Research, Writing, Editorial Reviewing, and Publishing as Social Justice Issues: The Effects of Stigma

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People with disabilities face problems, not only because of their specific impairments but because of social stigma. This article focuses on stigma as it relates to a broad range of physical, social, and behavioral characteristics, and on the effect of stigma on academic research. Effects examined here include decisions regarding the ways in which research questions are defined, what research is funded and how it is funded, the ways in which research is conducted (e.g., the use of community-based participatory research versus traditional approaches), the way in which publication decisions are made, and the way in which research is received by professional colleagues and the public.

Stigma is pervasive. Its effects are found everywhere, and nowhere is it more prevalent than among individuals with physical, intellectual, and or mental disabilities (Corrigan & Rao, 2012; Longdon & Read, 2017; World Health Organization & World Bank, 2011). People with disabilities may face problems, not only because of their specific impairments but because of social factors such as stigma. Hence, this article focuses on stigma as it relates to a broad range of physical, social, and behavioral characteristics, and on the effect of stigma on academic research. Effects examined here include decisions regarding the ways in which research questions are defined, what research is funded and how it is funded, the ways in which research is conducted (e.g., the use of community-based participatory research versus traditional approaches), the way in which publication decisions are made, and the way in which research is received by professional colleagues and the public.

Stigma can be defined as negative stereotyping. The process of stigmatization includes negative labelling, prejudice, and discrimination attributed to a person or to groups of people whose characteristics or behaviors are perceived as notably different from or inferior to societal norms (Ahmedani, 2011; Clement et al., 2015; Crisp et al., 2000; Holder et al., 2019). Stigma

may be projected onto demographic and social statuses (e.g., ethnicity, religion, age, impoverishment, immigrant status), or disease/condition characteristics (e.g., perceived communicability, changes in appearance, appearance of handicap or disability, etc.), including vulnerable and marginalized groups. However, irrespective of social and cultural developments throughout the United States, including the enactment of the American's with Disabilities Act (ADA), stigma remains an ongoing issue for people with physical, intellectual, and/or mental disabilities. Nondisabled people often view symptoms of disabilities as threatening and uncomfortable, and such attitudes usually foster stigma toward individuals with disabilities (Nieweglowski & Sheehan, 2017; Parker & Aggleton, 2003).

IMPACT OF SCIENTIFIC FUNDING, RESEARCH, AND PUBLISHING

To say the least, stigma is a multifaceted process enacted through organizational, structural, and individuals' processes (Bruce & Phelan, 2014; Millum et al., 2019; World Health Organization & World Bank, 2011), and facilitated by relationships of power and control (Bruce & Phelan, 2014), which create a hierarchy that devalues stigmatized people (Parker & Aggleton, 2003; World Health Organization & World Bank, 2011). Three types of stigma impact scientific funding, research, and publishing, and each has multiple impacts. *Social stigma* refers to disapproval or sanctioning of a person or group on socially characteristic grounds that differentiate them from other members of a society (Holder et al., 2019; Wallace, 2010). Some of these characteristics may be directly observable (age, ethnicity, physical disability), some may be inferred from social cues (homelessness, addiction, severe mental illness, speech patterns), and some may derive from social definitions not readily observable (religion, minor mental illness, diseases such as HIV/AIDS, etc.). A public opinion poll conducted in 2004 found that approximately two of every three respondents believed that people with physical disabilities were subject to prejudice and discrimination (Kaiser Public Opinion Spotlight, 2004). It is noteworthy that perceived departures from normality do not have to be objectively real. Paraphrasing W.I. Thomas, if a situation is perceived as real, it will be real in its consequences (Merton, 1995). For example, if society perceives people diagnosed with schizophrenia as dangerous, it will respond to them as a threat even though research shows that the rate of violence in people with schizophrenia may only be slightly elevated, and that it is much more likely that they will be victims of violence, not the perpetrators (Joyal et al., 2004; Walsh et al., 2002). In fact, much of the negativity on stigma of violence comes from entertainment and news media, which links cases of random violent acts against individuals with mental illness like schizophrenia (Saito & Ishiyama, 2005; Shakespeare, 1999).

