploma is reported to be somewhere between 4th-6th grade (Holt, Traxler, & Allen, 1997).

5. Self-help and peer support are critically important elements of recovery, but this is largely missing for someone who is deaf.

6. Sign language interpreter skills vary widely, and few interpreters are trained in substance abuse and treatment terminologies. Paying for interpreter services can be a challenge in many cases, as this service is not budgeted by providers, although it is required by the Americans with Disabilities Acts (1990) and its amendments (2008).

7. Interpreters cannot always be on site, so the Deaf consumer misses many conversations and encounters. When interpreters are secured, they may not be hired to provide services for all treatment services available. For example, a treatment provider in Ohio arranged for group therapy interpreting in 90 minute blocks, although the group therapy was conducted for two hours. This was explained as a financial decision, as the hired agency required a second interpreter for any job beyond 90 minutes given the physical and mental intensity involved in ASL translation. After 20 minutes of bilingual translation, an interpreter's accuracy may be significantly reduced, and many agencies require two interpreters for any engagement beyond one hour and mandate that the two trade off duties every 20
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8. Persons who are deaf experience confidentiality problems associated with attending substance abuse treatment. The relatively small size of the Deaf community means that many others in that immediate community will be aware of the individual's SUD status. A lack of confidentiality contributes to the reluctance within the Deaf community to admit to an SUD problem or seek services (Boros, 1989).

9. Persons who are deaf feel the need to fit in and not "make waves." This can mean that persons who are deaf do not understand aspects of what is going on in therapy or in taking prescribed medications, but they will not ask for clarification (Guthmann & Blozis, 2001).

Background on National SUD treatment for the Deaf

In 1998, the National Association for Alcohol, Drugs, and Disability, Inc. (NAADD) released Access Limited—Substance Abuse Services for People with Disabilities: A National Perspective (NAADD, 1998). This report detailed the needs of persons with disabilities regarding access to SUD treatment. Utilizing survey data from 30 California SUD treatment providers, NAADD reported that only 13% of the programs made sign language interpreters available to Deaf clients, no programs had visual emergency alarms for persons who are deaf, and only two programs maintained active TTY devices for communicating with the Deaf.

One of the longest standing programs to serve the SUD treatment needs of deaf individuals is the Minnesota Chemical Dependency Program for the Deaf and Hard of Hearing Individuals (MCDPDHHI). The program was established as part of the Fairview Health Services–University Medical Center in Minneapolis in 1989 and has served as a model for 20 years. One characteristic of the program that speaks to the need is that in any given year up to 60% of program consumers come from somewhere outside Minnesota. MCDPDHHI is a specialized program designed to meet the communication and cultural needs of deaf and hard of hearing persons in alcohol and drug abuse treatment. The program has treated
over 1200 deaf individuals over its history, and was one of the first programs established to provide specialized substance abuse treatment services to deaf individuals. All staff that work at the program are fluent in ASL, and many are themselves deaf. The program utilizes a self-help support, cognitive behavioral treatment approach that relies heavily on non-printed materials. This includes a strong focus on consumer-generated drawings and art that depict various aspects of addiction and recovery (Guthmann, Lybarger, & Sandberg, 1993). Since the creation of MCDPDHHI, the Americans with Disabilities Act (1990), the ADA amendments (2008), and the Paul Wellstone and Pete Domenici Mental Health Parity and Addiction Equity Act of 2008 were all passed. Consequently, one might assume that SUD services for the Deaf would have become more prevalent in the U.S. during that time. However, the opposite appears to be the case. In 1991, the Substance Abuse Resources and Disability Issues (SARDI) program in the Wright State University School of Medicine compiled a list of all SUD treatment programs in the U.S. that were especially oriented to serving persons with disabilities. Among the list of 22 programs identified nationally, 12 were specialized in deafness (SARDI, 1992). In 2001 only two programs were still in existence, including the MCDPDHHI. In each case of program closure, attrition of specialized programs was attributed to the high unit cost of operation, low census, or inability to find staff with the appropriate training and/or credentials. Low census is especially relevant to programs specialized in deaf SUD treatment, even when the services are established as state-wide entities.

Some treatment programs have attempted to resolve the communication issue by using a sign language interpreter and integrating deaf consumers into the regular treatment process. Programs that provide interpreters for a portion of the treatment programming are considered to be “mainstreamed” programs, which mean that the consumers in the program are predominantly hearing. Staff are typically unable to communicate to the consumer without the use of a sign language interpreter. Although some individuals are successful in this environment, many deaf people do not fully benefit from the treatment experience. Often, the interpreter is provided only
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for formal programming and the Deaf person is excluded from communication opportunities with other consumers during activities such as free time and meals. When “deaf” and “hard of hearing” are considered as one group, successful discharges from treatment are comparable to the general treatment population; however, additional research is needed that specifically investigates “deaf” populations (Moore & McAweeney, 2007).

Current SUD Treatment Programs Specialized For Serving Individuals Who Are Deaf

In February, 2008 and again one year later, an informal survey was sent out via e-mail along with video phone and voice phone contact to a number of professionals who work within the Deaf community on a national basis. The purpose of this contact was to identify programs that serve SUD treatment needs of deaf individuals on an outpatient and inpatient basis, as well as provide other SUD related services. The survey focused on programs identifying themselves as providing specialized treatment to deaf individuals. Programs are considered specialized treatment when staff are able to communicate in ASL, materials are modified to meet the individual needs of the consumer, and program content is culturally sensitive to the needs of the Deaf population. The informal survey was conducted by Debra Guthmann, Ed.D., one of the founders and former Director of MCDPDHHI. She has provided state-wide technical assistance throughout the country in SUD treatment specialized for persons with deafness or other disabilities. In addition, respondent agencies were asked if they were aware of any other programs specialized for SUD treatment of the Deaf that were not on the list.

The results of the informal survey indicate that on a national basis programs identified as providing specialized inpatient–residential treatment in 2008 were located in Minnesota, New York, Illinois, New Mexico, Washington, Florida, California, and Michigan. Again in 2009, the information was updated based on the results of the 2008 survey. Within one year, four of the inpatient–residential treatment programs for the Deaf had ceased operation. Survey results indicated that programs identified as providing outpatient, prevention, advocacy or
consultations were located in New York, Maryland, New Jersey, California, and Ohio. The results from 2009 indicate that from 2008-2009 one of these five outpatient programs ceased operations, leaving only four providers in these categories of service (Titus & Guthmann, in press). The results of these surveys are further evidence of the barriers and challenges for providing SUD services to this population.

**Deaf Off Drugs and Alcohol E-therapy Program**

In 2007, the Substance Abuse Resources and Disability Issues (SARDI) program in the Wright State University’s Boonshoft School of Medicine received a three year SAMHSA targeted capacity expansion grant in the e-therapy category to establish a state-wide program for addressing the SUD treatment needs of persons who are deaf. Established within the Consumer Advocacy Model (CAM), SARDI’s substance abuse treatment agency, this e-therapy project is called *Deaf Off Drugs and Alcohol*, (DODA, a word play on “CODA,” child of deaf adult). This Dayton, Ohio based program uses clinical approaches developed by MCDPDHHI. Individuals are served in the “least restrictive environment” throughout Ohio in a combination of locally-available treatment and ASL-based e-therapy. Community-based treatment is enhanced through electronic contact that supplements and strengthens the treatment episode, with an emphasis on supporting sobriety and learning about recovery maintenance. Group and individual counseling and support, and case management are offered via video conferencing and video phone technology. Consumer feedback and guidance from a project advisory board guide program content and service delivery. The design of services is provided with consumer input and based on the individual’s treatment plan. All DODA clinical staff are fluent in ASL, as well as licensed in Ohio in substance abuse and/or mental health services provision. In the first 19 months of operation DODA provided services to 69 consumers. The DODA program is based on the premise that the unique needs of persons who are deaf are better served by extending services over a larger geographic area. Demographics from the intake questionnaires, approximate numbers of consumer services, and drugs
of choice are presented in Tables 1 and 2.

**Intermediate Outcomes.** A total of 36 of 38 DODA consumers eligible for the follow-up window have completed six-month follow-up interviews. This represents a follow up rate of 94.7%, an especially robust rate for follow-up based on previous projects within CAM. DODA staff attribute the high follow-up rate to the level of need in the Deaf community for professional support and case management, as well as the culturally sensitive and accessible nature of the DODA program staff. A total of 24 (66.7%) DODA consumers report no alcohol use, and 23 (63.9%) report no illicit drug use over the past 30 days.

Table 1. Selected DODA consumer demographics and services characteristics (first 19 months of operation, through 5/2009: N=69)

<table>
<thead>
<tr>
<th>N or %</th>
<th>Descriptor</th>
<th>Comment</th>
</tr>
</thead>
<tbody>
<tr>
<td>58%</td>
<td>Male</td>
<td>Recent referrals have included higher % of females</td>
</tr>
<tr>
<td>66.7%</td>
<td>Caucasian</td>
<td>26.1% African American</td>
</tr>
<tr>
<td>40.6%</td>
<td>35–44 yrs of age</td>
<td>Range: 18–68 years</td>
</tr>
<tr>
<td>1,250</td>
<td>Emails transmitted or received from consumers</td>
<td>Includes text messages</td>
</tr>
<tr>
<td>35</td>
<td>No show or cancellation</td>
<td>Lower no-show rate than CAM-based program for persons with other disabilities (10% vs 17%): transportation issues minimized with e-therapy</td>
</tr>
<tr>
<td>332</td>
<td>Individual counseling or case management sessions</td>
<td>All services intended as adjunct to primary, in-community treatment. Some consumers are pre-contemplation and pre-treatment engagement</td>
</tr>
<tr>
<td>168</td>
<td>Case management contacts w/ providers and/or social services</td>
<td>Advocacy and problem solving are integral components of program</td>
</tr>
<tr>
<td>329</td>
<td>In person or video remote interpreting, or print transcription sessions</td>
<td>Numbers would be higher, but community providers often do not have PC or high speed internet available in treatment rooms; logistic issues take time even with freely loaned equipment from DODA</td>
</tr>
</tbody>
</table>
In contrast to the text-based TTY technology, teleconferencing services for ASL speakers provide a virtual person-to-person live experience. Expressed meaning in sign language is 85% gestures and facial expression, so visual contact between speakers provides more efficient communication than TTY or speaking through hearing interpreters. TTY is English-based, and therefore ASL speakers must translate their primary thoughts into English and type them in through an English alphabet keyboard, a further barrier to efficient and clear communication. For example, DODA counselors have found that resolving issues via teleconferencing takes roughly half the time necessary for similar issues addressed via TTY. In spite of this time savings, counseling and case management services generally take more than twice as long to accomplish as compared to CAM consumers from the hearing population. Staff also note that consumers will make multiple video calls to the office or attempt to engage the staff longer in conversation because of limited communication with people at home and the need to reduce feelings of isolation.

Table 2. Drugs reported as used by DODA consumers at intake interview

<table>
<thead>
<tr>
<th>Drug</th>
<th>Frequency</th>
<th>% Used</th>
</tr>
</thead>
<tbody>
<tr>
<td>Any alcohol</td>
<td>34</td>
<td>49.3</td>
</tr>
<tr>
<td>Marijuana/hashish</td>
<td>21</td>
<td>30.4</td>
</tr>
<tr>
<td>Cocaine/crack</td>
<td>13</td>
<td>18.8</td>
</tr>
<tr>
<td>Bezodiazepines: Diazepam (Valium), Alprazolam (Xanax); Triazolam (Halcion); and Estasolam (Prosom and Rohypnol, aka roofies, roche, and cope)</td>
<td>3</td>
<td>4.3</td>
</tr>
<tr>
<td>Heroin (smack, H, junk, skag)</td>
<td>1</td>
<td>1.4</td>
</tr>
<tr>
<td>Percocet</td>
<td>1</td>
<td>1.4</td>
</tr>
<tr>
<td>Darvon</td>
<td>1</td>
<td>1.4</td>
</tr>
<tr>
<td>Tylenol 2, 3, 4</td>
<td>1</td>
<td>1.4</td>
</tr>
<tr>
<td>Oxycontin/Oxycodone</td>
<td>1</td>
<td>1.4</td>
</tr>
<tr>
<td>Non-prescription methadone</td>
<td>1</td>
<td>1.4</td>
</tr>
<tr>
<td>Methamphetamine or other amphetamines (meth, uppers, speed, ice, chalk, crystal, glass, fire, crank)</td>
<td>1</td>
<td>1.4</td>
</tr>
</tbody>
</table>

Number of intakes used in calculation of the report=69.
Number of intakes is used as the denominator for this report.
Because a number of deaf individuals who were referred to DODA have been unable to successfully engage with local SUD treatment, as the host clinical agency for DODA, CAM will soon offer primary outpatient services in an e-therapy model as a treatment option. Group and individual sessions will be based on electronic communications supported by Nefsis® web and video conferencing software from WiredRed Corporation.

Persons receiving full outpatient services through CAM must be Medicaid eligible and have access to computers that are equipped with cameras and high speed internet access. CAM was primarily designed to serve persons with any co-existing disabilities from its beginning, and as such it is a somewhat unusual model that includes concepts of “less intensity—longer duration” and an emphasis on strong case management support (Heinemann, Corrigan, & Moore, 2004; Moore & Lorber, 2004). CAM was originally based on the “TBI Network” case management model developed by John Corrigan at Ohio State University in Columbus, Ohio (Corrigan, 1995).

DODA has established Deaf, ASL-based 12-step meetings through video conferencing. This technology allows up to ten locations to be online at the same time. The individuals can see each other and are able to interact in real time. This is a critical component of Deaf recovery, as it is culturally specific, non-threatening, and is based on peer assisted recovery principles. Since July, 2008, DODA has recruited individuals with long term sobriety willing to facilitate 12-step meetings. Individuals who are deaf and in recovery serve as sponsors and coordinators for these meetings after they receive a 90-minute technical training. The software is highly intuitive, and there have been few problems that have occurred to date over the nearly 150 meetings. Average attendance per meeting is six, but some meetings have been at full capacity of ten participants. There is a group and/or 12-step video meeting every day of the week, and staff are establishing specialized groups like the women’s group. Because the meetings are not governed by Ohio state laws regarding professional competency, persons in other states also may participate. A total of 17 states have been represented in e-mails or video phone calls regarding DODA to date.
DODA counselors note that the benefits of deaf-specific treatment extend beyond the simple receipt of services for deaf and hard of hearing consumers to a sense of community and interconnectedness. Many DODA consumers are isolated from the hearing community by their reliance on ASL, and the addition of substance use disorder adds to this sense of singularity. Meeting with other non-hearing consumers in the 12-step setting teaches them that others experience similar issues and barriers. Further, these consumers can support one another, share experiences, and air grievances to people who truly understand their perspective. For many, this is a new and liberating experience.

By using certified substance abuse counselors and case managers, the DODA program allows consumers and counselors to develop a stronger relationship than is possible in other situations that require an interpreter. When an ASL interpreter is used between a non-signing counselor and a deaf consumer, some of the attention necessarily focuses on the interpreter. Using ASL in direct communication fosters a more personal connection between the counselor and consumer, which seems to provide greater engagement in treatment and a richer therapeutic experience.

Addressing Barriers and Challenges to E-therapy

There are several reports of success using e-therapy models in SUD treatment (King, et al., 2009), including use of e-therapy for addressing the SUD treatment needs of the Deaf (Wilson & Wells, 2009). However, there continue to be several challenges in provision of this type of service (Castelnuovo, Gaggioli, Mantovani, & Riva, 2003), including certifications, jurisdiction, client protection, obtaining informed consent, confidentiality, duty to protect, and maintaining appropriate boundaries (Kanani & Regehr, 2003). Below, we describe ways that DODA has addressed each of these issues.

Certifications and Jurisdiction—A waiver was obtained from the Ohio Department of Alcoholism and Drug Addiction Services (ODADAS) so that e-therapy utilizing live picture technology constitutes the same level of service as “in person” services. The Ohio Department of Mental Health also
established a similar policy in regard to services for the Deaf.

Client Protection—A "lethality-criticality" assessment is built into the initial assessment so that persons at risk for harm to themselves or others are seen immediately in person. If a local treatment provider cannot meet this need, DODA staff travel to the site and meet with the individual. One recent case of a deaf individual showing up in an emergency room requesting detoxification services was addressed via 4 hours of text messaging with the person and a DODA counselor. The person was then admitted in the same day to a local detoxification program.

Obtaining Informed Consent—When time permits, potential DODA consumers are overnight mailed an informed consent with a self-addressed and stamped return envelope. In the next video phone or Nefsis® session, the consumer is informed about the content of the informed consent, any questions are answered, and the consumer signs the informed consent while on line. The paper form is then mailed back to DODA. Future variances with ODADAS may address creation of a video file showing the consumer covering the informed consent and signing it. In unusual cases, DODA clinical staff drive to meet the potential consumer and obtain informed consent in person. This situation is reserved for special circumstances due to the amount of time involved with the process.

