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Stigma and Intellectual Disability: Potential Application of Mental Illness Research

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Purpose: Individuals with intellectual disabilities (ID) and individuals with mental illness are consistently found to be among the most socially excluded populations and continue to face substantial health, housing, and employment disparities due to stigma. Although this has spurred extensive research efforts and theoretical advancements in the study of stigma toward mental illness, the stigma of ID has received only limited attention. In this article we explore the application of mental illness stigma research for ID. ***Design:*** We carefully reviewed the existing research on mental illness stigma as a foundation for a parallel summary of the empirical literature on attitudes and stigma related to ID. ***Results:*** Based on our review, there has not been a systematic approach to the study of stigma toward ID. However, multilevel conceptual models of stigma have received much attention in the mental illness literature. These models have been used to inform targeted interventions and have application to the study of the stigma process for individuals with ID. Nonetheless, there are indeed key differences between—as well as substantial variability within—the ID and mental illness populations that must be considered. ***Conclusions:*** Stigma is an issue of social justice impacting the lives of individuals with ID, yet there remains virtually no systematic framework applied to the understanding of the stigma process for this group. Future research can draw on the stigma models developed in the mental illness literature to guide more rigorous research efforts and ultimately the development of effective, multilevel stigma-change strategies for ID.

Keywords: stigma, intellectual disability, mental illness, social justice, discrimination

Impact and Implications

- Although the study of stigma toward mental illness has received much attention in the rehabilitation literature, stigma toward intellectual disability (ID) has generally been neglected. This article is the first to review the existing empirical literature on attitudes and stigma toward ID in tandem with a review of the stigma models developed in the mental illness literature. This article extends existing knowledge by drawing on the conceptual models of mental illness stigma and providing recommendations to advance research efforts related to ID stigma.
- This article calls attention to stigma as a social justice issue impacting the lives of individuals with ID; details the longstanding discrimination in health, housing, and employment faced by this population; and presents a case for systematic, theory-driven research in this area.
- In order to bring about improved quality of life and social inclusion of individuals with ID, policy development should be based on effective, multilevel stigma change efforts. Our findings will inform advocate and government efforts meant to reduce the stigma experienced by people with ID.

Introduction

Proponents of the Sociopolitical (or Minority) Model of Disability and empowerment for persons with disabilities view "disability" as the primary result of prejudicial and discriminatory social forces (Smart & Smart, 2006). There is robust support for a hierarchy of acceptance for people with varying types of disability, where people with "mental disabilities"—particularly individuals with intellectual disabilities (ID) or mental illness (MI)— are consistently found to be the least socially accepted relative to other disability groups (e.g., Hernandez, Keys, & Balcazar, 2000; Karnilowicz, Sparrow, & Shinkfield, 1994; Lyons & Hayes, 1993; Miller, Chen, Glover-Graf & Kranz, 2009; Thomas, 2000; Tringo, 1970; Wang, Thomas, Chan, & Cheing, 2003; Westbrook, Legge, & Pennay, 1993; Yuker, 1988). Both the ID and MI populations are among the most socially excluded and continue to face substantial health, housing, and employment disparities (Corrigan,

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2005; Cummins & Lau, 2003; Ware, Hopper, Tugenberg, Dickey, & Fisher, 2007). Although there has been notable progress and increased stigma change efforts over the past decades, social stigma continues to result in prejudice and discrimination toward the ID and MI populations, limiting full participation in community life—the fundamental goal of rehabilitation efforts (World Health Organization [WHO], 2001).

Despite shared experiences with prejudice and discrimination, the extent and manner in which stigma toward these two populations has been approached and studied in the disability and psychiatric literature differs markedly. The stigma long directed toward MI, such as depression and schizophrenia, and its negative consequences with respect to health and well-being have received mounting attention as a public health concern. Additionally, rigorous efforts to develop and test models of stigma for individuals with MI have taken place over the past decade, resulting in theoretical advancements and refinements guiding further study and targeted intervention strategies (e.g., Corrigan et al., 2001). In contrast, although notable efforts to change discourse and language (e.g., shift from "mental retardation" to "intellectual disability" in U.S. public and private policies and "learning disability" in the United Kingdom) have been undertaken in response to the stigmatization and considerable advocacy efforts of this population, the ID field lacks a systematic conceptualization of stigma. Although there is a substantial body of literature investigating attitudes toward ID, it falls short in explaining the ways in which the stigma process plays out in the lives of individuals with ID. A handful of qualitative studies have explored individual experiences of prejudice and discrimination for those with ID (e.g., Edgerton, 1967, 1984; Jahoda & Markova, 2004); however, there remains virtually no systematic framework applied to the understanding of the stigma process for this group.