Self-stigma exists when those who occupy a stigmatized category or condition judge themselves negatively or dismissively because they believe that the public holds prejudice and will discriminate against them (Clement et al., 2015; Corrigan & Rao, 2012). Overt discrimination need not occur for one to self-stigmatize. If people avert their eyes from an individual with an observable physical disability, that person may incorporate that reaction into his/her self-perception and may have lower feelings of self-worth or even suffer from depression (Corrigan & Rao, 2012). Even those whose stigmatized status is not directly observable may self-stigmatize based on public utterances. Thus, individuals who feel disvalued based on sexual orientation, heritage, HIV status, or "invisible disabilities" (e.g., dyslexia) may self-stigmatize without having been direct targets of discrimination. Self-stigma may lead an individual to experience low self-esteem and feel less worthy of medical treatment and rehabilitation services

(Corrigan & Rao, 2012). Anxiety and depression also may be triggered by the belief that one is stigmatized or the experience of being treated as stigmatized.

Also, self-stigma often occurs among persons suffering from "invisible disabilities," in part because the society or the individuals network communicates negative valuation of their condition (e.g., dyslexia, ADHD, addictions, schizophrenia, agoraphobia) even when the condition is not readily observable and they do not face social stigma during interactions with strangers (Jones & Crandall, 2017). Furthermore, when persons with invisible disabilities are identified as recipients of services or assistance, their lack of obvious symptoms means that they are particularly vulnerable to charges of "malingering," freeloading, bilking the system, and so on, from those with little knowledge of their life situation and even from health professionals.

Professional stigma occurs because professionals, who are part of the larger society, may uncritically accept social stigma in their environment or buy into a patient's self-stigma (Holder et al., 2019; Ahmedani, 2011). It can be reduced by being addressed directly during training and through continuing education. However, acknowledging and addressing it is in some sense a threat to the ongoing sense of professionalism on the part of the practitioner. Furthermore, practitioners may avoid social stigma that directly relates to their expertise, but uncritically accept it in other areas. Thus, the specialist in addictions may not share social stigma toward drug users, but may indiscriminately accept stigmatizing views of sexual orientation, or physical disability or extreme poverty. In the early days of HIV/AIDS many clinicians objected to patients with this stigmatized illness being treated in traditional hospital-based outpatient settings (Earnshaw & Chaudoir, 2009; Parker & Aggleton, 2003). Patients whose HIV status was linked to injection drug use were viewed as especially undesirable, and often were treated outside the main campus of medical centers. Furthermore, in many settings those who conducted research on stigmatized conditions reported feeling that they were perceived as less serious in their scholarship than colleagues studying conditions like heart disease, diabetes, or cancer that were not stigmatized (Longdon & Read, 2017; Tough et al., 2017). Thus, this propensity has encouraged a siloed approach to research on stigmas-related issues, stifling funding, and novel responses to the area of scholarship (Longdon & Read, 2017; Millum et al., 2019; Earnshaw & Chaudoir, 2009; Tough et al., 2017). As an example, to highlight this area of research, and address the challenges of conducting research with stigmatized groups and or stigmatized conditions in 2017 Fogarty International Center of the National Institutes of Health hosted a 3-day workshop with researchers from the United States, low- and middle-income countries (Millum et al., 2019).

Stigma is prevalent and problematic for individuals living with disabilities. As such, the domains of disability, mental health, behavioral health, and addictions are prime areas for all three types of stigma. Furthermore, there is considerable overlap among these issues. Stigma related to illness or disability can lead to issues of self-esteem, anxiety, and depression. This in turn can lead to a mental illness diagnosis with the prescription of potentially addictive drugs or to self-treatment of symptoms using alcohol or nonprescribed drugs that may lead to addiction. Addiction, which may be correctly considered a "chronic, relapsing disease that results from the prolonged effects of drugs on the brain" (Leshner, 1997, p. 45) is involuntary once it is established, but nevertheless, is a highly stigmatized condition. There is considerable overlap among these stigmatized groups. Data show that 50% of individuals with paraplegia or quadriplegia abuse substances as do one in seven persons with total hearing loss (Sunrise House, 2020). Similarly, Substance Abuse and Mental Health Services Administration (SAMHSA) reports that of 20.3 million Americans with substance use disorders (SUDs), 7.7 million had a co-occurring mental illness diagnosis (SAMHSA, 2018).

SUDs occur when recurrent alcohol or illicit drug use causes clinically significant impairment. For example, depression, drug use, and addiction each carry their own social, self, and professional stigma, creating a self-reinforcing syndrome of stigma. Furthermore, as noted below, science often treats them as separate phenomena in terms of funding, publication, and policy.