Confidentiality—All counselor and case manager space in the DODA office is partitioned so that others cannot see the sign language interaction with consumers. Although a consumer has the choice to interact with DODA staff from home (thereby potentially informing other family members of the conversation), the default policy is for the consumer to access equipment where both parties are assured of privacy. Deaf consumers are assured that they may choose or not choose their interpreters based on local situations or other involvement the interpreter may have with them or other family members. Rules for involvement in electronic 12-step meetings are reviewed at each session, and this includes not sharing personal information with other group attendees.

Duty to Protect—As in the normal treatment setting, consumers are made aware that DODA staff have a legal responsibility to protect the health and well-being of the consumer as
well as others who may have contact with the consumer. Since the majority of consumers enrolled in the DODA program to date have the dual disorder of mental illness issues, local mental health providers for the Deaf also are enlisted and included in the treatment plan. This is particularly important for emergency plans, which include identifying and linking with local providers who can intervene in crisis situations, especially for consumers who are geographically inaccessible to DODA staff. On a related topic, all video content of the DODA website involves actors or treatment professionals, not consumers enrolled in the program.

Maintaining Appropriate Boundaries—As in other areas involving services to the Deaf community, there can be boundary issues when addressing consumer needs. For this reason, consumers are continually educated about the appropriate roles for staff and consumers, as well as the roles for interpreters. It is not unusual for a deaf individual to turn to interpreters for clinical guidance, and this practice is discouraged by all DODA staff. Contract interpreters associated with DODA are trained in professional ethics and the specific applications that apply to SUD treatment, and receive advanced training in SUD-related terminology.

Program Sustainability

One challenge for the DODA program to date has been a policy of the federal funding source. The Center for Substance Abuse Treatment (CSAT/SAMHSA) maintains a “cost band” policy, where their targeted capacity expansion projects must serve a minimum number of persons per year in order to fall within program compliance. “Under-performing” programs that serve less than this number are in jeopardy of receiving reduced funding in continuing years of the grant, or in being de-funded altogether. The DODA program was identified as under-performing by not serving 80 persons per year, and the program was informed that the third of three years of funding would be reduced, or the program would be de-funded altogether, unless this target could be reached. This was in spite of the program serving more individuals than proposed and approved in the original grant application.
(25-50-75 individuals per year, respectively). Historically, the authors are aware of no program serving the Deaf in the U.S. that has been able to identify, recruit, and serve 80 persons per year, regardless of the geographic catchment area. In order to comply with this CSAT policy, the DODA program has had to divert staff resources into recruiting and serving additional hard of hearing individuals for what amounts to a different type of program service.

The other challenge imposed by the federal funding is that it is only a three year grant, rather than the usual five for a targeted capacity expansion project. It is very difficult to establish infrastructure, recruitment channels, sustainable funding, specialized treatment protocols, and obtain needed waivers and variances for e-therapy within such a short time. However, strong support for the program has been provided by the Ohio Department of Alcohol and Drug Addictions Services (ODADAS), and plans are on-going to establish funding mechanisms for this statewide project following the end of the funding cycle. In a recent 20th anniversary event, ODADAS recognized DODA as being one of the “Top 10” programs to ever serve Ohioans with SUD (OACBHA, 2009).

Additional grant funding is being investigated, along with the possibility of providing direct service that would qualify for Medicaid billing. Expanding the geographic scope of service would provide more consumers, but drug counselor certifications are state-specific, meaning that the Ohio-based DODA program cannot provide services outside the state. Further, the logistical limitations of statewide services above would be magnified for a national service. In the case of direct service, the difficulties of regular urinalysis via distance is one issue that has been suggested as a difficulty representative of others of a similar nature.

The challenges to providing appropriate and accessible SUD treatment for the Deaf are appreciable, but utilizing models that incorporate e-therapy may have promise for at least partially addressing the need. Future efforts in this area will need to investigate creative methods for underwriting the high costs for interpreters, as well as addressing capacity-building activities so that SUD counselors, case managers, and interpreters are better prepared to meet the unique needs of this population.
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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 dis-
ability category (Wagner, Newman, Cameto, Levine, & Garza,
2006).

Once these youth reach adulthood, the numbers are equally
discouraging—people with long-term psychiatric disabili-
ties 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 train-
ing and education programs (only one in five youth with emo-
tional 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 ap-
proximately 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 preced-
ing 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 interagency 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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Does the GI Bill Support Educational Attainment for Veterans with Disabilities? Implications for Current Veterans in Resuming Civilian Life

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A secondary data analysis of the 2001 National Survey of Veterans (NSV) for 2075 Gulf War-era veterans was conducted to investigate whether the GI Bill (the Servicemen's Readjustment Act of 1944, most recent provisions of which have been entitled the Montgomery GI Bill and the Post 9/11 GI Bill), considered as a social welfare policy, demonstrated protective effects for veterans with disabilities in terms of successful re-entry and sustained enrollment in higher education. Regression analyses to test the mediation effects of use of the GI Bill, use of non-Veterans' Administration (VA) financial aid, and use of VA health services suggested mediation effects; however, post hoc testing did not yield significant results. Analysis of this and an alternative multiple mediator model using bootstrapping strategies for assessing indirect effects suggested that total and non-labor income and social support, not the GI Bill, mediate the effects of disability on educational attainment among this population. Implications for social welfare policies and programs to support this population's access to and success in post-secondary institutions are highlighted.

Key words: GI Bill, disabilities, veterans, Veterans Administration, resiliency, life trajectory, educational attainment, ADA, accommodations, assistive technology

Military service as a positive or negative turning point in life trajectory has received conflicting reviews in the literature. On the one hand, some cohorts of veterans have experienced military service as an opportunity for enhanced chances for...
an improved life trajectory (Elder, 1998), while others, scholars have argued, have experienced military service as a sacrifice of civilian employment and educational opportunities for which veterans’ benefits such as the GI Bill (the Servicemen’s Readjustment Act of 1944, most recent provisions of which have been entitled the Montgomery GI Bill and the Post 9/11 GI Bill) are merely compensatory (Angrist, 1993, 1998; Angrist & Johnson, 2000; Cohen, Segal, & Temme, 1992). In today’s All Volunteer Force (AVF) context, the desire to earn educational benefits for higher education has been identified as the primary incentive for military enlistment across service branches (National Priorities Project, 2006).

For Americans who leave military service with service-connected disabilities, benefits policies have been articulated variously since the Civil War era as ensuring civil rights to be protected from discrimination so as to return to expected improved post-service life trajectories as well as full social inclusion, or, conversely, to rehabilitate them so as to return to pre-military service functioning or as welfare entitlements to provide income replacement for lost wages, based on means testing and medical limitations testing as eligibility requirements (Carden-Coyne, 2007; Gelber, 2005; Ingram, 2006; Skocpol, 1992). The enactment of the Americans with Disabilities Act (ADA) and the Individuals with Educational Disabilities Act (IDEA) has only partially resolved the interpretation of benefits and accommodations for veterans and other Americans who are differently abled as alternately an anti-discrimination provision or a redistributive welfare entitlement (Gelber, 2005; Ingram, 2006; tenBroek & Matson, 1966). In addition to veterans’ disability pensions, the GI Bill has historically offered enhanced benefits for veterans with service-connected disabilities to use as part of their vocational rehabilitation plan in pursuing post-secondary education (Dole et al., 2007). Health care enrollment priority groups enacted in 1996 (U.S. Department of Veterans Affairs, National Survey of Veterans [NSV], 2001) also give priority to veterans with major service-connected disabilities for free health care within the Veterans Health Administration (VHA) delivery system.

A patriotic sense of moral obligation to veterans has influenced social policy on veterans’ benefits, with the political
debate shifting away from the social equity argument with the elimination of conscription and initiation of the All Volunteer Force (Gerber, 2003, Kelly, 1997; Larsen, Highfill-Roy, Booth-Kewley, 2008; McMilford & Severo, 1989; Skocpol, 1992). The status of the veteran with disabilities has figured significantly in these policy deliberations, and advocacy groups for this population have been active in arguing for interpretation of policies as anti-discrimination, civil rights statutes, not simply income replacement provisions (Gelber, 2005; Merrow, 2008; Zdechlik, 2005). Currently, the VA has noted a dramatic increase in the filing of disability claims related to PTSD since 1999, which include not only current veterans from Operation Iraqi Freedom (OIF) and Operation Enduring Freedom (OEF), but also those from earlier eras who are experiencing delayed or chronic forms of this disorder in later life (Committee on Veterans' Compensation for Posttraumatic Stress Disorder [CVCPTSD], 2007; Martz, Birks, & Blackwell, 2005; Smith-Osborne, 2009).

This paper reports a study of Gulf War veterans to investigate whether the GI Bill and related VA benefits and non-VA financial aid mediate the effect of service-connected disabilities on educational attainment for veterans. A resiliency theory framework was the basis for selecting variables supported by the literature as potentially mediating the risk factor of service-connected disability on educational attainment for veterans. This veteran cohort was selected for study as it is the group closest in characteristics to the current OIF/OEF military force for which a large, population base random sample was available (Smith-Osborne, in press).

Methodology

Sample

The National Survey of Veterans, or NSV (primary data set), collected data from a total of 20,048 American veterans, selected using two national sampling frames: a random digit dialing (RDD) methodology using national phone bank list (N=12,956) and a stratified systematic sample drawn from VA administrative files (N=7,092). Samples from the two sampling frames were weighted to represent the entire veteran population, with the RDD sample benchmarked to the 2000 Census...
data to account for under-coverage due to omission of non-telephone and unlisted telephone households. The weight calculations also accounted for original selection probability, non-response, and households with multiple residential telephone lines.

This study (secondary data analysis) drew a subsample from the NSV data set of 100% of veterans who served in the Gulf War era. These veterans would have been approximately 18 years of age or older at the beginning of the Gulf War, which was ten years earlier from the time of NSV interview. Seventy-five percent of the sample drawn was between the ages of 18 and 36 at the start of the war. Since 1996, the VA has identified veterans by health care enrollment priority group (U.S. Department of Veterans Affairs, 2001), so these categories, inclusive of veterans with service-connected disabilities, were also available for study.

Measures and Data Analysis

Most independent variables utilized in multivariate analyses, as well as variables included in the descriptive statistics, were unmodified items from the NSV interview questionnaire. The initially extracted Gulf War sample from the NSV was 2,075, with a final sample size of 206 for this study. A priori power analyses using Power and Precision 2 software (Borenstein, Rothstein, & Cohen, 2001) found the sample size sufficient for a power of .80 with a small effect size. Statistical analyses were conducted using SPSS 14.0 software. A series of hierarchical multiple regression analyses met the requisite assumptions (Cohen, Cohen, West, & Aiken, 2003), and, following the method of Baron and Kenney (1986), were done to explore potential protective factors. Post hoc testing was done to determine the significance of individual and multiple mediators utilizing the product of coefficients method (Sobel, 1982) and alternate bootstrapping strategies utilizing 1,000 resampling iterations and calculation of 95% confidence intervals (Preacher & Hayes, 2008).
Results

Descriptive Statistics

Selected descriptive statistics may be found in Table 1; this table presents data comparing the full sample used for the mediation analyses with the sub-sample of Priority Group 1 veterans (i.e., veterans with 50% or more service connected disability rating). This highest-rated disability group represented 22.8% of the study sample, and is the only group granted automatic free services by the VHA (U.S. Department of Veterans Affairs, 2001). Additional descriptive statistics for the full Gulf War sample from the NSV have been reported in tabular form elsewhere (Smith-Osborne, in press). Thirty-three percent of these Gulf War veterans, a lower proportion than the 56.1% for all veterans surveyed, were calculated by the VHA to fall in Health Care Priority Group 7, the lowest need group, while the next largest group, 17.7%, fell in Priority Group 3, indicating the presence of disabling conditions, including service-connected disabilities rated at 10-20% (the next largest group for all veterans was the low income, non-disabled Priority Group 5).

Additionally, 49.2% stated they had a service-connected disability rating; of those, 23.4% had a rating of 50-100% disabled. Of the 11% of veterans who were unemployed and not looking for work, 41% stated their main reason was being disabled.

Multivariate Analyses

An initial regression analysis (see Table 2) examining the association of VA policies and non-VA financial aid as potential protective factors with lifetime educational attainment was performed. The policies were: the GI Bill as applied to post-secondary education, VA treatment for mental health and substance abuse conditions, and non-VA financial aid for college. The model was significant (F=14.99; p<.0005), but accounted for only 18% of the variance in education attainment, with the two forms of financial aid being the significant predictors.

Mediation analyses examining these same variables as potential mediators of the effect of disability rating as a risk factor on educational attainment did not demonstrate reduction of
Table 1. Descriptive statistics for key variables

<table>
<thead>
<tr>
<th>Type</th>
<th>Full Sample (n=2,075)</th>
<th>Priority 1 Sub-Sample (n=242)</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>Number</td>
<td>Percent</td>
</tr>
<tr>
<td><strong>Sample Demographic Characteristics</strong></td>
<td></td>
<td></td>
</tr>
<tr>
<td><strong>Gender</strong></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Male</td>
<td>1,726</td>
<td>83.2</td>
</tr>
<tr>
<td>Female</td>
<td>349</td>
<td>16.8</td>
</tr>
<tr>
<td><strong>Ethnicity</strong></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Non-minority</td>
<td>1,476</td>
<td>71.1</td>
</tr>
<tr>
<td>Minority</td>
<td>586</td>
<td>28.2</td>
</tr>
<tr>
<td><strong>Marital Status</strong></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Married and living w/spouse</td>
<td>1,431</td>
<td>69.0</td>
</tr>
<tr>
<td>Other</td>
<td>642</td>
<td>30.9</td>
</tr>
<tr>
<td><strong>Education in Years</strong></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Range 11-20</td>
<td>Average 14.15 (SD = 2.14)</td>
<td>Average 14.5 (SD = 2.22)</td>
</tr>
<tr>
<td><strong>Total Annual Family Income</strong></td>
<td></td>
<td></td>
</tr>
<tr>
<td>$10,000 or less</td>
<td>69</td>
<td>3.3</td>
</tr>
<tr>
<td>$10,001-20,000</td>
<td>175</td>
<td>7.5</td>
</tr>
<tr>
<td>$20,001-30,000</td>
<td>248</td>
<td>12.0</td>
</tr>
<tr>
<td>$30,001-40,000</td>
<td>330</td>
<td>15.9</td>
</tr>
<tr>
<td>$40,001-50,000</td>
<td>329</td>
<td>15.9</td>
</tr>
<tr>
<td>Over $50,000</td>
<td>944</td>
<td>45.5</td>
</tr>
<tr>
<td><strong>Full Range $0-480,000</strong></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Avg. $56,641.57 (SD = $37,787.61)</td>
<td></td>
<td></td>
</tr>
<tr>
<td><strong>Priority 1 Range $0-160,000</strong></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Avg. $49,190.91 (SD = $28,361.83)</td>
<td></td>
<td></td>
</tr>
<tr>
<td><strong>Number Sources of Non-labor Income (N = 2,061)</strong></td>
<td></td>
<td></td>
</tr>
<tr>
<td>0</td>
<td>55</td>
<td>2.7</td>
</tr>
<tr>
<td>1</td>
<td>528</td>
<td>25.6</td>
</tr>
<tr>
<td>2</td>
<td>570</td>
<td>27.7</td>
</tr>
<tr>
<td>3</td>
<td>511</td>
<td>24.8</td>
</tr>
<tr>
<td>4</td>
<td>326</td>
<td>15.8</td>
</tr>
<tr>
<td>5</td>
<td>55</td>
<td>2.7</td>
</tr>
<tr>
<td>6</td>
<td>15</td>
<td>.7</td>
</tr>
<tr>
<td>7</td>
<td>1</td>
<td>.5</td>
</tr>
<tr>
<td><strong>Range 0-7</strong></td>
<td>Average 2.37 (SD = 1.22)</td>
<td>Average 5 (SD = 3)</td>
</tr>
</tbody>
</table>

(continued next page)
### Table 1. Descriptive statistics for key variables (continued)

<table>
<thead>
<tr>
<th>Type</th>
<th>Full Sample (n=2,075)</th>
<th>Priority 1 Sub-Sample (n=242)</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>Number</td>
<td>Percent</td>
</tr>
<tr>
<td><strong>Predictor Variables</strong></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Used VA Educational Benefits</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Yes</td>
<td>633</td>
<td>30.5</td>
</tr>
<tr>
<td>No</td>
<td>1,442</td>
<td>69.5</td>
</tr>
<tr>
<td>Used VA Educational Benefits for College</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Yes</td>
<td>470</td>
<td>74.2</td>
</tr>
<tr>
<td>No</td>
<td>163</td>
<td>25.8</td>
</tr>
<tr>
<td>Used Non-VA Sources of College Financial Aid</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Yes</td>
<td>451</td>
<td>21.7</td>
</tr>
<tr>
<td>No</td>
<td>1,624</td>
<td>78.3</td>
</tr>
<tr>
<td>Number of Non-VA Aid Sources Used</td>
<td></td>
<td></td>
</tr>
<tr>
<td>(N = 451)</td>
<td></td>
<td></td>
</tr>
<tr>
<td>1</td>
<td>321</td>
<td>71.2</td>
</tr>
<tr>
<td>2</td>
<td>105</td>
<td>23.3</td>
</tr>
<tr>
<td>3</td>
<td>22</td>
<td>1.1</td>
</tr>
<tr>
<td>4</td>
<td>1</td>
<td>.0</td>
</tr>
<tr>
<td>5</td>
<td>2</td>
<td>.1</td>
</tr>
<tr>
<td>Range 1-5</td>
<td>Average 1.35</td>
<td>(SD = 0.63)</td>
</tr>
<tr>
<td>Have a Service-Connected Disability Rating (N = 2,056)</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Yes</td>
<td>1,099</td>
<td>53.5</td>
</tr>
<tr>
<td>No</td>
<td>957</td>
<td>46.5</td>
</tr>
<tr>
<td>Percentage Disability Rating (N = 1060)</td>
<td></td>
<td></td>
</tr>
<tr>
<td>&lt;10%</td>
<td>50</td>
<td>4.7</td>
</tr>
<tr>
<td>10-20%</td>
<td>445</td>
<td>41.9</td>
</tr>
<tr>
<td>&gt;20-&lt;50%</td>
<td>323</td>
<td>30.5</td>
</tr>
<tr>
<td>50-100%</td>
<td>242</td>
<td>22.8</td>
</tr>
<tr>
<td>VA Treated Past Year for Mental Health/Substance Abuse Condition (N = 2063)</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Yes</td>
<td>125</td>
<td>6.0</td>
</tr>
<tr>
<td>No</td>
<td>1,950</td>
<td>94.0</td>
</tr>
</tbody>
</table>
the risk factor beta value, as required by the mediation strategy (see Table 3), suggesting that the set of variables did not reduce the impact of veterans' disabilities on furthering their education after military service.