Although we recognize key differences between the ID and MI populations, we believe that there is much that can be learned from the stigma models developed and studied in the MI literature that can be used to guide further study of the stigma process for individuals with ID. Thus, the aim of this article is to understand the implications of MI stigma research for the ID field by outlining the current models of stigma applied to the MI population, reviewing current knowledge regarding the impact of stigma on individuals with ID, and providing recommendations for future research directions. In the process, we advocate for greater recognition of the negative impact of stigma on the lives of individuals with ID and their families and underscore a need for effective stigma reduction approaches at the system, public, and individual levels.

Stigma Models in Mental Illness Research

Goffman (1963) describes *stigma* as the public's attitude toward a person who possesses an attribute that fails to meet societal expectations and who is consequently perceived as "deeply discredit[ed] within a particular social interaction" (1963, p. 3). Despite society's tendency to discount individuals on the basis of a stigmatized attribute (or "mark"), theorists point out that stigma does not reside within the person but is conceptualized as a social construction—a label attached to a group by a culture at a particular time (Crocker, Major, & Steele, 1998; Jones et al., 1984; Link & Phelan, 2001). Over the years, criticisms that stigma conceptualizations have been vague have prompted the development of more complex theoretical models (e.g., Link & Phelan, 2001). The conceptual models of stigma that have emerged in the MI research literature emphasize the cognitive (stereotypes), emotional (prejudice), and behavioral (discrimination) components of a more global stigma process, following from initial cues or labels that signal membership in a target group.

Stereotypes are knowledge structures used for categorizing information about social groups. They represent collectively agreed upon categorical statements about groups of people and tend to be associated with negative attributes. There is evidence to suggest that by 10 years of age, children are aware of many stereotypes (McKown & Weinstsein, 2003). *Prejudice* involves the endorsement of these negative beliefs that leads to an emotional reaction (Devine, 1989, 1995). People may be aware of specific stereotypes (e.g., individuals with MI are dangerous), but they may not necessarily agree with them (Jussim, Nelson, Manis, & Soffin, 1995). On the other hand, prejudice indexes negative emotional responses among those who do endorse stereotypes (e.g., fear toward individuals with MI). These cognitive and affective components of stigma can lead to *discrimination* (Crocker et al., 1998), expressed by behaviors such as avoidance, overprotection, pity, and rejection (Goddard & Jordan, 1998). For individuals with MI, stigma has been found to have a deleterious impact on employment opportunities (Corrigan, Larson, & Kuwabara, 2007; Drehmer & Bordieri, 1985; Gouvier, Sytsma-Jordan, & Mayville, 2003; Link, 1982; Wahl, 1999); access to safe housing (Page, 1995; Segal, Baumohl, & Moyles, 1980); access to health care (Desai, Rosenheck, Druss, & Perlin, 2002; Druss & Rosenheck, 1998), and experiences with the criminal justice system (Johnson, 2011; Steadman, 1981).

As a process, stigma operates at multiple interconnected levels (minimally the social, institutional, and individual). *Public stigma* is the process by which members of the general population endorse prejudice and act in a discriminatory manner (Corrigan & Penn, 1999). It represents society's actions toward people known to have a stigmatized label such as "mental illness." A second type of stigma is *structural stigma,* which developed in the field of sociology and includes discriminatory policies and laws as well as cultural norms that do not reflect equality but instead encourage exclusion (Corrigan, Markowitz, & Watson, 2004). Structural stigma and discrimination can be both intentional (e.g., rules or policies consciously and purposefully restricting rights and opportunities of minority groups) and unintentional (e.g., consequences of laws or policies that restrict opportunities of minority groups in unintended ways; Corrigan et al., 2004; Link & Phelan, 2001).

Finally, *self-stigma* has been conceptualized as a key aspect of the stigma process in the MI literature. Members of a stigmatized group may internalize and direct prejudicial views toward themselves and/or their own group. However, personal awareness of a stereotype does not necessarily mean agreement with it (Jussim et al., 1995). Corrigan and Watson (2002) propose that a fundamental paradox exists for individuals with MI—that is, perceived social stigma by the individual may lead to different response trajectories depending on whether such stigma is viewed as legitimate or illegitimate. Individuals who are aware of and concur with stigmatizing social attitudes and apply negative stereotypes to themselves have diminished self-esteem, whereas those who disagree with public stereotypes may become either righteously angry or complacent, depending on their degree of group identification. Self-stigma has been conceptualized as lying on a continuum, with

self-stigma at one end and empowerment (involving the rejection of self-stigma) on the other.