Communication regarding disability and behavioral health can be important in mediating the experience of stigma. The language and vernacular may unintentionally convey stigma in everyday communication outside professional discourse. A colleague who is a psychiatrist recently revealed a personal struggle to stop using everyday phrases like "I'm crippled with fatigue," "that's crazy" or "that's an insane price." Such colloquialisms are common in everyday language but can alienate person with disabilities and mental health problems contributing to stigma. Others that we may hear from family members or from our students as colloquialisms are even more pejorative: "That story is lame"; "That décor is so gay"; "That assignment was so retarded." Clearly, as professionals there is an obligation to discourage the use of unintentionally pejorative language among our students.

IMPACT ON RESEARCH, WRITING, EDITORIAL REVIEWING AND PUBLISHING IN REHABILITATION

The way that we define diseases and conditions and the degree and type of stigma attached to them, individually and in combination, affects research in many ways. Funding streams that support research by the National Institutes of Health often break out by conditions or diseases that have varying degrees of stigma. Separate institutes address both basic and applied research on mental health (NIMH), illicit drug use (NIDA) alcoholism (NIAAA), and intellectual and developmental disabilities (NICHHD) while research on disability, independent living, and rehabilitation is housed separately in the Department of Education through the National Institute on Disability, Independent Living, and Rehabilitation Research (NIDRR). Rough estimates suggest that well over half of the American population experience one or more of these problems during their lifetime (addictions 10%, mental illness 46%, disability 13%). By contrast a bit less than 40% will have cancer during their lifetime. Yet the budgets for all the agencies listed above, when combined, add up to only about 75% of the budget for the single best funded NIH institute—the National Cancer Institute. Furthermore, the division of responsibility for these stigmatized conditions reinforces the notion that these are separate (and separable) phenomena and each agency has to overcome stigma when seeking more funding from Congress. In addition, taking a broader social justice view, one notes that questions need to be asked at both the micro and macro level, that is, not only should we ask if a fair share of current research funding addresses these issues, but if a fair share of the nation's budget goes to research versus, for example treatment costs or military adventures abroad.

Publishing very often follows a similar set of divisions that can leave a paper that does not neatly fit into a genre (mental health, rehabilitation, substance use/abuse, etc.) searching for an appropriate journal for publication and challenging editors to identify reviewers with interdisciplinary knowledge. Journal editors and reviewers are largely drawn from people with expertise and credentials in a specific field such as rehabilitation counseling, addictions treatment, behavioral, and mental health. Decisions about whether a manuscript is appropriate for the readership of a journal reflect this segmentation and also may be guided by stigmatizing views of some populations studied.

As a rehabilitation professional, one may share in professional stigma that can affect research interests and perceptions about appropriate choices of research topics. For example, many professional meetings in public health, which defines itself as a broadly interdisciplinary field, contain little content on disability, drug abuse, addictions, and only slightly more on mental health, although all of these are widely described as pervasive public health problems and as to some degree as preventable conditions. The same exclusion on "turf" grounds seems even more likely in professional meetings of more narrowly defined disciplines.

Professional stigma and social stigma may affect the assumptions that underlie our research questions and/or the language used to formulate and implement those questions. Individuals working across disciplines may experience unfamiliarity with precise terms such as impairment, disability, handicap, substance abuse, addiction, and various classifications of mental illness that may not be differentiated in everyday language, but that have precise meanings within professional fields. This can lead to interdisciplinary friction and perceptions of insensitivity on the part of the "outsider."

Social stigma may impact our efforts to translate research findings into action or policy. Ultimately, the "buy in" of politicians and government agencies is needed to put research findings into policy and practice. When the group that will benefit from a new policy, practice, or expenditure is perceived as a stigmatized "them," rather than as "us," it may be difficult or impossible to garner that support. Thus, convincing the city council or state legislature to add services for physically disabled seniors may be much easier than seeking a similar expenditure for seniors with drug addictions or mental illnesses.

Professional stigma may affect the methods we select to conduct our research or the fidelity with which we execute our methodology. The concept of Community-Based Participatory Research (CBPR) states that research should be conducted in close collaboration with, and for the long-term benefit of the individuals and community being studied (Damon et al., 2017). A recent study assessing the use of CBPR among drug users in Vancouver, BC, Canada, reported that some investigators espoused CBPR principles, but did not truly engage participants. With respect to one study that was widely criticized for failure to engage community members, the authors noted that:

> While this project provided opportunities for peer researchers to administer surveys, participants were highly critical of the power dynamics with the lead researcher. Specifically, participants expressed that they believed that the lead investigator "did not want to be close to [them]" and that the researcher, "just wanted their statistics or whatever information and then left." Among participants, this research was widely criticized for taking a "top-down" approach in their research and "ordering" participants around. Participants in such projects that did not meaningfully include them in the research process expressed frustration and resentment, feeling "disheartened" and seeking to "wash their hands" of the project. In the long run, the CBPR elements of the study backfired because of stigma reproduced through inequitable relationships between academic and community-based or peer researchers (Damon et al., 2017, pg. 10).