Table 2. Final model of regression analysis for potential protective factors on education for Gulf War Veterans (N = 206).

<table>
<thead>
<tr>
<th>Variable</th>
<th>B</th>
<th>SE B</th>
<th>β</th>
<th>t</th>
<th>p</th>
</tr>
</thead>
<tbody>
<tr>
<td>Non-VA financial aid</td>
<td>0.36</td>
<td>0.20</td>
<td>0.12</td>
<td>1.81</td>
<td>0.07</td>
</tr>
<tr>
<td>VA educational benefits</td>
<td>1.95</td>
<td>0.32</td>
<td>0.39</td>
<td>6.04</td>
<td>&lt;.0005</td>
</tr>
<tr>
<td>VA treatment for mental health or substance abuse</td>
<td>-0.58</td>
<td>0.77</td>
<td>-0.05</td>
<td>-0.75</td>
<td>0.46</td>
</tr>
</tbody>
</table>

$\Delta R^2=.18$, $R^2=.18$.

The product of coefficients method, also known as the Sobel test (Sobel, 1982), is currently the most commonly used post hoc method used to test the contribution of specific intervening variables to the overall mediation effect in the relationship of predictors, particularly risk factors, with dependent variables/outcomes of interest (MacKinnon, Lockwood, Hoffman, West, & Sheets, 2002; Preacher & Hayes, 2008). When the Sobel method of post hoc significance testing was applied to each potential mediator, non-VA financial aid was the only variable to approach significance (Sobel statistic=1.496; $p=0.07$). The bootstrapping method of post hoc testing was then applied, as it has been suggested to provide more accurate results when assessing indirect effects, such as mediation, in models with multiple mediators in smaller sample sizes (MacKinnon et al., 2002; Preacher & Hayes, 2008). The potential mediators also failed to demonstrate mediation effects according to this method, as all confidence intervals included "0" within their range (see Table 4).

An alternative set of potential mediators was identified outside the policy domain, based on theory and prior literature on veterans with disabilities. These variables were marital status, number of dependents, number of sources of informational social support, number of non-labor sources of income, and total family income. The bootstrapping method was applied to analyze this set of multiple mediators (see Table 5).
Table 3. Regression analyses for mediating effects of potential protective variables on disability risk factor for education.

<table>
<thead>
<tr>
<th>Variable</th>
<th>B</th>
<th>SE</th>
<th>β</th>
<th>t</th>
<th>p</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Step 1 for Mediation</strong> - DV = Percentage disability, N = 206</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Model 1</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>VA educ. benefits</td>
<td>1.52</td>
<td>2.97</td>
<td>.03</td>
<td>.51</td>
<td>.61</td>
</tr>
<tr>
<td>Non-VA financial aid</td>
<td>-4.88</td>
<td>1.82</td>
<td>-.18</td>
<td>-2.68</td>
<td>.01</td>
</tr>
<tr>
<td>VA MH/SA treatment</td>
<td>36.94</td>
<td>.32</td>
<td>-.54</td>
<td>-9.02</td>
<td>&lt;.0005</td>
</tr>
<tr>
<td><strong>Step 2 for Mediation</strong> - DV = Highest grade, N = 206</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Model 1</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Percentage disability</td>
<td>.01</td>
<td>.002</td>
<td>.07</td>
<td>2.99</td>
<td>.003</td>
</tr>
<tr>
<td><strong>Step 3 for Mediation</strong> - DV = Highest grade, N = 206</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Model 1</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Percentage disability</td>
<td>.01</td>
<td>.01</td>
<td>.07</td>
<td>.93</td>
<td>.35</td>
</tr>
<tr>
<td>VA educ. benefits</td>
<td>1.94</td>
<td>.32</td>
<td>.39</td>
<td>6.02</td>
<td>&lt;.0005</td>
</tr>
<tr>
<td>Non-VA financial aid</td>
<td>.39</td>
<td>.20</td>
<td>.13</td>
<td>1.95</td>
<td>.05</td>
</tr>
<tr>
<td>VA MH treatment</td>
<td>-.84</td>
<td>.82</td>
<td>-.07</td>
<td>-1.02</td>
<td>.31</td>
</tr>
</tbody>
</table>

The final model was significant (CI=.0001-.0048). The results were that non-labor income and informational social support had a positive mediational effect, and number of dependents had an inverse mediational relationship, suggesting that more sources of cash benefits and increased density of social networks (i.e., social support directed to providing access to information) mediated the risk of disability on educational attainment, while increasing numbers of dependents had a suppressor effect on educational attainment.

Table 4. Bootstrapping mediation analyses for potential protective variables (N=206).

<table>
<thead>
<tr>
<th>Variable</th>
<th>Point Estimate</th>
<th>Product of Bootstrapping Coefficients SE</th>
<th>Bootstrapping BCa 95% CI Lower</th>
<th>Bootstrapping CI Upper</th>
</tr>
</thead>
<tbody>
<tr>
<td>Non-VA financial aid</td>
<td>-.0030</td>
<td>-.0072</td>
<td>.0005</td>
<td></td>
</tr>
<tr>
<td>VA educational benefits</td>
<td>-.0012</td>
<td>-.0096</td>
<td>.0047</td>
<td></td>
</tr>
<tr>
<td>VA treatment for mental health or substance abuse</td>
<td>-.0028</td>
<td>-.0103</td>
<td>.0005</td>
<td></td>
</tr>
<tr>
<td>TOTAL</td>
<td>-.0070</td>
<td>.0155</td>
<td>.0012</td>
<td></td>
</tr>
</tbody>
</table>
Table 5. Bootstrapping mediation analyses for alternative protective variables (N=206)

<table>
<thead>
<tr>
<th>Variable</th>
<th>Point Estimate</th>
<th>Product of Coefficients SE</th>
<th>Bootstrapping BCa 95% CI Lower</th>
<th>Upper</th>
</tr>
</thead>
<tbody>
<tr>
<td>Non-labor income</td>
<td>.0052</td>
<td>.0009</td>
<td>.0034</td>
<td>.0070</td>
</tr>
<tr>
<td>Number of dependents</td>
<td>-.0029</td>
<td>.0007</td>
<td>-.0042</td>
<td>-.0016</td>
</tr>
<tr>
<td>Total family income</td>
<td>.0001</td>
<td>.0001</td>
<td>-.0001</td>
<td>.0004</td>
</tr>
<tr>
<td>Marital status</td>
<td>-.0004</td>
<td>.0002</td>
<td>-.0010</td>
<td>.00001</td>
</tr>
<tr>
<td>Informational social support</td>
<td>.0004</td>
<td>.0002</td>
<td>.00001</td>
<td>.0009</td>
</tr>
<tr>
<td>TOTAL</td>
<td>.0024</td>
<td>.0012</td>
<td>.0001</td>
<td>.0048</td>
</tr>
</tbody>
</table>

Discussion

A secondary data analysis of the 2001 National Survey of Veterans for 2,075 Gulf War-era veterans was conducted to investigate whether the GI Bill, considered as a social welfare policy, demonstrated protective effects for veterans with disabilities in terms of successful re-entry and sustained enrollment in higher education. Regression analyses to test the mediation effects of use of the GI Bill, use of non-VA financial aid, and use of VA health services, following the method of Baron and Kenney (1986), suggested mediation effects; however, post hoc testing using the product-of-coefficient approach (Sobel, 1982) did not yield significant results. Analysis of this and an alternative multiple mediator model using resampling (i.e., bootstrapping) strategies for assessing indirect effects suggested that non-labor income and informational social support, not the GI Bill, mediate the effects of disability on educational attainment among this population, while larger numbers of dependents may have a suppressor effect. While the original set of potential mediators was suggested to examine policy effects, and the second set to explore the effects of personal and interpersonal variables, the finding of positive association with non-labor sources of income clearly has policy implications. This variable's mediational effect suggests that income
benefits such as VA disability pensions and SSDI may play an important role in enabling veterans with disabilities to pursue their dreams of higher education, even more so than direct educational financial aid, as is the case with the veteran population overall (Smith-Osborne, in press). Further, policies and programs aimed at providing this population with increased access to informational social networks, personal assistance, and mentoring may be more important to enhancing their optimal civilian achievement than for the general, non-disabled veteran population. An implication of study results may be that veterans with disabilities not only need such benefits and networks, but have a right to expect them as part of their right to equal opportunity to pursue their educational and vocational goals after military service. If that is the case, then these mediators may be considered in the context of anti-discrimination efforts to ensure equal rights for the differently-abled veteran.

The recent scandal at the Walter Reed Army Medical Center (WRAMC) [Priest & Hull, 2007; Zwerdling, 2007] illustrates underlying causes relevant to the needs vs. rights issues affecting veterans with disabilities. One contributor to the negative conditions which precipitated the scandal was the perception that access to personal assistants was a need but not a right. Injured military personnel who were assigned to outpatient status and out placed from the WRAMC facility to outlying ("outside the post") rooming houses were not assigned co-located or visiting personnel (personal assistants) to help manage their schedules, thus effectively denying them access to needed medical care and subsistence resources (e.g., the mess hall, sanitary living space, personal hygiene supplies). Although they hypothetically had equal access to transportation to post and equal access to medical services, the functional impairments associated with their injuries prevented them from effectively experiencing equal access—the precise circumstances associated with health disparities groups. This study’s implications for educational access are parallel: for this population, the availability of the GI Bill is not sufficient to support their access to higher education without effective collateral social and income support systems. It is possible that the more generous provisions of the post 9/11 GI Bill, to be implemented in August,
2009, may function as a more protective factor for the OIF/OEF veterans with disabilities than the Montgomery GI Bill for the study's sample of Gulf War veterans (Lehrer, 2000; McChesney, 2008), in that it will cover more tuition and living expenses and thus may function more as another nonlabor source of income. However, the literature on the higher education experience of non-veteran populations with disabilities similar to the signature conditions (Smith-Osborne, in press, 2009) of the current wars (PTSD, traumatic brain injury, persisting post-concussive symptoms, depression, substance abuse) suggests that more intensive and multidimensional assistive services may be required (Megivern, Pellerito, & Mowbray, 2003; Smith-Osborne, 2005). Such services in all likelihood will go beyond the current array of services and accommodations available in many post-secondary institutions (Bobkoff, 2008; Merrow, 2008; Ofiesh, Rice, Long, Merchant, & Gajar, 2002). Therefore, implementation of policies designed to benefit veterans with disabilities should be undertaken from the standpoint of civil rights, even in income replacement/subsidy programs.

References


Theories regarding the social cognitive origins of parenting risk have recently emerged. This work not only has implications for the nature of interventions with parents, but also for the approaches taken by the social service systems that work with them. This paper reviews the evidence that there is a significant number of parents with cognitive disabilities within child protection caseloads and outlines the types of human capacity building and organizational development that are needed to support the parents' needs. Such capacity building will not only increase the effectiveness of child protection interventions with parents with cognitive disabilities (PCD), but will also attend to the support and training needs of the professionals who work with them. Capacity building for work with PCD goes beyond the typical training provided in social work programs by including developmentally sensitive intervention techniques and greater linkages with systems outside of child protective services.

Key words: Child Protective Services; intellectual disabilities; mental retardation; parenting; staff training

Our nation's child protective services (CPS) systems are charged with the task of preventing and remediating parental difficulties that affect families who enter their purview. In 2007,
3.8 million children received preventative services and over 1 million received post-investigative services (Administration for Children, Youth and Families [ACYF], 2007). CPS workers are given the responsibility of determining child safety, communicating system mandates to parents and collaborating with them to plan reparative services they will need to retain custody of their children. The task is extremely demanding and failures are often highlighted by the public at large.

Worker recruitment, burnout, turnover, and retention have been the topic of much concern (Curry, McCarragher, & Dellmann-Jenkins, 2005; Savicki & Colley, 1994). Workers' sense of preparedness and efficacy have been cited as factors. Although arguments can be made for hiring social workers with advanced degrees in social work as a solution (Rittner & Wodarski, 1999), we will argue that more focused training, outside of what is currently in the general social work domain, in combination with ongoing consultation, may be needed. This training should emphasize the capacities needed to effectively support the special populations of parents that CPS confronts. These populations may not be responsive to the typical crisis-oriented services provided and thus may account for the repeated involvement of some cases in the CPS system (e.g., chronic neglect cases use up to nine times the service dollars in the system) [Loman & Siegel, 2006]. Based on our theorizing and that of others regarding the role of cognitive processes in parenting risk (Azar & Twentyman, 1986; Azar & Weinzierl, 2005; Crittenden, 1993; Milner, 2003), one can assert that a number of these chronic cases involve parents with cognitive disabilities (PCD). Because cognitive disabilities can include problems with attention, risk assessment, perspective taking, planning, frustration tolerance, and trial and error learning, they would explain the chronic day-to-day difficulties in care giving seen in neglect cases (e.g., failure to monitor, poor medical care and hygiene, inconsistent school attendance). Indeed, in one prospective study, maternal self-reports of “trouble learning” were found to predict later neglect (Slack, Holl, McDaniel, Yoo, & Bolger, 2004). We will further argue that cognitive disabilities that remain unidentified and that do not trigger a shift in workers' approach (i.e., accommodation to different learning styles of parents) can also negatively affect parental capacity to
participate in decision-making and to comprehend responses required of them. Together, these will limit parents' ability to benefit from the traditional manner in which CPS services are provided, and such failure is grounds for termination of parental rights.

This paper will discuss ways to build human capacity within the CPS system in order to provide necessary accommodations for PCD so they may maximally benefit from services and ways to improve providers' sense of preparedness and efficacy. We will discuss cognitive disabilities and why specific efforts are needed to address the needs of this population within CPS. We then argue for specific systemic capacity building to improve caseworkers' and other service providers' skills in working with PCD and linkages with formal and informal supports required for this population.

CPS Involvement and Cognitive Challenges: A Hidden Issue

The exact number of PCD in the CPS system is difficult to estimate for a variety of reasons (e.g., lack of common definitions, variable screening, inconsistent record keeping) [IASSID Special Interest Group on Parents and Parenting with Intellectual Disabilities, 2008]. Most U.S. and international research on cognitive disabilities and parenting has used low IQ, as opposed to a formal diagnosis of intellectual disabilities, (American Psychiatric Association, 2000) to delineate samples, i.e. parents with IQ's in the Borderline to Mild Mentally Retarded ranges. Although larger scale epidemiological studies are needed, findings suggest that a higher than expected proportion of low IQ parents find themselves in the CPS system, with estimates ranging from 33 to 78%, most involved for neglect (Aunos, Goupil, & Feldman 2003; Ethier, Couture, & Lacharité, 2004; McGaw, Shaw, & Beckley, 2007; Morch, Skår, & Andresgård, 1997; Schillings, Schinke, Bylthe, & Barth, 1982; Tymchuk & Andron, 1990). These rates are much higher than in the general population (10.6 per 1,000 children) [ACYF, 2007]. Although less data is available, parents with low IQs also appear to constitute a larger than expected proportion of CPS cases based on population prevalence of parents in these IQ categories. Indirect data comes from poverty studies.
Poverty has been strongly associated with child maltreatment (Sedlak & Broadhurst, 1996) and studies of Temporary Assistance to Needy Families (TANF) samples suggest that between 25 and 35% have IQs below 79, and as many as 50% have learning disabilities (U.S. General Accounting Office [GAO], 2001). Rates of PCD within CPS caseloads are likely close to this range. Only one study could be identified where a rate for a CPS sample was computed directly and it, unfortunately, was a select sample (cases that had court involvement). This study found a rate of 15% (Taylor, Norman, Murphy, & Jellinek, 1991), almost double the prevalence of adults who fall within these IQ ranges (8.4%) [Wechsler, 1997]. In addition, this study did not report learning disability data, which may involve a much larger group based on the TANF findings.

