



AMERICAN
PSYCHOLOGICAL
ASSOCIATION

August 14, 2007

Constance Pledger, Executive Director
Interagency Committee on Disability Research
U.S. Department of Education
550 12th St., Room 6050, Potomac Center Plaza
Washington, DC 20202-2700

Dear Dr. Pledger:

On behalf of the 148,000 members and affiliates of the American Psychological Association (APA), I appreciate the opportunity to offer suggestions on ways to improve future research to benefit the lives of individuals with disabilities. Enhancing our knowledge of best practices in education, employment, health care, and independent living through research will translate into public policy that improves the quality of life for all Americans with disabilities. We look forward to working with you to implement these and other initiatives in pursuit of this goal.

APA is the largest scientific and professional organization representing psychology in the United States and is the world's largest association of psychologists. Comprised of researchers, educators, clinicians, consultants, and graduate students, APA works to advance psychology as a science, a profession, and a means of promoting health, education and human welfare. As such, issues impacting individuals with disabilities are of great importance to our members. This is reflected in part by our APA Committee on Disability Issues in Psychology and our divisions on rehabilitation psychology, mental retardation, and developmental disabilities. Psychological research has played a pivotal role in our understanding of the social, emotional, and physiological aspects of human behavior, including disability.

We are pleased that the Interagency Committee on Disability Research (ICDR) will conduct a detailed examination on a broad range of issues. What follows are specific research themes and areas that we recommend the ICDR consider:

Linking Physical and Mental Health in Disability Research

As society moves away from the medical model of disability to the social model, it is important to recognize the impact of socio-emotional, behavioral and attitudinal aspects of disability. Mental health is key to overall physical health, as has been demonstrated in

research on cancer and other physical disorders.¹ As an example, perceived discrimination against people with disabilities has been associated with psychological distress, lower well-being, self-reported ill health, and number of days confined to bed.² While mental health and physical health are clearly connected, there is a lack of research at the nexus of these care systems and the role they play for people with disabilities.

APA supports the inclusion of mental health concerns, not only in the definition of disability but also as a focus in other areas such as employment and rehabilitation. Such an integrative and holistic new paradigm takes into account the interconnectedness of biological and psychosocial issues with the sociopolitical, economic, and legal systems within which people with disabilities function every day.

Employment

While efforts have been made to increase employment for people with disabilities, the unemployment rate has remained virtually unchanged since the passage of the Americans with Disabilities Act in 1990. Specific research is needed that directly addresses societal barriers, such as stigmatization and discrimination, and their impact on people with physical, mental and neurological disabilities. This is critical because although the consideration of employment data can be useful, broad-brush explanations fail to explain the human, provider, and systems motivations that contribute to such high unemployment rates and are less likely to offer a scientifically solid basis for developing effective models for future action and public policy.

Mental health conditions are the leading causes of disability worldwide, accounting for nearly 25 percent of all disability across industrialized countries.³ Data on labor force participation rates indicate that persons with mental disorders are disproportionately excluded from employment when compared to persons with other types of disability.⁴

While estimates of the number of individuals with a mental health condition who face discrimination based on their illness in the workplace is tentative, it is estimated that about 30 percent of charges of discrimination to the U.S. Equal Employment Opportunity Commission are based on psychological claims. Workplace characteristics such as the stigma associated with mental illness, the lack of accommodations, labor market characteristics and outright discrimination are central barriers to employment, yet they

¹ Fawzy, F.I., Fawzy, N.W., Hyun, C. S., Elashoff, R., Guthrie, D., Fahey, J.L. et al. (1993). Malignant melanoma. Effects of an early structured psychiatric intervention, coping, and affective state on recurrence and survival 6 years later. *Archives of General Psychiatry*, 50, 681-689. Turner-Cobb, J.M., Sephton, S.E., Koopman, Cl, Blake-Mortimer, J., & Spiegel, D. (2000). Social support and salivary cortisol in women with metastatic breast cancer. *Psychosomatic Medicine*, 62, 337-345.