It is important to recognize that this is the perspective of participants who were highly aware of being a stigmatized population. One might ask whether these perceived slights were real or simply perceived due to a high rate of distrust. Did the lead researcher approach the project from a position of professional stigma? Did subjects own self-stigma make them prone to negatively interpret the researcher's behavior? Whatever the answer, the report should encourage all researchers to ask whether there are groups or individuals encountered in their own professional role that may be subject to social stigma, self-stigma, and/or professional stigma, and

to reflect on how that affects the way that professionals serve them or conduct research with/about them.

STRATEGIES FOR REDUCING THE EFFECTS OF STIGMA

Throughout this article, we have emphasized the important of addressing stigma at the organizational, structural, and individual levels and how the different types of stigma impact scientific funding, research, publishing, and implication for policy. A focus on strategies of stigma reduction can help researchers, funders, and publishers overcome the systemic influences by advocating for broader societal policies promoting social justice. For example, historically the United States uses legal and policy interventions to protect and normalize marginalized and stigmatized groups, starting with the Civil Rights Act of 1964, which prohibited discrimination by race, color, religion, and national origin. Likewise, the landmark 1990—ADA became federal law for its legislation of outlawing discrimination against people living with physical or mental disabilities. However, while all these policies may have made a difference, we still have a long way to go before society is fully inclusive of the more than 60 million people living in this country with some form of disability. Strategies and policies must be responsive to these realities to reduce the effect of stigma. Such strategies could include but are not limited to:

Increasing Awareness

Because stigma is both pervasive, and often invisible to those who engage in stigmatizing behavior, efforts to reduce its impact in rehabilitation science must begin with increasing awareness of stigma and raising self-awareness of stigma. This includes creating a clearer understanding of stigma and its effects, encouraging professionals to be aware of and responsive to self-stigma among clients, and using continuing education and professional training to reduce professional stigma. The development of some self-evaluation tools for professionals and trainees could help increase our awareness of our own errors.

Identification of a Nonstigmatizing Vocabulary

As a professional, one has an obligation to try to expunge stigmatizing terms from both professional and personal vocabularies, and to point out the corrosive effects of such statements where possible, for example, in interactions with students, behavioral and health professionals. More subtle are misuses across disciplines of imprecise of pejorative terms. A rehabilitation counselor who would never describe a patient as "crippled" may nevertheless dismiss another patient as "an addict" (and vice versa). Because of the overlap of addictions, mental illness, and disability, we need to assure that professionals in all fields share precise, clinically correct terminology in referring to clients/patients and in describing their problems to colleagues. It is especially unfortunate if pejorative terms appear in scientific papers or presentations. Editors and reviewers should be urged to be alert to this issue. When a paper is interdisciplinary, regardless of the discipline of the journal, a panel of reviewers should be selected with appropriate content knowledge to be aware of stigmatizing language. Similar measures should be taken in the review of funding proposals.

Review of Funding Streams and Education Programs

A barrier to study of stigmatized conditions is that professional stigma may carry over to issues of the location and funding of such research and to treatment of scholars. Professional groups

that study stigmatized conditions can help to counter this with lobbying for increased funding for these conditions including earmarking funds across funding agencies to support interdisciplinary research. This should be bolstered by providing broad interdisciplinary continuing education and residency training programs to raise awareness and increase correct knowledge about the issues and by recognizing outstanding scholarship in their field using tools of public relations.

Addressing Broader Societal Stigma

Many stigmatizing conditions disproportionately affect individuals who are also stigmatized for social statuses including sexual orientation, unemployment, poverty, lower levels of education, or ethnicity. This exacerbates the problems of condition-associated stigma just described. Eliminating this broader societal stigma may be beyond the power of clinicians, researchers, reviewers, or editors to remedy, but all of them assiduously must avoid accepting those stigmatizing views and seek opportunities to mitigate them and to address them directly with colleagues and trainees.

CONCLUSION

In summary, equity in the area of scientific funding, research, publishing, and policy cannot be achieved without engaging in conversations and social justice initiatives. Stigma is pervasive, and many clients in rehabilitation may have one or more statuses or conditions that are stigmatized. Social justice requires that as professionals and scholars we make every effort to identify and rectify the impact of stigma in scholarly writings and in research as well as in clinical practice.

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