Routine assessment for cognitive issues is not done by CPS and thus, cognitive disabilities may go undetected by intake workers. If parents are aware of their cognitive difficulties (i.e., have been formally labeled as being mildly mentally retarded, learning disabled, and/or having special needs), they may not identify their designation to CPS investigators because they no longer identify with a label they were given in childhood, want to avoid stigma and/or may not see the relevance of divulging it. Even if self-identification occurs, parents may not be able to articulate the accommodations they may need from service providers.

There also exists a group of parents that will not be aware of their disabilities. Some adults in our society are not appropriately labeled in childhood due to limitations of school assessment resources or parental wishes, and the specificity of their cognitive difficulties may remain unknown to them. Other adults may develop cognitive problems over the life span (i.e., after the age of 18) that impact parenting (e.g., head injuries in veterans and civilians) [Hoge, Goldberg & Castro, 2009; Jager, Weiss, Coben, & Pepe, 2007; MacCready, 2009].

These last groups may be more common among diverse members of our society who are overrepresented in caseloads (Azar & Goff, 2008). They tend to reside in urban settings where school resources for testing may be low and where violence and head injuries may occur at higher rates (U.S. Department of Justice, 2000). Moreover, health care disparities exist for
minorities, which lowers the probability of their difficulties being identified (Collins et al., 2002). For example, head injuries in minorities may not receive as much attention or after care (e.g., Bazarian, Pope, McClung, Cheng, & Flesher, 2003). Thus, subtle, residual cognitive problems may remain unidentified.

Most relevant to our discussion is recent theorizing that has argued that selective cognitive difficulties lead to parenting risk (Azar & Weinzierl, 2005). IQ may merely be capturing a group with a higher density of specific cognitive problems that more closely link to difficulties in parenting (poorer monitoring of children, inconsistent medical care, poorer hygiene, etc.) [See Benjet, Azar, & Kuersten-Hogan, 2003.] However, these difficulties will be present across the full spectrum of IQs. We and others have identified links between social information processing (SIP) difficulties and parenting risk. We also have preliminary data with a small sample showing that low IQ parents exhibit inappropriate expectancies of self-sufficiency from their children (i.e., maladaptive schema), poorer problem solving capacities, and more negative appraisals of their children’s behavior (Azar & Robinson, 2008). As with existing categories of cognitive disabilities (formal diagnosis of mental retardation; learning disabilities), these subtler SIP problems are not easily detected by untrained eyes. Service adaptations, we argue, are required to appropriately identify and intervene with all of these (Azar, 1989) before skills work can be done with parents.

In summary, existing data suggest a significant portion of CPS cases have some form of cognitive challenges that may affect their parenting (e.g., planning capacities needed to maintain home cleanliness and to monitor children’s safety) and that these cases may go unidentified by the system. These same challenges have functional significance for how well service providers (CPS workers, parent trainers, therapists) work with parents. It is the promotion of cognitive capacities in service providers that is the focus of our discussion. We use SIP theorizing to consider providers’ social cognitive system and the potential to make errors and be less effective in service provision when the impact of parental cognitive challenges go unidentified “in the moment.” Ultimately, this impacts on providers’ own sense of efficacy in their work.
In considering systemic changes, we will focus on the parent with identified challenges, as this is where biases may emerge and adaptations are easily made. Because failures to identify challenges are likely, we will also argue for a "universal design" approach to systems changes.

Parents with Cognitive Disabilities: A New Frontier of Systems Change

Much progress has been made in the societal treatment of the cognitively disabled over the last century. For example, educational systems have "flexed" their boundaries and developed a whole system of specialized services for children with cognitive disabilities. This system is equipped with well-trained staff that have the skills to work with disabilities. Adulthood, however, presents new challenges, and society has not shown the same level of systemic flexibility. In fact, biased views continue to exist, and this bias is particularly apparent when it comes to parenting by adults with cognitive disabilities (Aunos & Feldman, 2002).

In the earliest forms of discrimination toward parenting by individuals with cognitive disabilities, society went so far as to allow their sterilization (Buck v. Bell, 1927; Landman, 1929). Although such treatment has thankfully been abolished, it has been argued that biases continue and discriminative practices occur, although in less blatant forms (Field & Sanchez, 1999; Hayman, 1990; McConnell & Llewellyn, 2000). It has been noted that the pregnancy of an adult with cognitive challenges is not celebrated and, instead, is seen as a cause for concern for those around them, especially professionals (Llewellyn, 1994). Rather than creating a network of supports to enhance parents' optimal functioning in this role, societal supports may be minimal or non-existent in most communities. In fact, reaction may be more punitive, with some states' procedures allowing CPS to remove children at birth in the hospital until risk is ruled out.

Even if societal action does not take place at this point, because of their greater need for supports (health issues, social support) and the randomness with which supports are more likely to occur (e.g., the mailman being willing to read the mail
Parental Disabilities and Capacity Building

for the parent), PCD may struggle. At the same time, their parenting practices may be scrutinized more closely than parents without such disabilities (Field & Sanchez, 1999). Unless they have supportive families and communities that compensate for their impairments, CPS involvement and removal of children may be more likely.

Additionally, once children are removed, heightened risk of termination of parent rights has been found (Feldman, 1998; Seagull & Scheurer, 1986; Field & Sanchez, 1999; McConnell & Llewellyn, 1998). Differential treatment appears to occur, despite legal mandates such as the American with Disabilities Act (ADA, 1990), which specifically states that such disabilities should "in no way diminish a person's right to fully participate in all aspects of society" (Title 42, Chapter 126, Sec. 12101), and case law that prohibits categorical a priori assumptions of risk (i.e., diagnoses must be linked to functional incapacities that lead to significant child risk). Despite the influence of the ADA on changes in a number of social welfare areas, including housing, education, vocational services, and public health, there is a notable lack of focus upon the rights of PCD to reasonable accommodations in their parenting services (Bartell v. Lohiser, 1998). We will argue for the kinds of human capacity building that is required for CPS staff and its contracted service agencies to provide accommodations and facilitate linkages to other systems that serve people with intellectual disabilities.

We believe that CPS will be less effective with cases involving PCD because of a mis-match of their typical approaches to what may be the special needs of the parents involved (e.g., a high reliance on parents orchestrating their own services, time-limited parent education as the vehicles for change, and traditional service provision, such as psychotherapy) and residual biases that still exist toward this population. A more refined approach that has more of a rehabilitation focus may be more effective, reduce the number of chronic CPS cases, and improve workers' efficacy in their jobs.

Building Capacity

Capacity building is a crucial element of system change and involves activities that (1) strengthen the knowledge,
abilities, and skills of service providers, and (2) provide improvements to institutional structures and processes such that CPS can efficiently meet its mission and goals in a sustainable way. Capacity building is much more than training and includes human resource development and organizational development. *Human resource development* provides fluidity, flexibility and functionality to CPS caseworkers and contracted agency staff and facilitates adaptation to the needs of PCD. This may be accomplished by improving pre-professional training, setting new priorities in hiring standards for staff, continuous enhancement in service delivery, and ongoing supervision/consultation with established personnel. *Organizational development* can include not only changes within the organizational structures (more refined supervision and consultation resources), but also the management of relationships between the organizations and other sectors (public, private and community). We will focus our discussion upon human resource development and touch on organizational development.

The TANF system has begun to make changes to improve its effectiveness and has recently identified disabilities as an area where efforts are required (U.S. General Accounting Office, 2001). Additionally, as noted earlier, the educational system has already made such changes with varying levels of success. CPS can benefit from the efforts in both these systems. Below, we first outline a framework for capacity building, then highlight human resource enhancements and finally, touch upon organizational development that may improve practice using this framework.

**Social Information Processing as a Foundation for Capacity Building**

Human capacity building requires that progress take place on multiple levels of the service system, ranging from CPS policies and procedures to individual caseworker support and skill-base. This paper will primarily focus on caseworker support and skill as a route to increased effectiveness of parenting interventions provided by CPS. Social information processing (SIP) theory provides a foundation for building the human capacity of CPS workers (Azar, 1996, 2000). SIP models outline the processes whereby the human cognitive system takes in
and utilizes social information. Such models have been used to discuss social cognitive processes that precede problematic and ineffective interpersonal interactions. For instance, the models have been widely applied to parents and risk for child abuse and/or neglect perpetration (Azar, Robinson, Hekimian, & Twentyman, 1984; Milner, 2003) and also extended to attempt to understand professionals working with marginalized populations, such as parents living in poverty (Azar, 1996). These models break down SIP into three core components: (1) biased schemas or knowledge structures (e.g., role schema, expectations of parents, stereotypes); (2) executive functioning capacities (e.g., problem solving, memory, attention); and (3) appraisals or judgments we make about the causes of others' behavior. The first and third elements, schema and appraisals, are most relevant to the facilitation of human capacity building. Although most providers have adequate executive functioning, professionals' flexibility and problem solving capacities may be depleted under stress and it might require extra efforts to remain flexible in thinking and/or to be open to supervisory or consultation input to keep performing effectively (Azar, 2000). PCD may have particular difficulty here, and workers must take this into consideration as they assist them (Azar, Read, & Proctor, 2008).

The first element, schemas, act as the foundation for SIP. Schemas are knowledge structures stored in memory that help people organize past experiences and respond to novel situations (Mandler, 1979). These knowledge structures grow out of interpersonal experiences, including interactions within one's family, exchanges with other individuals, encounters with institutions, exposure to media representations, and even through professional training (e.g., social worker training). The schemas held by professionals regarding people with intellectual disabilities are often tainted with negative elements. Although it might be argued that professional training and knowledge guard against the use of heuristics that stem from one's own personal background, the training of CPS workers in the U.S. includes limited, if any, information about parents with intellectual disabilities (Hughes & Rycus, 1998). Changes in training and supervisory support to facilitate adaptive support schemas will be discussed.
The final element of SIP, appraisals, are causal explanations given to situations that do not meet professionals' expectancies. Inaccurate schema may lead to misappraisals of the causes of parental behavior. For example, when a parent misses appointments consistently, a worker may label them as "resistant" or "not caring" because the parent is not adhering to CPS expectations. However, this label would be different should the worker consider that the parent may be unable to tell time, has planning difficulties, or does not understand bus schedules. Consideration of a PCD's strengths and needs may reduce inaccurate negative appraisals.

The following sections will outline skills designed to increase the human capacity of the dedicated CPS workforce. Throughout this discussion, SIP processes will be highlighted as the underlying mechanisms of a successful supportive relationship between the worker and PCD.

Working with the Parent with Cognitive Disabilities: Human Resource Development

Identification skills. Identifying the presence of cognitive disabilities is a crucial first step to making appropriate adaptations. Two forms can occur: formal screening (with triaging for further testing for verification and identifying capacity issues, e.g., optimal learning style) and "in the moment" identification (with adaptation to address a communication difficulty).

As noted above, the CPS does not currently routinely screen for cognitive challenges. Such screening is beginning to take place in other systems (TANF) [Center on Budget and Policy Priorities & Center for Law and Social Policy, 2007; U.S. General Accounting Office, 2001], and some attempts have been made to develop screening tools for functional deficits relevant to parenting (Connecticut Department of Children and Families, 2008; Whitman & Accardo, 1990), although validation of such instruments is quite limited. Nonetheless, they may provide some starting point for CPS staff. Additionally, formal identification focusing on functional capacities may be more useful (see Tymchuk, 2006 for empirically derived batteries), though such assessment may not be practical at CPS intake and might be better done by staff at provider agencies (with feedback given to ongoing CPS staff to ensure continuity).
Given the status of screening instruments and the sheer number of CPS parents that may have difficulties, a more universal design may be more efficient at present. This approach would require the professional to take care at all times to recognize points of disconnect between their communications and what all parents have grasped. Although we recognize that this may be viewed as just good social work practice, obstacles specific to PCD must be noted. It has been said that the individual with cognitive challenges will adopt a “cloak of competence” (Edgerton, Bollinger, & Herr, 1984) in which they may portray themselves as understanding material when they do not. PCD may also be prone to styles of coping that inhibit their capacity to seek and/or accept expert assistance. Also, parental inability to understand what is being asked of them may result in frustration and avoidance of contact, which may be misappraised by CPS or a service provider. Therefore, the professional has to be extremely sensitive to those moments when assistance is needed (e.g., constantly checking parents’ understanding and their behavioral capacities to enact what is being asked of them), and doing it in a way that is not stigmatizing or infantilizing. Skills, therefore, at reducing “disconnects” between parent level of functioning and CPS expectations may need to be a focus of staff development.

Process strategies. PCD often do not respond well to traditional didactic parent education (Whitman & Accardo, 1990). They often have difficulties with purely auditory instruction (Bakken, Miltenberger, & Schauss, 1993). Multimodal approaches that include auditory, visual, and kinesthetic strategies, using concrete examples, and in-home work to promote generalization work best (Feldman, 1994; Green & Cruz, 2000). This information should alter the expectations held by CPS workers and the larger system for parent response to intervention as well as provide tools of intervention and interaction.

First, training of CPS workers and staff of contract agencies needs to accommodate different learning styles. Adaptations may need to be made regarding the rate at which material is presented, the time frame in which change is expected, and the duration of and types of supports needed to maintain parenting capacities over time (e.g., a network of doctor’s offices that provide more active prompts for child
appointments, the use of visual aids). The ability of a caseworker to correctly identify the range in which a parent can complete a task with appropriate scaffolding, though not independently (i.e., the "zone of proximal development") [Vygotsky, 1978] relies upon appropriate expectations. Realistic expectations of parental capacity may result in an attribution that additional, possibly long-term, support is needed. The disparity between the time-limited focus of many social service interventions and the long-term support needed by many PCD must be directly met in CPS system change, and there are no easy solutions. Discussions of "supported" parenting programs are taking place nationally (see Through the Looking Glass, 2008; North American Coalition for Parents with Intellectual and Cognitive Challenges, 2008) and input may eventually come from these groups.

Second, capacities in functional assessment of parenting behaviors will provide a tool to increase the workers' sensitivity to where the parents' cognitive problems interfere with their mastery of a skill (e.g., being able to identify when the parent's limited ability to take the child's perspective is interfering with an interaction and that this capacity needs addressing first). Functional assessment looks beyond the behavior itself in order to identify the underlying purpose (function) for the behavior (e.g., the reason for what is often labeled as parents' "lack of motivation" to engage with CPS intervention) and how and why the trained behaviors are not being maintained (e.g., limited organizational or planning skills that require assistance). The function of a behavior can be determined via assessment of the antecedents that occur prior to and consequences that occur after the behavior. By focusing on the antecedent conditions, which include characteristics of the parent, such as beliefs, attitudes and level of functioning, the caseworker is better able to understand the behavior of the parent and adjust and elaborate on interventions accordingly. Formally, functional behavioral assessment (FBA) is a multi-method strategy that has been used with adults and children (Gresham, Watson & Skinner, 2001; Hanley, Iwata, & McCord, 2003). However, the principles of FBA are relatively simple, and are a helpful frame for working with adults with cognitive challenges in CPS. Once the maintaining factors are
determined, professionals can work alongside the parents to increase the conditions that support successful parenting and decrease obstacles.

Finally, lists of competencies for professionals working with disabilities have been suggested by various training organizations (see Institute for Human Services, 2008). For example, triage and referral skills are needed. Deep understanding of multiple systems of care (DMR, MH, EI) is also needed, such that consultation and assistance can be sought respectfully and with the right level of specificity of referral information and careful follow-up. Here, too, a SIP framework is helpful as the various professions use different language and approaches and tensions can be identified that have their roots in these differences rather than real differences of opinions. Abilities to provide more than crisis management, such as identification of the need for more long term planning, intervention, and perhaps lifetime supports, are also required.

Breaking down biases and promoting empowerment. Biases continue to exist toward the PCD that may interfere with the work that is done by CPS and with the professionals at contracted agencies. Biases can include a belief in parental incompetence and expectations of failure in the role of parenting, and/or a view that parents cannot act as agents on their own behalf and are not amenable to intervention. Efforts to sensitize staff to implicit biases and active skills training in empowerment strategies may both be important to break down barriers to success.