² Williams, D. R., Yu, Y., Jackson, J. S., & Anderson, N.B. (1997). *Racial Differences in Physical and Mental Health: Socio-Economic Status, Stress and Discrimination*. *Journal of Health Psychology*, 2, 335-351.

³ World Health Organization. (2001). *The World Health Report 2001 – Mental Health: New Understanding, New Hope*. Geneva: World Health Organization.

⁴ Trupin, L., Sebesta, D.S., Yelin, El., & LaPlante, M.P. (1997). Trends in labor force participation among persons with disabilities, 1983-1994. *Disability Statistics Report*, (10). Washington DC: U.S. Department of Education, National Institute on Disability and Rehabilitation Research.

have received little research attention. Research is needed to overcome these societal barriers which continue to restrict employment for people with all disabilities including physical, cognitive, mental and neurological.

Research is also critically needed to examine the causes and impact of poverty and economic disparity on people with disabilities. Given the high rate of unemployment among people with disabilities, it is of little surprise that poverty is one of the critical challenges they face. Unless poverty is addressed, the lives of people with disabilities cannot substantially change.

Health and Wellness

Basic and clinical research funded across the federal government should include an increased focus on the psychological and social factors that affect the quality of life of those living with disabilities.

One area of prime emphasis should be the relationship between comorbid mental health conditions, such as depression, anxiety, and substance abuse, and other disabling conditions. Individuals with disabilities experience substance abuse rates at 2-4 times higher than the general population with prevalence rates approaching or exceeding 50 percent for persons with traumatic brain injuries as compared to 10 percent of the general population.⁵ Individuals with a substance use disorder and a coexisting disability are not being identified as such and the psychological intervention for substance abuse is treated as secondary (if at all) to the process, with its focus on physical independence.⁶

We suggest that ICDR's research recommendations include treatment aspects for comorbid physical, psychological and neuropsychological disabilities and substance abuse, including early detection, prevention, access to care, and impact upon rehabilitation, work and family for persons with disabilities.

People with disabilities, regardless of sex, race, ethnicity, or age, have higher rates of obesity than persons without disabilities.⁷ In addition, obesity is frequently comorbid with disability. As such, a second area of emphasis should be on the impact of overweight and obesity on individuals with disabilities.

APA would like to underscore the need for research on the public health implications and on the need to develop public health policies and interventions to prevent or reduce risk factors that may be associated with overweight and obesity among people with disabilities. This research should include critical quality of life factors, including health promotion, nutrition, physical activity, injury prevention and pain management. Only

⁵ Office on Disability, U.S. Department of Health and Human Services, Substance Abuse and Disability Fact Sheet. http://www.hhs.gov/od/about/fact_sheets/substanceabusech26.html. Last visited: August 9, 2007.

⁶ National Association on Alcohol, Drugs and Disability - Congressional Testimony, 2001. <http://www.naadd.org/>. Last visited: August 9, 2007.

⁷ Morbidity and Mortality Weekly Report 51(36):805-808, 2002. Centers for Disease Control and Prevention (CDC)

through this research will it be possible to identify and support effective mental and physical health promotion programs specifically aimed at people with disabilities.

Rehabilitation and Ethnically Diverse Populations

Racial and ethnic minorities comprise a substantial segment of the population, yet rehabilitation systems do not adequately address their diverse needs. This is particularly problematic considering that ethnic and racial minorities tend to have disabling conditions at a disproportionately high rate.⁸ Attention should be given to the psychological aspects of rehabilitation, education, employment and community living for persons with disabilities who are from diverse backgrounds.

Culture influences many aspects of disability, including how individuals from a given culture view themselves because of their disability, how they may express and manifest symptoms of mental disorders, their style of coping, their family and community supports and their willingness to seek rehabilitation services. While there are efforts to improve services for culturally diverse populations, significant barriers still remain in access, quality, and outcomes of care for minorities. People with disabilities from culturally diverse backgrounds experience twice the discrimination experienced by non-disabled people in the minority community.⁹

Disability and race are often studied in isolation from each other, but to reach a greater understanding it is necessary to study how the confluence of multiple factors shapes experience and success for individuals with disabilities. APA strongly supports increased research on disability in the context of personal, social, cultural characteristics such as race, ethnicity, gender, sexual orientation, and age.