Values assessments (exploration of the nature of one's schema toward the cognitively disabled individual) and staff discussions are crucial to begin to challenge biases toward PCD. Our research group is developing methods using new technology for assessing prejudice attitudes in professionals to facilitate a recognition of their own potential for bias (see the Implicit Association Test (IAT) demonstration by Project Implicit at https://implicit.harvard.edu/implicit/demo/ and the discussion in Azar & Goff, 2008). Ongoing consultation with professionals whose career focuses on working with cognitive disabilities (DMR staff, special education staff) may be useful and can provide role models for the kinds of slow and methodical work required to affect change. They can also
model the kind of self-challenging of biased schema elements required using strategies used in cognitive behavioral therapy (e.g., cognitive restructuring or problem solving therapy) [Azar, 1996; Beck, 1993]. Evidence-based programs on reducing biased schema regarding other stigmatized groups have been used in other professions and might be adapted for use as a first step (e.g., physicians, mental health staff) [McDowell et al., 2003]. It should be noted, however, that the data regarding these programs’ long-term effectiveness are less than satisfying (e.g., effects may deteriorate over time). Continued work in supervision as a follow-up to such programming may assist in maintaining their effects.

Skills with empowering parents to participate in program development are also crucial (see the North Dakota Center for Persons with Disabilities, 2009; Kennedy Krieger Institute’s PACT: Growing Together Program, 2009). Individuals with intellectual disabilities have been said to exist within a “culture of dependency” (Whitman & Accardo, 1990), in which they rely upon the support of others to obtain goals that are often determined by others, especially providers and family. Recently, there has been movement towards self-determination and empowerment. Although these interventions have no single definition, they generally focus upon removing the responsibility for the creation and maintenance of goals from external sources and providing at least part of the responsibility to the individual with cognitive disability (Swift & Levin, 1987; Wehmeyer & Mithaug, 2006). These interventions inform the individual of options and choices regarding the form and content of support, facilitate individuals’ independent decision-making, and permit the individual to provide input to her or his intervention (Mansell & Beadle-Brown, 2004; Neely-Barnes, Marcenko, & Webber, 2008). This control over one’s own treatment has been found to increase the quality of life (e.g., vocational rehabilitation, reported life satisfaction) of adults with chronic mental illness (Rosenfield, 1992). Some efforts to increase empowerment have occurred in the child welfare system, but these are mostly directed toward the extended family of the parent who has perpetrated maltreatment (e.g., Family Group Decision Making Models) and have grown out of an increased use of kinship care (Crampton, 2007).
While empowerment interventions have gained popularity throughout the mental health field, questions remain regarding the feasibility and impact of such interventions. One question is whether PCD experience the interventions as empowering or not. A second question is whether it is feasible to "level" the playing field for PCD, given the differential power relationships that often exist between parents and CPS (e.g., mediation) [Barksy, 1996]. While these questions require further research, supervision designed to constantly challenge the worker's expectations and appraisals regarding the parent's agency in decision-making and goals may start a process of shifting away from long held biases in this area (Azar, 2000).

Working with the Parent with Cognitive Disabilities: Content of Programming

Programs exist in the U.S. and internationally that provide examples of the human capacity adaptations needed to maximize effectiveness of CPS interventions for PCD (e.g., Feldman & Case, 1999; Feldman, Case, & Sparks, 1992; Green & Cruz, 2000; Heinz & Grant, 2003; Lutzker, Bigelow, Doctor, Gershater, & Greene, 1998; McConnell, Matthews, Llewellyn, Mildon, & Handmarsh, 2008; Tymchuck, 1999, 2006). Remembering that a single, prescriptive formula for meeting the needs of PCD is an oversimplification of the issue (Llewellyn, McConnell, & Bye, 1998), these programs offer a variety of tools for working with the special population. They utilize many of the functional adaptations outlined above, such as multi-modal skill-based intervention, individualized plans and collaborative goal setting and management, while targeting basic parenting skills relevant to this population (e.g., basic child care such as safety, hygiene, and medical care) [Feldman & Case, 1999; Tymchuck, 2006].

Although the explicit adaptations made to the interventions in content and processes of implementation, implicit in these programs are developmentally sensitive expectations of the parents' style and speed of acquisition of information (i.e., adaptations to schema). These realistic expectations likely decrease negative attributions that would increase caseworker withdrawal and feelings of helplessness (e.g., attributions of parental incapability, laziness and/or lack of motivation) and
increase attributions that will increase caseworker motivation and self-efficacy (e.g., attributions of parental need for specialized, adapted support) [see Azar, 1989 for how this is done explicitly in the context of purely behavioral approaches]. Evidence-based adapted approaches that target both behavioral and SIP elements, such as those cited above, should be incorporated into CPS practice in ways that allow PCD an active role in determining their treatment goals. For instance, PCD report wanting more services addressing vocational needs and assertiveness skills and report being “over-serviced” in the child care area (Walton-Allen & Feldman, 1991) that CPS prioritizes. Adapted interventions exist in these domains that could be integrated into parenting programs for PCC (see Greenspan, Shoultz, & Weir, 1981).

Beyond the Parent: Establishing Better Social Support Networks

Along with evidence-based contracted work, attention needs to be given to building formal and informal networks of support for individual cases. This is essential to break up the social isolation that is common among PCD. Individuals with cognitive challenges are less likely than individuals without these challenges to live with a partner or have close friends or neighbors (Hassiotis et al., 2008; Llewellyn & McConnell, 2002). Increasing social networks with other parents (ones with and without disabilities) will help reduce social isolation, build parent empowerment, and help with the sharing of resources and information (Tarleton & Ward, 2007).

In addition, programs have emerged that utilize community mentors and lay advisors for PCD. Community mentors and lay advisors can accompany parents to appointments, help “translate” legal and medical information, help scaffold problem solving in parenting situations, and help access resources. Programs that combine community mentors who can help parents navigate in the community and residential placements for entire at-risk families have shown effectiveness in increasing self sufficiency and family preservation (Barth & Price, 1999). Efforts to operationalize this have occurred (Arc of Franklin & Hampshire Counties, 2007; Legal Services Law Line of Vermont, 2008) and could be incorporated into CPS interventions.
However, external sources (i.e., caseworkers) cannot be the sole creators and maintainers of social support networks. Instead, PCD must be provided with effective training on skills to increase the probability of continuity in their social support network. Such skills include assertiveness training, skill-based workshops offered in an individual or group setting. In fact, social skills training with a focus upon modeling and/or in vivo practice and feedback has been found to be effective with adults with intellectual disabilities (Bidwell & Rehfeldt, 2004).

**Organizational Support Networks across Public and Private Systems**

PCD interact with multiple service systems (e.g., housing, welfare, schools, and courts) [U.S. GAO, 2001], which can cause confusion and fear on the part of the parent. Integration of these multiple services is needed. In fact, fewer service providers along with faster service implementation has been linked to satisfaction with CPS generally (Chapman, Gibbons, Barth, McCrae, & NSCAW Research Group, 2003) and may be more crucial for PCD. The CPS system should focus attention on building ongoing networks of support within existing systems for the benefit of both PCD and CPS workers. Networks of professionals in the local community that have expertise relevant to cognitive challenges are necessary. An example would be medical professionals who can provide more appointment reminders, translate medical jargon, and patiently provide information on medical problems and how to handle emergencies to scaffold parents’ effective utilization of child health care (Heinz & Grant, 2003).

In addition, CPS workers can feel isolated and overwhelmed due to the multiple needs of parents with PCD. Other systems have staff with more training in working with cognitive challenges (Department of Mental Retardation) and linkages with these systems may enhance services CPS can provide. Informal associations (such as consultation, staff sharing) may be possible through cooperative agreements. CPS workers would also benefit from partnerships between CPS and community agencies for adults with cognitive challenges (e.g. ARC), as they would help integrate efforts and resources, reduce the burden for individual caseworkers, and facilitate relationships.
between PCD, the community and other individuals. Some evidence exists that this occurs in some locales (Arc of Franklin & Hampshire Counties, 2007) or at the case level, but it is unclear how widespread or systematic this collaboration is. Ultimately, these extended supports could reduce recidivism by increasing connections that can serve as resources in times of crisis and reduce barriers related to PCD biases (Tymchuk, 1999).

Conclusions

In this paper, we have built an argument for PCD as comprising a significant proportion of CPS caseloads. Cognitive disabilities, as reflected in SIP deficits, affect parents’ capacity to interact with CPS workers in many cases and require accommodated services in order to provide effective parenting support. Though other systems have made efforts to include individuals with disabilities, CPS has been less touched by the mandates of ADA. We call for similar, pervasive system change with human capacity development and organizational linkages to provide support for the CPS system and the PCD within the system. Although our focus has been on parents with a formal diagnosis, we argue for the benefit of a more universal approach so that unidentified, “silently” disabled parents may benefit as well.

We believe with increased CPS worker skills and knowledge, moment-by-moment interactions with PCD (both those with formally identified disabilities and those who may have unidentified difficulties) will be less fraught with difficulties. With accommodated programmatic changes in the content and process of interventions, effectiveness will increase. These adaptations would both remedy broader concerns regarding worker burnout and allow parents to retain custody of their children and more easily enact this important parenting role.
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Reaching Beyond the “Moron”:
Eugenic Control of Secondary
Disability Groups

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While much has been published about the American eugenics movement, few authors have considered the relative status of various disability populations as targets of eugenic control. While many writers focus on persons diagnosed as feeble-minded as the central focus of control, little has been written regarding the status of additional disability groups. This is important since, as described here, a central component of coming to understand past social injustices against marginalized groups and the contemporary relevance of such injustices is gaining an awareness of why specific populations were accepted by control authorities as appropriate or viable targets for control measures.

Key words: Eugenic Movement; Disability Discrimination; Feeble-mindedness

Much has been written over the past few decades about the American eugenics movement. The movement has great importance for social work and related professions as well as our understanding of the mechanisms of social and economic injustice. Indeed, eugenics is again coming to the fore in part because of contemporary discussions relative to the potential social and economic justice aspects of genetic research. Historical eugenics also has current relevance for any social policies or programs that seek to limit the procreative capacity

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of specific segments of the population. Importantly, while most of the various components of the American eugenic movement have been described in great depth in recent years, there has been little systematic analysis of the targets of eugenic control during the first quarter of the twentieth century. While most works focus heavily on the persons with "feeble-mindedness," and particularly "morons," as foci for sterilization or institutionalization, much discussion among eugenicists pertained to the possibility of expanding eugenic policies to other disability and non-disability (e.g., criminals, those living in poverty) groups. This is an important issue since we must, in order to effectively advocate for social and economic justice concerns, develop an awareness not only of the injustices of the past, but of the various rationales that were applied for bringing specific target groups under the control of oppressive social policies.

Following a brief overview of the American eugenics movement, this article will consider the status of persons with various disability conditions as candidates for eugenic control. A large part of this analysis will be given over to the role of insanity within the context of eugenic rhetoric and practice, since this was the prevailing secondary target of eugenic control. Other conditions discussed include epilepsy and sensory impairments.

The American Eugenics Movement

The principle elements of the eugenics movement in the United States have been described in great depth by a number of scholars (see, for example, Chase, 1977; Gould, 1981a; Kevles, 1985; Kline, 2001; O’Brien, 1999; Trent, 1994), and therefore will only be superficially delineated here. Drawing on the writings of England’s Sir Francis Galton (1870, 1904, 1907), and gaining research legitimacy following the rediscovery of Mendel’s laws in 1900, American eugenicists held that the human species could be directed in a positive evolutionary path if attention was paid to breeding. Eugenicists supported both “positive” and “negative” eugenics. The former included efforts to expand the reproduction rates of the more fit classes, while the latter centered on policies to diminish child-birth among the less fit classes. Obviously fitness was a concept that
was rife with inexactitude and subjectivity, a matter to which we return below.

The movement in the U.S. reached its peak between 1910 and 1930. As the movement grew, efforts to enact eugenic legislation that would restrict breeding among disfavored community groups became its central goal. The majority of states passed involuntary sterilization (Laughlin, 1914; Reilly, 1991) and/or restrictive marriage legislation (Humphrey, 1913); forced institutionalization was often allowed for “dysgenic” persons who were liable to become parents (“Feeble Minded Boys ...,” 1915), and eugenic concerns about the health or mental status of immigrants were an important rationale for passage of the 1921 and 1924 restrictive immigration laws (“Europe as an ...,” 1924). A small number of eugenic advocates within the country also supported euthanasia as a potential eugenic solution (Hollander, 1989; McKim, 1901; Pernick, 1996, “Was the Doctor Right?” 1916).

Eugenic supporters argued that the “unfit” segments of the population were breeding in much greater numbers than their “fit” contemporaries, and would eventually outnumber them. Drawing on the earlier writings of Thomas Malthus and Herbert Spencer, eugenicists contended that this was a particular concern since such groups would, because of their presumably high procreative rates, eventually outnumber the “normal” segment of the population. They often contended that modern charity and governmental support was allowing dysgenic persons to survive, and thus the need for eugenic control was essential (Batten, 1908).

Many eugenicists contended that if these eugenic measures were widely legislated and implemented, important social problems such as crime, poverty and prostitution would be largely diminished, since such problems presumably arose largely from the groups that were targeted by the policies. Of course, this all begged the question, how did one diagnose eugenic unfitness with any degree of rigidity?

The Confusion of Categorization

Especially early in the eugenics movement, unfitness was described by a plethora of inexact and overlapping “diagnoses,” many of which were exceedingly vague. As Wright (1891)
To a considerable extent these...defective classes link into one another. It is hard to say whether a tramp is a pauper or a criminal. ...A very large per cent of criminals become insane in prison or afterward. A considerable number of paupers become insane. The children of one class pass easily into the other class. ...Here and there in our country, and in every other one, are knots of defectives all tangled up together, families closely related furnishing a whole population of criminals, idiots, and lunatics among themselves.... The interchangability of these defects is very clearly shown in these cases. (p. 227)

Many early supporters of eugenic control simply spoke of defectives, unfit persons or degenerates, and imprecise classifications such as moral insanity, moral imbecility, or moral defectives were developed in an effort to move in the direction of clarity (Broomall, 1887-1895, p. 40). Most eugenicists felt that the various “negative” social behaviors largely were found in the same group of persons, and thus focusing on one trait (e.g., alcoholism, prostitution, poverty) was not necessary. Some writers talked of the “bottom 10%” of the population, a group that was characterized by a preponderance of interconnected negative traits (Grant, 1916). When Richard Dugdale wrote his famous book on the “degenerate” Juke family in 1877, no single trait stood out as the primary indicator of eugenic unfitness (Dugdale, 1910). Henry Goddard (1912) noted that Dugdale described a family whose members experienced the full range of anti-social traits, with no clear patterns in regard to either a “master dysgenic characteristic” or even the hereditary transmission of traits. Grandparents with epilepsy and insanity might have children who were identified as prostitutes and paupers, who themselves sired children with feeble-mindedness and alcoholism.

Eugenics Finds its Target: The Menace of the Moron

As noted above, at the beginning of the century no particular group was singled out as the primary target of eugenic
control. Criminals, prostitutes, paupers, the insane, those with epilepsy, persons with physical impairments and individuals diagnosed with feeble-mindedness were by and large accorded similar attention. As the first decade of the century drew to a close, however, feeble-minded individuals began to take center stage as the presumptive primary source of dysgenic evil within society. "Feeble-mindedness" was the broad term to describe persons who would later be labelled as mentally deficient, mentally retarded, or cognitively or intellectually disabled. This classification included, from "lowest" to "highest" functioning, idiots, imbeciles and morons. Within a few short years of the turn of the century, eugenic unfitness would come to be inextricably connected to moronity. This development would be caused by the merging of a number of factors, the most important of which were the rediscovery of Mendel's laws and the development of the intelligence test.

The rediscovery of Gregor Mendel's laws of heredity in 1900 proved to be an extremely important factor in the growth of the American eugenics movement. While some advocacy for a eugenic program existed prior to this point, supporters realized that the nature of trait transmission was an extremely important question that remained to be answered before such a program could be launched in earnest. If environmental modifications could improve the status of "unfit" individuals, then a positive evolutionary path could be fostered through the development of such modifications. Mendel's laws were therefore important in providing focus for a eugenic "target of control." If particular social problems were hereditary in nature, at least in the main, such problems might well be dealt with by reducing procreation among those groups. Educational and environmental uplift would do little to increase the capacity of such families if their "impairments" were intrinsic and largely unalterable (Gould, 1981a; Kevles, 1985).