Families with Disabilities and Maltreatment of Children with Disabilities

Families play a crucial role as caregivers for many children and adults with disabilities. Research is needed that focuses not only on children with disabilities, but also on sibling relationships, partners with disabilities, and parents with disabilities. Parents of children with disabilities are more likely to report high levels of stress, depression and anger, but more information is needed about family adaptation, coping skills, and roles, as well as the needs of these families and best practices for the provision of support systems and services.

Most disability advocates believe that without the substantial and active involvement of family members in providing supports to individuals with disabilities, their current long term care needs would not be met. Because of the effort necessary to sustain such care, families with a member with a disability can experience significant stress, loss of employment, financial burdens, and familial difficulties. Psychologist researchers have

⁸ Smart, J.; Smart, D (1997). The racial/ethnic demography of disability, *Journal of Rehabilitation*, Oct-Dec.

⁹ Wright, T. J. (1988). Enhancing the professional preparation of rehabilitation counselors for improved service to ethnic minorities with disabilities. *Journal of Applied Rehabilitation Counseling*, 19(4), 4-10.

been actively involved in identifying ways in which home-and community-based services and supports can help people with disabilities and their families more fully participate and integrate into the community. APA encourages the ICDR to support sound research on the impact of disability on family systems and targeted study on family preservation as related to families where at least one member has a disability.

Children with disabilities are a distinct high-risk group for abuse and neglect. An estimated 300,000 children with disabilities are maltreated each year, two to three times more than children without disabilities.¹⁰ As a consequence of the lack of available research in this area, the knowledge base on maltreatment of children with disabilities is severely limited. APA encourages research to help identify risk factors (e.g., anger, depression, and stress) that may lead to abuse and neglect, and determine the multiple service needs of people with disabilities and their families.

Professional Development

What constitutes effective training for professional service providers to individuals with disabilities is an essential and underdeveloped area for research. Many fundamental programs that are committed to supporting the progress and success of individuals with disabilities in the areas of rehabilitation, employment, education and even general health and functioning rely heavily on professionals who are well-trained and knowledgeable about disability.

Given the current shortage of such professionals, it is important to be able to evaluate what are the processes for training these professionals trained to work on disability issues. Assessments and evaluations of training programs on disability would offer a unique insight into the preparation of this vital portion of the workforce that plays a significant role in the lives of people with disabilities.

Research Process

APA supports participatory action research and diversity initiatives to encourage people with disabilities to become researchers and principal investigators. Likewise, researchers should be encouraged to include people with a broad range of disabilities in their study samples, including those with multiple and/or hidden disabilities. Several disability groups are notably understudied; methods of incorporating such populations in research and in the grant review process should be developed and implemented.

APA also strongly recommends the provision of a stable source of funding for long-term research. All too often, funding ceases just as the research achieves great promise. Disability research should not be driven purely by funding priorities, but by the priorities that grow out of current research, community involvement, and from people with disabilities themselves.

¹⁰ APA - Children, Youth and Families Office. Resolution on the Maltreatment of Children with Disabilities (2003). <http://www.apa.org/pi/disability/maltreatment.html>. Last Visited: August 14, 2007.

In closing, APA would like to thank you once again for the opportunity to comment on ICDR's consideration of ways to improve future research that will bring about positive results for people with disabilities. We appreciate the Committee's commitment to enhancing the lives of people with disabilities and look forward to partnering with you in this effort. If you have any questions, please contact Day Al-Mohamed, J.D., of our Public Interest Government Relations Office at (202) 336-6061 or DWilliamsAl-Mohamed@apa.org.

Sincerely,

A handwritten signature in black ink, appearing to read "A. Toro". The signature is fluid and cursive, with a large initial "A" and a long, sweeping underline.

Annie G. Toro, J.D., M.P.H.
Associate Executive Director for Government Relations
Public Interest Directorate