Eugenicists such as Charles Davenport, the Director of the Eugenic Record Office, argued that there was a clear genetic explanation to most types of feeble-mindedness. As he wrote in 1921:

It appears probable, from extensive pedigrees that have been analyzed, that feeble-mindedness of the middle
and higher grades is inherited as a simple recessive, or approximately so. It follows that two parents who are feeble-minded shall have only feeble-minded children and this is what is empirically found. (p. 393)

The heritability of feeble-mindedness came to be readily accepted by most eugenicists in large part based on eugenic family studies such as Henry Goddard’s famous 1912 book on the Kallikak family (Gould, 1981a). Through the extensive use of field research, these studies presumably demonstrated that most negative social traits ran in family lines. Most importantly, using newly developed intelligence tests, the researchers contended that the vast majority of the Kallikaks and similar families were characterized by a massive degree of inherited moronity. This belief was presumed by some professionals, especially those who worked in the area of feeble-mindedness, even before they had knowledge of intelligence testing or Mendel’s laws. Barr (1898), for example, wrote that “[n]o other class of defectives transmit ill with such certainty as the feeble-minded” (p. 483), and Bicknell (1895-1896) added that “[t]he curse of feeble-mindedness descends from parents to child as no other defect does” (p. 81).

The intelligence test, developed in France and introduced in the United States shortly after the turn of the century, was helpful to eugenic researchers in pointing out “morons” in the population. This term was coined early in the century by Henry Goddard to describe that segment of the feeble-minded population that graded over into the “normal” population (Gould, 1981a), and therefore could go “undiagnosed” in the community (Stoddard, 1923). As one might speculate, it was this large group of “higher functioning” feeble-minded persons who were said to pose the most threat to the community. As the intelligence test was used more frequently, ever-increasing numbers of morons were found to be living—and procreating—in the country. As Jessie Taft wrote in 1918,

[t]here is no question that the swift rise of the mental test as a center of interest and experiment in applied psychology has had much to do with the growth of popular recognition of feeblemindedness as a social problem. (pp. 543-544)
As supporters of eugenic policies came to embrace the presumption that moronity was the core feature that identified the "unfit" segment of the population, many also believed that it was moronity that caused or at least set the stage for these other social problems (MacMurchy, 1916). Nicole Rafter, in discussing one of the family studies, wrote (1988) that it focused heavily on feeble-mindedness as central identifying feature of family members, but was "also concerned with alcoholism, blindness, criminality, epilepsy, insanity, sex offending, syphilis, and the propensity to wander" (p. 6). Some of the family studies, Rafter (1988) noted, pointed to the centrality of feeble-mindedness in the pseudonym that was given the family. The "Family of Sam Sixty," for example, acquired its name from the presumed I.Q. of the progenitor of the family (p. 28; see also, Koster, 1916).

The focus on moronity benefited eugenic advocates in multiple ways. First, drawing on the intelligence tests as a "scientific" measure of feeble-mindedness allowed them to argue that they were not being arbitrary in what groups were targeted for control. On the other hand, however, diagnoses were not only based on intelligence test results (not that these were in any way objective measures of inborn knowledge), but also on the subjective presumptions and judgments of diagnosticians. As a result, persons from multiple marginalized groups, including those living in poverty, racial minorities, undesirable immigrant populations, and others could easily be pulled into the feeble-minded category (Gould, 1981a).

Interestingly, eugenic advocates won their most important victory at a point in time when the movement was rapidly losing "scientific" legitimacy. In an historic 8-1 decision, the Supreme Court upheld North Carolina's proposed sterilization of Carrie Buck, a young woman who had been placed in an institution after bearing a child out of wedlock. Following dubious I.Q. tests on herself, her mother and her daughter (the "three generations of imbeciles" described by Justice Oliver Wendell Holmes in his decision on the case) and discussions by eugenic authorities, the Court agreed to allow Buck's sterilization. This provided Constitutional approval for the procedure, and allowed States to engage in the measure without fear of judiciary retribution (Gould, 1981a; Smith & Nelson, 1989).
Additional Disability Targets of Eugenics Control

To the supporters of eugenic control, feeble-mindedness was the perfect target classification for proposed policies for the reasons stated above. During the eugenic alarm period, however, there were recommendations and efforts to bring additional disability categories under the eugenic umbrella. We will describe three of the most prominent groups, including: (a) persons with mental illness; (b) persons with epilepsy; and (c) persons with sensory impairments.

Persons with Mental Illness

Prior to the eugenic era, some psychiatrists saw policies that would limit procreation among persons with chronic mental illness as an important factor in controlling such conditions. One is quoted as saying

I am, indeed, not sure that in the progressive future, it will not be deemed a measure of sound policy and commendable statesmanship to stamp out insanity, by castrating all the insane men and spaying all the insane women. (cited in Haller, 1963, p. 30)

Throughout the eugenic period, many supporters of social control policies included insanity alongside feeble-mindedness as a primary indicator of eugenic unfitness. To those eugenicists who weren't experts in medicine or psychiatry, in fact, there was little if any differentiation between the two groups. Many simply spoke of persons with mental disease or other such vague terms, which usually included both broad categories. Many experts, however, saw a clear distinction between insanity and feeble-mindedness even as early as the mid-1800s, when large-scale institutional development for persons with mental illness expanded greatly. While most eugenicists in the United States were in agreement about the advancing "menace" of feeble-mindedness and the necessity of eugenic policies to stop the spread of the condition, this was not true of mental illness, for a number of reasons.

First, feeble-mindedness was seen largely as a singular condition, varying only in its extremity. While some professionals in the field noted that conditions such as Down syndrome could
be classified as a specific type of feeble-mindedness, such cases were seen as encompassing only a small percent of the whole. Mental illness, however, was known to be of various types, each differing from the others in a number of ways. Especially important were questions about the heritability of the various forms of mental illness. While many researchers noted that certain types demonstrated an inheritance pattern, there was much uncertainty about this (Holmes, 1914, p. 307), and many eugenicists felt that mental illness arose from a combination of hereditary and environmental causes, which also made eugenic approaches of questionable effectiveness (Popenoe & Johnson, 1933, p. 126).

The diagnosis of moronity was accepted by most specialists as more accurate than the various forms of insanity. The intelligence test led most to believe that feeble-mindedness was being accurately measured, whereas insanity was much more speculative, especially in its milder stages. Michael Guyer wrote in 1927,

In general, there is more doubt about the inheritability of some of the insanities than about cases of mental deficiency. The term insanity is merely a loose descriptive one, and we shall gain little definite knowledge about the inheritance of such maladies until we study each separate insane diathesis specifically. Psychiatrists recognize many different forms of insanity, some of them very distinct from others and the product of unrelated underlying causes. ...It is almost impossible in some instances to tell just where the border-line between and abnormal and a normal constitution lies. (p. 341)

When persons might be diagnosed is also an important issue in whether eugenic policies were viewed as appropriate for those with mental illness. Many of those who are so diagnosed only exhibited symptoms (at least to the extent that they came within the purview of professionals), during the middle or later stages of their lives, often after they (especially females) had moved much of the way through their procreative years. Certainly eugenic policies would be of only partial value in diminishing such conditions then. As Popenoe and Johnson (1933) wrote, "[t]he fact that only one in every four of the first
admissions to American psychiatric hospitals is as early as 30 years of age shows a serious limitation of this sort of segregation from a eugenic point of view" (p. 138). Since moronity was believed to be present from birth, it was seen as a much more preventable condition, given the possibility of early diagnosis and procreative control of those so diagnosed (pp. 127-128). For example, Carrie Buck's daughter Vivian was supposedly diagnosed as an imbecile when she was an infant (Smith & Nelson, 1989, p. 135). It was on this diagnosis that Holmes's "three generations of imbeciles" rested.

Additionally, much of the severely mentally ill population was already institutionalized when the eugenic era began. As Ferguson (1994) wrote,

[t]he rates of institutionalization for the two populations...differ dramatically. Even at the height of the eugenics era, less than 10 percent of the identified population of mentally retarded people was actually confined in large, public institutions. By the end of the nineteenth century, the comparable rate for mental illness was in the 70 to 80 percent range. (p. 10)

A major reason for the fear of sweeping moronity was that the vast majority of such individuals were believed to be walking around unrestrained within the community. Eugenicists would argue that the nation's success in institutionalizing the insane supported similar measures directed at morons. "Many progressive states," Fenald (1904) wrote, "have already adopted this policy [permanent segregation] in the care of the insane. The feeble-minded have an equal or greater claim in every way" (p. 388). Those involuntary institutionalization procedures that were already in place were especially apt to be employed against females with mental illness (Geller & Harris, 1994).

Finally, especially as Freud's writings began to be embraced in the United States after the First World War, many specialists in the area believed that persons exhibiting insanity could be assisted to regain some measure of pre-morbid functioning. Such hopes did not exist in the case of feeble-mindedness. Indeed, the term "pre-morbid functioning" was largely meaningless in discussing a population that was viewed as impaired from
(or even prior to) birth. A prevailing belief during the eugenic period was that many cases of mental illnesses such as anxiety or hysteria developed largely from the pace of modern urban life (Popenoe & Johnson, 1933, p. 127). Too much stimulation presumably led to such conditions. Environmental etiological causes such as this ran counter to the hereditary focus of the eugenicists. If one’s environment caused or exacerbated the symptoms of a mental illness, it was possible that other environmental modifications or therapy could diminish it.

There were a few eugenicists who argued that various aspects of insanity made this population a particularly important target for eugenic control, even if hereditary transmission was not proven. Lothrop Stoddard, for example, noted (1923) that;

[un]like feeble-mindedness, insanity is often associated with very superior qualities, which may render the afflicted individuals an acute menace to society. The feeble-minded never overturned a state. An essentially negative element, they may drag a civilization down toward sodden degeneracy, but they have not the wit to disrupt it. The insane, on the other hand, are apt to be intensely dynamic and to misuse their powers for destructive ends. (p. 98)

For the most part, however, eugenic rhetoric was fueled by a fear of moronity rather than insanity. Importantly, however, while eugenic propaganda did not largely target persons with mental illness, restrictive procreation policies had a substantial impact on both populations. According to Osborn (1951), “the total number of sterilizations performed in the United States up to January 1, 1950 was 50,707, of which 22,844 were on insane cases, and 25,903 on feeble-minded; 1,860 were sterilized for other reasons” (p. 59). Most marriage restriction policies covered both populations, and certainly a large number of the forcible institutions of persons with mental illness during the eugenic era arose at least in large part from a fear of procreation.

**Persons with Seizure Disorders**

Throughout the eugenic period, but especially during its
formative years early in the century, persons with epilepsy were a principle target of eugenic control. To a large extent this was due to the fact that feeble-mindedness and epilepsy were closely linked. To quote Wilmarth (1902):

...the epileptic and imbecile, ...are almost inseparably connected. Considerably over one-half of the feeble-minded have, at some time of their life, suffered from convulsive disorders as a complication of their condition; while, on the other hand, only a small percentage of confirmed epileptics escape without mental deterioration. (p. 153)

Guyer (1913) added a decade later that “[a]lthough epileptics are not classed as imbeciles ordinarily, as a matter of fact no sharp distinction can be drawn between the two classes” (p. 37).

Not only did many eugenicists perceive persons with seizure conditions to be feeble-minded, they also contended that such persons were incapable of controlling themselves and in many cases were “criminalistic,” exhibiting a higher degree of violence than most morons. They were said to “be dangerously antisocial, epilepsy being frequently connected with the worst crimes of violence. The spreading of epileptic strains among sound stocks is unquestionably disastrous, causing grave social dangers...” (Stoddard, 1923, p. 99).

To some degree this pejorative view of persons with epilepsy was fostered by the writings of the early Italian criminologist Cesare Lombroso in the later half of the nineteenth century. Lombroso was interested in the classification of various groups, and, like the phrenologists of the same age, was compelled to study the relationship between physical characteristics (both congenital and acquired) and internal qualities or behaviors of individuals, specifically focusing on the “criminalistic” portion of the populace (Ettinger, 1932).

Lombroso’s most influential text was the book L’uomo Delinquente (The Criminal Man), which was published in 1876. Writing in the wake of Darwin, Lombroso proposed a theory that criminals constituted an atavistic throw-back to an earlier period of human evolution. Such individuals were, he said, representative of a primitive, more brutal stage in our
cultural past, somewhere presumably between humans and apes. Lombroso utilized phrenology to support his theories, and held the opinion that criminal tendencies originated in the individual's biological constitution. Lombroso contended that he saw ape-like characteristics in the physical features of criminals, which he believed provided evidence to support his theory (Gould, 1981a, 1981b; Lombroso, 1968; 2006).

Lombroso was especially interested in the correlation between criminality and epilepsy, and he contended that the majority of those with epilepsy would eventually become criminals. Such individuals, he said, were unstable and could not be trusted to control themselves. They were likely to turn evil at any time, and therefore their social control was warranted (Lombroso, 1968, pp. 365-375, also see Lombroso, 2006). According to Gould, Lombroso went so far as to recommend a preventative criminology, reasoning that "society need not wait (and suffer) for the act itself." For since "physical and social stigmata define the potential criminal," such persons should "be identified (in early childhood), watched, and whisked away at the first manifestation" of criminal behavior (Gould, 1981b, p. 225).

Having a strong interest in the physiological indicators of psychological and behavioral phenomenon, or in the hereditary etiology of criminal behavior, many of the American eugenicists were advocates of Lombrosian theories. His belief in the degeneracy of persons with epilepsy tied in nicely with the eugenic denigration of moronity, especially since the two conditions were closely related to one another in the minds of the early eugenicists. Just as they supported widespread institutionalization of persons with feeble-mindedness, many eugenic supporters called for "sexual segregation" of persons with epilepsy.

As the movement evolved, however, epilepsy became a relatively minor target of control. This was due in large part to the fact that many eugenicists believed that control of moronity would inevitably entail a control of epileptics, since the latter was viewed as one of many indicators of the former condition. As eugenic policies came to be increasingly implemented against the moron class, it was assumed therefore that those with epilepsy were (at least the most problematic segment
of this population) falling within this "net." Additionally, a number of writers began to question earlier assumptions about the hereditary nature of epilepsy. Popenoe and Johnson (1933), for example, contended that "[t]he ancestry of epileptic patients usually shows a few cases of epilepsy and many other evidences of weak nervous systems such as alcoholism. Cases in which the epileptic actually comes of epileptic parents are the exception" (p. 126).

**Persons with Sensory Disabilities**

Individuals with sensory disabilities, and especially those who were blind and/or deaf, never were a central target for eugenic control. Many eugenicists would include such individuals, especially those with "hereditary" conditions, into the general class of degenerates, but they were not a group that attracted a great deal of attention from eugenicists. In part this was due to the fact that many visual and hearing impairments were acquired rather than hereditary, and little was known at the time about the heritability for either condition. Eugenic advocates Popenoe and Johnson (1933) believed that in only about ten to twenty percent of such cases heredity was the primary etiological explanation. To a large degree, two important personalities of the late nineteenth and early twentieth century had a great deal of impact over how the problem of persons with sensory disabilities would be perceived by American eugenicists. These were Alexander Graham Bell and Helen Keller.

Bell was very interested in deafness, and his wife was deaf. His invention of the telephone, moreover, came about from his efforts to communicate with deaf persons. Bell believed that hereditary deafness arose largely from intermarriage among the deaf population, especially since many such individuals went to segregated schools and largely interacted with other deaf persons. He argued that the integration of deaf persons within the broader community would foster their marriage with non-deaf persons. Since he believed that such intermarriage naturally led to hearing children (since this trait was, to use a term that would later be coined by geneticists, "dominant"), he decried the expansion of segregated environments and any other social practices that would encourage deaf
persons to congregate together (Baynton, 1996; Haller, 1963).

Bell was an early leader in the eugenic movement. Like some others who were so interested, he engaged in animal breeding as a hobby. Bell was primarily interested in “positive eugenics,” which would encourage the birthrate among the more “fit” segment of the population, and he argued that only through such policies would eugenicists reach their major goal of improvement of the species (Bell, 1914). As the movement came to focus almost exclusively on negative eugenic policies such as involuntary sterilization, however, he became disen-chanted with it.

Helen Keller had a profound symbolic and practical impact on the image the public, as well as professionals, had of persons with sensory disabilities. Her ability to overcome what seemed like insurmountable odds led people to believe in the potential of such individuals. A fundamental reason why those with sensory disabilities were not targets of eugenic control was that they were not viewed as mentally impaired. The story of Helen Keller demonstrated to people that even when they appeared that way, this could simply be due to communication inabilities. One of the aspects of her story that makes it so compelling is the realization that had it not been for Anne Sullivan’s perseverance, Helen might have been institutionalized or otherwise relegated to the world of imbecility.

Helen Keller herself fostered this dichotomy between persons with physical and mental impairments, as well as the belief that they should be given differential consideration and treatment. In a 1915 letter published in the New Republic she responded to the recent “Bollinger baby” case, whereby a Chicago physician allowed, with the consent of the parents, a newborn to die in large part because the baby was thought to be intellectually disabled (Keller, 1915. Also see Gerdtz, 2006). Keller (1915) wrote:

[i]t is the possibilities happiness, intelligence and power that give life its sanctity, and they are absent in the case of a poor, misshapen, paralyzed, unthinking creature. I think there are many more clear cases of such hopeless death-in-life than the critics of Dr. Haiselden realize. The toleration of such anomalies tends to lessen the sacredness in which normal life is held. (p. 173)
Discussion

The eugenic movement in the United States had an important impact on the evolution of the movement in Germany, and was used to provide moral cover for the Nazi's early eugenic programs, such as their 1933 sterilization law and 1935 marriage restriction policies (Kevles, 1985; Kühl, 1994). While the Nazis fostered a highly pejorative view of all persons with what were presumably hereditary disabilities, their eugenic policies largely impacted those with mental disabilities as opposed to sensory or other physical conditions. An example is the sterilization law, which was primarily directed at nine disability groups. The vast majority of the operations, however, were performed on persons with feeble-mindedness or "hereditary" forms of mental illness. The formal T4 extermination program, which included the first widespread use of poison gas for the purpose of mass murder, also largely targeted "insane" and "feeble-minded" persons.

The Keller (1915) quote above highlights the demarcation between persons with physical and intellectual/mental impairments that characterized the eugenic era, and the presumption that the "weeding of the human garden" (p. 173) should be accomplished by focusing on those with severe cognitive deficits. This prerogative was given weight by the belief that morons were unproductive, that they were lazy and selfish parasites burdening the community, but also by presumptions that such persons were hypersexual, irresponsible, potentially criminalistic and corrupting of the social body, both metaphorically and in the actual spread of venereal and other diseases (O'Brien, 1999). Furthermore, such persons were closely linked to other marginalized groups, including disfavored immigrant populations and the poor.

Additionally, persons diagnosed as being feeble-minded were largely uneducated. In many cases, surely, the pre-existing lack of education paved the way for the diagnosis. Especially in an age predating informed consent guidelines, such persons were easy targets for eugenicists and eugenically-based institutions, as they had little capability of providing a strong defense. As the case against Carrie Buck, the legal cards were stacked against them throughout the entire process (Smith & Nelson, 1989).
Lastly, a bureaucratic infrastructure composed of a new brand of professionals (psychologists, psychiatrists, social workers, public health workers) and encompassing a broad range of social control institutions had developed prior to and during the decades following the turn of the century. This infrastructure was maintained in part by the need to enforce policies of eugenic control. While many eugenicists certainly believed the fear they proselytized, many others saw intelligence testing, institutional-building, sterilization, and other forms of control as a way of expanding their authority and demonstrating the need for their professional expertise.

References


This exemplary book introducing human rights and its implications to the social work profession serves as an introductory textbook for international social work. With increasing economic and social adversities in the world, the rights of many impoverished and vulnerable people have been sacrificed. At a time when social work is faced with tough challenges, understanding human rights and its relevance to professional practice provides a platform for service delivery and research. In her book, Mapp discusses current violations of human rights such as violence against women, war and conflict, forced labor, inadequate healthcare and the conscription of children as soldiers. She draws a landscape of 'human rights' realities for students as well as social work practitioners. A thorough understanding and commitment to human rights in social work will not only enhance practice responses to these issues, but also facilitate research in the area, creating a stronger knowledge base in social work to deal with these problems.

In the first part of the book, Mapp explains the concepts of development and human rights in relation to social work. Having built a theoretical foundation for social work in light of human rights, she focuses on some universal and yet largely invisible problems in social work literature. The universal declaration of human rights states that no one should be held in slavery and servitude. However, slavery still exists in the form of forced labor often emerging out of unfavorable economic and social circumstances. The way slavery now exists is often
ignored and needs the attention of social workers, particularly those involved in policy studies and macro practice. In this section of the book, she elucidates the veiled realities of ‘human trafficking,’ ‘illegal immigration and domestic servitude,’ ‘sexual slavery,’ as well as the exploitation of private citizens. The book then goes on to describe the increasing exploitation of child labor in the Global South drawing attention to the United Nations Convention on the Rights on the Child to show how social workers can help to address the problem within a human rights context. Having discussed children’s rights and social work, the book deals with the challenge of war and conflict, which is a highly topical issue. Conflict not only impacts the mental and physical health of the affected population but also leaves long lasting scars of socio-economic oppression. The issues of displacement and refugees and the lack of services to meet the needs and basic rights of this population requires great attention from the social work professional community. Mapp succinctly depicts the role of social workers in building knowledge as well as services for refugees and internally displaced people.

The concluding chapters of the book deal with often debated issues in social work. The author provides a thorough account of HIV-AIDS, and efforts to curb the spread of this disease. She also gives attention to the ever increasing numbers of women contracting the HIV virus. She discusses issues impacting women today, such as family violence, female genital cutting, dowry deaths and honor killings. In spite of human rights instruments such as the Convention for Elimination of all Forms of Discrimination Against Women (CEDAW), violence against women continues.

The author calls on social workers to take action to respond to these issues and to commit themselves to a human rights approach in social work practice. A helpful feature of this book is its last part where the author gives factual information about the resources social workers can use to contribute positively to change the lives of those vulnerable sections of society who are as yet not effectively protected by human rights law. This book is not only important for social workers but an excellent read for anyone interested in current affairs and for those in related fields such as law, public policy and social administration.

Nairruti Jani, University of Texas at Arlington

Fred McKenzie's book provides a comprehensive approach to social work practice with adolescents by utilizing development theories and linking theory and practice. The transition to adolescence is a time of drastic change. Adolescents are changing biologically, physically, emotionally, cognitively, and socially. During this transition, adolescents experience puberty, dramatic changes in their family and peer relationships, they begin to think more abstractly and have more reasoning abilities. This transition can be difficult for adolescents, their families, and practitioners who work with them.

McKenzie, an associate professor and director of the School of Social Work at Aurora University, explores adolescence through theoretical underpinnings from renowned theorist like Freud, Piaget, Kohlberg, Gilligan, Erikson, Bowlby, Skinner, and Ellis. McKenzie acknowledges that generally most adolescents do not volunteer for therapy. Moreover, they are referred by teachers, school counselors and social workers, or by their parents. Thus, he provides an assortment of traditional and nontraditional techniques for assessing, engaging, and continuing work with adolescents. McKenzie focuses on hobbies and personal interests such as text messaging, listening to music, journaling, and instant messaging as areas that practitioners can explore to engage adolescents and to develop a trusting therapeutic relationship. McKenzie presents and applies a comprehensive assessment and intervention planning model for practitioners to incorporate into their practice. The assessment method allows practitioners to gain an in-depth understanding of the adolescent's biopsychosocial functioning.

A major strength of the book is the extensive integration of research findings into practice. The book is also well organized into engaging and thought provoking chapters. The case examples presented at the end of each chapter serve as real world referents and illustrations of the techniques and interventions discussed in the chapter. In these case examples, McKenzie passionately and elegantly talks about his
professional experiences to clarify topics discussed. In addition to case examples, McKenzie also provides additional sources for further reading and a list of films and movies that demonstrate the topics discussed.

However, there are two drawbacks of the book. McKenzie presents a variety of situations and behaviors in which adolescents are referred for therapy and discusses interventions to treat identity crisis issues, mental health issues, gender issues, substance use and abuse, self-harming behaviors, and eating disorders. However, McKenzie fails to mention interventions that can be incorporated into practice with pregnant and parenting adolescents. Adolescent parents have unique circumstances and needs; therefore, they require unique interventions. A second notable drawback is that the chapter on culturally competent practice is inadequate. Although the author acknowledges that one chapter cannot cover all the techniques needed to work with diverse populations, more than one ethnic group should have been represented in the case example. Cultural competence is critical in that a significant number of clients that social workers serve are minorities. This chapter could have been expanded. However, readers will gain a comprehensive understanding of the techniques and skills that are grounded in theory to work with adolescents that enter therapy with a variety of circumstances and issues. Professors can use this book as a teaching tool with students and practitioners can use the book as a reference tool for their practice with adolescent clients.

Nila Ricks, University of Texas at Arlington


In an age dominated by visual imagery, it may be difficult to appreciate the extent to which the print media previously informed popular opinion. In the absence of cinema, television and internet images, popular attitudes and beliefs were shaped by newspapers, novels, magazines and works of non-fiction such as biographies and autobiographies. Of course,
these publications also reflected popular attitudes and beliefs. By analyzing this literature, scholars have not only obtained powerful insights into the cultural and social values of past societies but have shown how prevailing values, norms and social structures were perpetuated. In addition, they have shown how the print media was used to construct new attitudes and social values that suited the interest of particular segments of society.

It is in this context that Philip Holden examines the role of autobiographies in shaping popular attitudes during the imperial and postcolonial eras. Drawing on the insights of postmodernist, feminist and postcolonial scholarship, he contends that the autobiographies of key nationalist independence leaders such as Gandhi, Nkrumah, Nehru, Lee Kuan Yew and Mandela played a vital role in nation building. These autobiographies were widely read and helped fire the imaginations of millions of people. They also played a vital role in the construction of national identity and in the conception of what constituted the emergent nation. Although these texts span many decades and attracted both national and international attention at different times during the process of decolonization, they share many common features. One of the most significant, Holden believes, is the emphasis on masculinity as reflected in frequent references to the masculinity of the independence leader, and in the subtle ways notions of masculinity pervaded these different autobiographies. Holden provides many fascinating examples which bolstered the image of the nationalist leader as a strong, determined, self-controlled and dependable man. The masculinity of the leader, in turn, was extrapolated to the emerging notion of the new nation as strong, forward-looking, resolute and responsible. These developments, he points out, were not only driven by the personal dispositions of the independence leaders themselves, but by the wider imperial project which was permeated with notions of masculinity and patriarchy.

This is a work of prodigious scholarship which provides powerful insights into the lives of the leaders who shaped the postcolonial era. It is meticulously documented and demonstrates an impressive ability to incorporate the theoretical insights of contemporary scholarship into an analysis of what may appear to be the fairly mundane task of analyzing
autobiographical texts. It will contribute significantly to an un-
derstanding of the role of the nationalist leaders in the struggle for independence, and the way the postcolonial era was con-
structed through the shared imagination of these leaders and their followers.

James Midgley, University of California, Berkeley


Although the left and right divide is popular in political discourse and analyses, its meaning and usefulness remain contested. Split on whether or not the left-right divide is still relevant for contemporary politics, political science literature also offers alternative positions. Whereas the left-right divide is closely associated with Western democracies, its applicabil-
ity to non-Western and non-democratic countries has been questioned. Alain Noël and Jean-Philippe Thérien join this dialogue proposing that the left-right divide forms the core of global politics, and "makes contemporary politics intelligible, within, but also beyond, the boundaries of nation-states" (p. 3). They add that the left-right divide changes through time and space.

The authors suggest that to fully understand the influence of the left-right divide, readers need to view it as a social fact, which in spite of being "abstract and constructed socially" has profound influence on individual and collective behavior uniting different actors across space and time. After an infor-
mative delineation of the left-right divide, controversies and caveats in explaining global politics, they turn to empirical evi-
dence to illustrate the significance of the left-right divide. The authors use a mix of historical analyses and survey evidence, to persuasively illustrate how the left-right divide has influenced individual and collective perceptions and attitudes about equality, redistribution, the role of the state, world affairs, de-
velopment, multiculturalism, terrorism and the environment.

For example, chapter two presents data on left-right self-placement surveys from 78 countries, highlighting
relationships between the left-right scale and citizens’ attitudes about immigration, same-sex couples, and qualities to promote in children. In addition, the authors examine the connection between left-right self-placement and demographic characteristics such as gender, age and socio-economic status. This empirical evidence is intriguing and informative for researchers and students interested in social justice issues.

A major strength of this book is that it is easy to understand, yet very enlightening about the left-right divide and how it plays out in world politics. In addition, Noël and Thérien include useful current statistics on the growing income gap between developing and developed nations, agricultural subsidies and other pertinent social justice topics. Apart from political science, the book appears relevant to researchers and students in disciplines such as social work, sociology and development studies where social justice and equality topics are also discussed.

A weakness of the book is that while interesting supporting evidence is presented, the authors acknowledge numerous caveats and alternative explanations, and point out that “the left-right metaphor does not explain everything” (p. 229), which may leave readers questioning the relative importance or superiority of the left-right divide in explaining global politics. For example, while the authors recognize the growing prominence of the global civil society in world affairs with values that contrast those of the left-right divide, they do not persuasively demonstrate the relative importance of the left-right divide over global civil society. Another weakness is that the survey evidence that the authors use does not demonstrate how the left-right scale influences attitudes over time, yet one of their main claims is that the left-right divide changes with time. Nevertheless, Noël and Thérien demonstrate the universality of the left-right divide in global politics in a compelling and instructive manner.

Josphine Chaumba, University of Georgia

In the late 20th century, men in American society were, to some significant extent, marginalized in their role as mentors, teachers, and caregivers. All too often in popular media, as well as academic discourse, men have been collectively depicted as aggressive, violent, and disconnected from family roles. This negative perspective of males in society is to be expected, due largely to widespread media attention to the exploitation of children by male pedophiles (who are frequently in a mentoring role with the child), the rising rate of children who are unsupported financially or emotionally by fathers, and the increase in female providers of traditionally male-leadership roles in the lives of children, especially for children-at-risk.

*Men on a Mission* serves to provide a starkly different perspective of the very important role that men play in the lives of children. All across the United States, in urban and rural cities and towns, men coach, teach, and guide children, both formally as professional child-workers in various careers, as well as informally as volunteers seeking to give children the love, support, education, and moral guidance they need to become healthy, productive adults. Through the ethnographic study of men who work and volunteer with children, as well as from two decades of research conducted on fatherhood, Mardiglio provides compelling evidence that men are extensively involved in the lives of children, belying the growing myth of the uninvolved, dispassionate male. His work provides rich understanding of the motivations and experiences of men conducting youth work in the community. Mardiglio’s also argues that the potential of men who could and should become involved in youth-work is under-realized, leaving a gap in the care giving network in society. If men are expected to be involved in the lives of youth, and if they are re-cast in the role as caregiver and teacher, men will fulfill the role.

This book is a well-written account of the sociological phenomenon of men’s youth-work, drawing on strong ethnographic methodology. His work is timely and important, bringing to light the experiences of men in an area of male societal
roles that has received little academic attention. The book is informative and useful to academics and their students engaged in the study and formation of family theory and social policy, as well as for youth agencies seeking to increase support for the children they serve.

*Will Rainford, Boise State University*


Since its early years in the 19th-century, the social work profession has had a strong commitment to addressing the problems of poor, urban communities and it has historically drawn on the insights of sociologists to provide theoretical frameworks to inform and inspire community interventions. The work of the Chicago school of urban sociologists, ethnographic studies of urban ethnic neighborhoods, analyses of community networks and more recently the notion of social capital have all informed community practice. However, as is well-known, much community practice has been based on a deficit model which emphasizes the problems and challenges facing urban communities. This is reflected the historical dominance of a pathology-focused social disorganization approach in urban sociology which has only recently been challenged by a strengths-based model that recognizes the resilience and capabilities of low income communities.

Sanchez-Jankowski's book makes a major contribution towards understanding the strengths of poor communities and particularly ethnic minority communities in the United States. It will be welcomed by social workers and community practitioners who are increasingly persuaded that the deficit approach fails to capture the complexity of community relationships and the potential of poor people to cooperate and work for the benefit of their localities. The book is based on a series of in-depth ethnographic studies of poor communities in Los Angeles and New York over a ten year period. Unlike many other community ethnographic studies, which have usually been based on household interviews, the author
focused on local community institutions or what he calls "establishments" which form the center of community life. These are public housing projects, local neighborhood grocery stores, barber shops and hair salons, gangs and high schools. In addition to direct observation, loosely structured informal interviews as well as structured interviews were undertaken. Another innovative approach was the length of the study and the author's wish to understand how local people have adapted to social change in the context of these institutions over the years.

Jankowski's book makes a major contribution to social science understanding of the way poor people in low income communities lead their lives, cooperate with each other and adapt to change. While the author rejects the dominant social disorganization paradigm which has informed sociological community studies for many years, he does not present a romanticized image of poor communities and instead offers a nuanced interpretation which recognizes the debilitating effects of poverty but balances this against the resilience, striving and opportunity maximizing efforts of poor people. The author's extensive use of theory and summary of the major perspectives in American urban sociology will be particularly helpful to students and practitioners. His rich ethnographic account and insights will be equally valuable. The book is an important addition to the literature and deserves to be widely read.

James Midgley, University of California, Berkeley


Over the past several decades aging populations have become an increasing source of concern for social security systems in industrial nations. Early retirement provisions and generous old age and disability pensions have contributed to more people receiving benefits, accompanied by declining birth rates and a diminishing proportion of younger workers. Thus, there are fewer contributors to support benefits being
paid out by social security at a time when there is strong political pressure from conservative factions to reduce government programs and, especially, government spending for social safety nets. Over the years, the situation has generated calls for a wide range of policies aimed at modifying social security, including proposals for partial to total privatization.

Efforts to encumber social security in favor of privatization are also found in economically developing societies. The global economic meltdown has added fuel to the fire and has policy makers everywhere scrambling to find expeditious ways of ensuring that social security systems are effective and sustainable. The resulting, often heated, public discourse gives rise to a multitude of myths and misperceptions about the role of social security in the economy and development. This is particularly true in the United States where, despite its longevity and success, social security is often misunderstood and frequently misrepresented in the popular media and by politicians. Moreover, most Americans have little understanding of the scope of social security in other nations, the international conventions that guide social security systems, or the lessons that can be learned from foreign experiences.

This book provides an insightful discussion of the complexities of social security systems as an instrument of economies and development that both informs and stimulates debate. It is particularly effective in addressing the neoliberal view that social security has a negative fiscal impact, weakens work incentives, and distorts labor markets. This book successfully refutes this perspective by addressing gaps in the understanding of social security systems and the critical role they play in the economy and development. The introductory chapters provide an astute overview of the origins and features of a variety of approaches to social security around the world, including social assistance, social insurance, provident funds, employer mandates, and social allowances. This is followed by a discerning discussion on the implications of social security on economies. The remaining chapters are case illustrations of the diverse nature of the role social security plays in the economic development of nine nations: South Africa, Chile, China, the United States, Korea, Norway, the United Kingdom, Singapore, and India.
The authors leave no doubt that government and society has "a judicious collective responsibility for social welfare." And, that government income maintenance programs through social security are not only compatible with economic development, but actually facilitate it. Indeed, they argue convincingly that it is desirable to "harmonize" economic and social policies using social security as a primary instrument of policy.

A minor criticism is that not enough credit is given to current initiatives by the International Labour Organization (ILO), the International Social Security Association (ISSA), and, to a certain extent, even the World Bank, regarding comprehensive approaches to reducing poverty and inequality through social safety nets that include direct monetary transfers as well as public work programs, food distribution programs, and education and health subsidies for the poor. There are specific references to ILO and ISSA involvement, but more might have been made of new initiatives relative to welfare development by these agencies to reduce poverty and improve social security's capacity to reduce poverty, build social inclusion, and extend protection to informal work sectors. Nevertheless, this book is a particularly valuable text for graduate, as well as undergraduate, students engaged in the study of economics and development in an international context in many academic disciplines.

Martin B. Tracy, Social Insurance Research International


Although social workers have engaged in international activities for many decades, the frequency and intensity of these activities have increased exponentially in recent times as globalization has emerged as a defining phenomenon of the late 20th and early 21st centuries. It is appropriate therefore that contemporary debates about international social work should be framed within the wider context of globalization discourse and the ways social scientists conceptualized and analyzed the
Payne and Askeland are among a small group of scholars who recognize the significance of globalization for an understanding of international social work. However, they also link the study of international social work to the cognate concept of postmodernism. Globalization, they contend, is closely associated with postmodern attitudes, beliefs and lifestyles. It gives expression to the demise of grand ideologies and systems of thinking and to economic, political, cultural and social activities that affect the growing contingency, uncertainty and indeterminacy of modern life. Using these conceptual frameworks, the authors offer a lengthy exposition of international social work which seeks to answer a number of core questions. These include whether there is such a thing as international social work; whether Western social work's influence has shaped international social work; and what can be done to create an international social work that is open to local control requirements.

The book has ten chapters dealing somewhat discursively with a number of issues relating to globalization, postmodernism and international social work. It begins with an introductory chapter on the definition of globalization and postmodernism as well as postcolonialism which the authors also recognize as having relevance to a proper appreciation of contemporary realities. One chapter deals with the importance of political reflection in social work practice and another addresses issues of racism, social exclusion and cultural translation. Another chapter discusses the role of knowledge in social work and another debates social work's identity in postmodern agencies and universities. An interesting chapter examines how social workers can negotiate the chaotic world of globalization through living and experiencing different cultures.

The authors are to be commended for their use of theoretical ideas, but it is not entirely clear how these abstract notions inform international social work practice. Also, the author's assumptions about their diffusion of postmodernism and their definition of globalization will be contested by those who take different views. Despite their commitment to promoting a cross-cultural perspective, the book presents an essentialist Western perspective on the globalized world. Islamic scholars
would hardly agree that their grand narrative is now irrelevant and Marxists would argue that the current global recession demands a grand narrative that can challenge the hegemony of a failed capitalist system. Nevertheless, this is a valuable although very expensive addition to the literature which will be a valuable resource for anyone working in the field of international social work today.

_James Midgley, University of California, Berkeley_


In recent years, the concept of transnationalism has received significant attention from social science scholars in immigration studies. By definition, the transnationalism discourse primarily focuses on the dual nature of immigration life, traveling between home and host countries. However, different generations of immigrants at various historical periods face problems that are unique to a particular time and place. Surprisingly, modern social science studies of immigration that have adopted a transnationalism framework tend to focus on the present situation, overlooking the historical context in which immigrant groups lived. This limits our understanding of why and how different immigrant groups are treated differently in the U.S., and, perhaps even more importantly, why the same groups have received differential treatment at different times.

The authors of this book, most of whom are historians, provide a detailed and erudite account of what the study of history can offer to fill this knowledge gap. Using the transnationalism framework, they provide compelling evidence that, throughout history, immigration policy often served the international interests of the government rather than the interests of immigrant groups residing in the country. How immigrant groups were treated, therefore, is a dynamic interplay dependent on U.S. relations with the home countries of immigrant groups, and the negotiation of immigrant groups themselves, creating their own place and space in the U.S. Unlike assimila-
tion, the development of inter-racial relations within a trans-national framework is neither a linear nor a static process. Cultural understanding between mainstream society and ethnic groups is often undermined by the wider social and political environment.

The authors take on the challenging task of capturing the experience of Chinese Americans as an immigrant and ethnic group in the U.S. over the last two centuries. In her introductory chapter, Sucheng Chan provides a detailed review of the academic and popular literature on Chinese Americans, documenting and analyzing chronologically, the issues that have been discussed since the mid-19th century. In particular, she demonstrates how political events shape the way in which Chinese nationals and Chinese Americans were portrayed. Chan concludes by making a provocative point that "The subjects that authors choose to write about, the tone of the literature produced, and the uses to which knowledge is put all underpin the idea that there are no eternal 'objective' truths" (p. 47). She argues that to increase our understanding of the history of any given immigrant group, we must first confront our own biases.

The seven essays that follow are also organized chronologically, covering a wide array of issues in Chinese American community life over the years. These issues include fighting the right to public school education during the Chinese Exclusion era; organizing community activism and political participation in war time; fitting-in to the mainstream society with commercialization during and after World War II; forming racial identity and resolving cultural conflicts between Chineseness and Americanization; and embracing community self-support and social entrepreneurship in modern time.

This is a remarkable collection of papers, all well-written. Together, these papers provide a comprehensive picture demonstrating how internal and external forces intertwined with culture and politics to shape the Chinese American community. They will not only be appreciated by scholars in Chinese American studies but by readers from many different fields who will appreciate the detailed documentation, critical analysis, and thought-provoking insights that the authors offer. They not only help us understand past discriminatory
immigration struggles, but encourage an exploration of how we can improve inter-racial relations, and facilitate immigration incorporation now and in the future.

Julian Chun-Chung Chow, University of California, Berkeley


Times Square is now a striking emblem of New York City's “quality of life” campaign and “zero tolerance” policing, defining features of the Giuliani administration. Once a seedy refuge for prostitution, drug dealing, X-rated films, and panhandling—dark and dangerous but also exotic and even, for many, alluring—it has now been “Disney-fied,” say many, turned into a safe and antiseptic destination for tourists, complete with an Applebee's® and a vast array of corporate brand stores. Other New York neighborhoods underwent similar transformations in the 1990s, as public space was “reclaimed,” “order” was restored, and the visible markers of poverty and social disorganization were scrubbed away like so much graffiti. Crime is down, tourism is up, and New York is no longer, as Times film critic Vincent Canby wrote in 1974, “a metaphor for what looks like the last days of American civilization.”

Alex Vitale's City of Disorder offers a rich and thoughtful account of these transformations, although his subtitle does him a small disservice: what makes this book distinct is that it is not merely another recounting of the results of Rudolph Giuliani's efforts to restore order but is instead a more nuanced and historically-informed examination of how three decades of local politics and policymaking created conditions so favorable for this aggressive new regime. It's a story of causes as much as consequences. Not content to single out Republican Mayor Giuliani for blame or credit, Vitale traces the rise of intensive policing and the criminalization (but not amelioration) of poverty and homelessness to the failures (and complicity) of urban liberals. While he notes, as others have, that many
of the policies identified in the public mind with Giuliani were in fact initiated by Democratic Mayors Koch and Dinkins, the larger argument, and the indictment, digs deeper, showing how a long line of Democratic mayors helped cause the problems Giuliani would exploit. As Vitale summarizes (p. 27):

Three primary contradictions in urban liberalism contributed to and accelerated the urban crisis that led to the rise of quality-of-life politics. First, while urban liberals were willing to spend billions of dollars subsidizing corporate economic development, they treated homelessness and disorder as social problems to be funded by poorly funded social programs rather than as symptoms of their own misguided economic development strategies. Second, while they supported the concept of community empowerment, their economic and social policies were designed and administered by centralized bureaucratic experts, with almost no meaningful input by the community. Third, even though they supported calls for social tolerance of diversity, urban liberals did little to create opportunities for diverse groups to coexist in a socially stable way.

Vitale systematically unpacks each of these interdependent claims, often drawing connections between the macro-level forces of the post-industrial global political economy; neighborhood-level efforts at political and policy influence; and the political, social, and economic forces driving (or pinioning) New York's elected leaders. It's a dense and layered accounting, but one which is always intelligible and almost always persuasive.

Given that much of the story he tells parallels other analyses of the neoliberal shift in national politics and the increasing dependence of the Democratic Party on corporate interests, a more extended effort to draw out these urban-national connections would have made the book even more powerful. And while Vitale does attend to questions of race, more attention seems warranted on this front, especially given that so many of the targets of hyper-policing and gentrification were poor black communities, or laborers—street vendors, "squeegee men," and sex workers—who were disproportionately people
of color. But these are minor complaints and, as much as any-
thing, merely reflect a wish that Vitale had written a longer
book. It's a sharp and clear-eyed account, one which offers
valuable lessons for those who would improve the quality of
life for the most marginalized city residents, and not just the
middling classes.

Stephen Pimpare, Yeshiva University

Bruce J. Schulman and Julian E. Zelizer, Rightward Bound:
Making America Conservative in the 1970s. Cambridge, MA:
Harvard University Press, 2008. $49.95 hardcover, $19.95
papercover.

There has been a good deal of scholarly speculation about
the factors responsible for the rise of the political right since
the Reagan revolution of 1980s. Although it was thought that
the Clinton Presidency would reverse the conservative tide,
the electoral victories that secured both houses of Congress
for the Republican right in 1994, and the subsequent two-term
presidency of George Bush, led many to believe that a perma-
nent right-wing hegemony had been established. Of course,
the Obama election and current Democratic majorities in both
houses suggest otherwise. But it is too soon to tell whether
these recent developments will change America from being
what has sometimes been called the "Right Nation." Scholarly
insight into complex social, economic, cultural and other
factors that shape the political agenda can obviously help in-
terpret these events.

In this interesting book, Schulman and Zelizer have assem-
bled a number of commentaries on the diverse influences that
contributed to the resurgence of the political right in the 1970s.
Their central argument is that popular interpretations that at-
tribute the rise of the political right to a backlash against the
1960s youth culture, race conflicts, the Vietnam war and inse-
curity arising from rapidly changing mores and beliefs, do not
pay sufficient attention to the concerted efforts of activists from
different spheres of life who toiled tirelessly to bring about a
shift towards conservative politics. While broad, impersonal
social forces undoubtedly played a role, the success of the
political right owes more to a commitment from literally hundreds of groups and organizations to reassert traditionalists values. The purpose of the book is to document and analyze their contribution and to provide a more nuanced account of what made America conservative in the 1970s.

The book's 14 chapters are wide-ranging and focus attention on issues as diverse as the revivalism of Protestant evangelicals, the role of corporations and wealthy families in funding conservative political and social activities, efforts to counteract liberal intellectual dominance in the universities, the contribution of the anti-abortion movement, the formulation of a white ethnic strategy that drew white blue-collar workers away from the Democrats, and popular media images that ridiculed president Carter's international diplomacy. Many of these contributions are highly original and support the book's central thesis that a concerted effort to consolidate right-wing conservatism was made. Particularly interesting for academics is the chapter on the successful efforts of corporations to popularize business studies at American universities. The rise of the MBA and undergraduate education in business did not evolve naturally but came about through the influence of large corporations and the provision of financial incentives.

This is a highly readable book which is packed full of interesting information. It certainly provides important insights into the determination of conservative groups to revitalize their agenda. Some of the chapters are particularly important for addressing neglected issues. Unfortunately, there is no chapter on welfare policy, which is surprising in view of the book's wide-ranging sweep and the attention that has previously been paid to struggles over welfare issues in the construction of a conservative majority. Nevertheless, this book is strongly recommended. It will be a useful resource for anyone wanting to know more about the political history of the United States over the last three decades.

James Midgley, University of California, Berkeley

Because the majority of the elderly are poor women, a book on the gender impact of pension reform is an important addition to the social security literature. The authors’ goals are to compare the gender effects of two types of pension systems—namely, traditional, publicly-managed social insurance systems versus newer multipillar systems, comprised of a privately-administered, defined contribution, a retirement account component and a supplementary publicly-financed system. The authors discuss the gender dimensions of pension reform with reference to three case studies: Chile, Argentina and Mexico. Due to space limitations, the focus here is on Chile’s paradigmatic case and the general assumptions and conclusions of the book.

Due to lower wages and contributions, women’s accumulations are somewhere between 35 and 49 percent of male accumulations in Chile’s for-profit, privately-administered retirement account system, and women’s annuities are about one third of the annuities bought by males. Moreover, because women live longer and retire earlier, the actual pension is even smaller. Having established that the retirement account system creates large differences between male and female pensions, the authors then concentrate on the positive effects of the Chilean government’s Minimum Pension Guarantee (MPG), which is given to retirees whose funds cannot generate a pension at least equivalent to the value of the MPG. The MPG (about $78 monthly) represents 37 percent of the average female wage and 27 percent of the average male wage. This noncontributory state-funded supplementary pension largely benefits women because their accumulated funds are smaller and because more women than men are at the minimum MPG floor. Thus, replacement rates for women rely heavily on the public component of the system, and specifically on MPG’s indexation. However, the book’s argument that the MPG is an anti-poverty policy entirely ignores intense discussions taking place in Chile regarding poverty and vulnerability. The MPG does bring retirees above the official poverty level set at $2 per
day, but leaves them entirely vulnerable, and in practice still poor.

The authors attempt to reverse their own conclusions regarding the retirement account system’s negative effects by arguing that women have gained because in the country’s previous social insurance system, women with less than 10 years of contributions did not get any benefits, and because under the social insurance system women had to choose between their pension or their widow’s benefit. In the private retirement account system they can keep both. A major problem with these assertions is that the authors treat the old Chilean social insurance system as a unit, when in fact it was comprised of more than 600 different funds, each with a different formula for calculating pensions and other benefits.

As expected, comparisons between male and female pensions under the social insurance and private retirement account systems show that pension differences were lower in the social insurance system for a woman with average earnings, and that the retirement account system works better for women in the upper income brackets. It is undeniable that the privatized retirement account system benefits upper income groups both male and female, and that this type of pension increases inequality both within and among genders. Research shows that the pension Gini coefficient is higher than the already very high Gini based on actual income.

The other Latin American cases and the short analyses of pension reform’s effects in Eastern Europe, Sweden and Australia provided in the book confirm the findings for Chile both regarding the negative impact of defined contribution, retirement account systems on women and the mitigating effects of public transfers for the lowest earners. In summary, in the multipillar system, the retirement account has a negative effect on women pensioners while the publicly financed MPG reduces that effect. The authors also show that the pension gender gap will continue to increase in the future and that women in lower income groups will be the most affected by this gap. To solve these problems, the authors recommend increasing women’s retirement age, indexing the public component, and reducing the MPG’s eligibility requirements. In other words, the state and women should pay for the failures
of the privatized system.

One then wonders why private retirement account pension systems should exist? If only the public component of the multipillar system has a positive effect on women's pensions, the question is why they should contribute to the private retirement account component at all? It is notable that institutions such as the World Bank and the authors (who have promoted the adoption of retirement account systems throughout the world) are now advocating multipillar systems with an indexed public component geared to reduce the negative effects of the retirement account system on both poor old men and women, but especially on women. Actually, the retirement account systems' objectives have little to do with pensions and pensioners, and much to do with an ideological commitment to reducing the public sector, transferring the administration of pension funds to for-profit corporations that, at least in the Chilean case, charge extremely high commissions and enjoy enormous profits. The privatized system also reinforces the power of pension fund administrators and insurance companies involved in this very lucrative business.

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