Research Related to Attitudes and Stigma of Intellectual Disability

Even though there has been only limited research looking explicitly at stigma and ID, we are able to draw from notable efforts to document and understand public attitudes toward this group. Unlike stigma, attitudes can be thought of as beliefs without endorsement, evaluation, or typology. Measures of attitudes tend to index general cognitive assumptions regarding a specific group, whereas stigma examines the far more specific process by which particular stereotypes can lead to prejudice and ultimately discrimination. Tripartite models of attitudes comprising cognitive, affective, and behavioral components (e.g., Eagly & Chaiken, 2007) do share some overlap with how stigma has been conceptualized; however, stigma models extend further to incorporate the process of internalization of social stigma (self-stigma) as well as emphasize the importance of recognizing structural and institutional manifestations. By looking at the stigma process as a theoretical model, a multilevel approach to analyzing stigma can be considered.

Most of the work on social attitudes toward ID has been conducted with children and youth in light of the shift to more inclusive schooling practices. Numerous studies over the decades suggest that children and youth hold negative attitudes toward their peers with ID (e.g., Nowicki, 2005; Nowicki & Sandieson, 2002; Rillotta & Nettelbeck, 2007; Siperstein & Bak, 1980; Siperstein, Bak, & O'Keefe, 1988; Siperstein, Parker, Norins, & Widaman, 2007). It is also clear that stereotypes of ID differ from those of MI, although more study is needed. Stereotypes and characterizations of MI include "crazy/insane" and "dangerous," whereas individuals with ID have been characterized as "depending on others," "childlike," "looking physically different," and "happy and loving" (Gilmore, Campbell, & Cuskelly, 2003; McCaughey & Strohmer, 2005). Additionally, a review of popular media portrayals of people with ID found that they tend to be depicted as one-dimensional, vulnerable, and pitiable characters (Special Olympics, 2005). Thus, whereas stereotypical characterizations of MI often elicit notions of dangerousness and blame, ID tends to be viewed in terms of dependency and childlike innocence and frequently results in an uneasy combination of pity, discomfort, and fear from the public (Jahoda, Wilson, Stalker, & Cairney, 2010; Scheerenberger, 1983).

Research by Fiske and colleagues looking at in- and out-group status and stereotype formation provides further evidence of the existence of differential perceptions and attributes associated with people with ID and MI. Fiske (2012) suggests that people make sense of their social worlds based on the dimensions of warmth and competence. People with ID, such as Down's syndrome are likely to be regarded as high on warmth, but low on competence—that is, viewed as well-intentioned and trustworthy, but incompetent. This may translate into social stigma and stereotypes involving pity and dependency. On the other hand, individuals with MI—particularly severe MI—are viewed as low on both the dimensions warmth and competence leading to perceptions that they are potentially more difficult to relate to (Fiske, 2012).

Perceived attribution also appears to play a role in attitudes and stigma formation related to mental disabilities. Across groups, varying levels of attribution or "blame" exist. For instance, unlike people with physical disabilities, people with MI are perceived to be responsible for their condition (Weiner, Perry, & Magnusson, 1988). Findings by Corrigan and colleagues (2000), for example, suggest that students stigmatize "mental disabilities" differently. Specifically, individuals with ID tended to be more stigmatized in terms of the stability of their condition (i.e., permanence of their disabilities), whereas MI was associated with a higher degree of controllability (i.e., responsibility for their disabilities). Although both attributions led to stigma, the causes differed in significant ways. In spite of these differences holding at a very general level, more limited evidence from a study by Panek and Jungers (2008) suggests that even within the ID population, affective responses tend to be more positive when the cause of disability is perceived as "uncontrollable" (i.e., Down's syndrome) than when perceived as "controllable" (characterized in their study as *self-inflicted by drinking toxic chemical at an early age*), yet this remains an area requiring further investigation. Given the diverse etiologies of ID, further exploration of variations in causal attributions is suggested as well as investigation of the implications of such attributions for stigma change.

Another key difference between MI and ID is perceived cognitive capability. One potential concern with applying a stigma model conceptualized in the MI literature to individuals with ID would be that individuals with ID, because of cognitive difficulties, are simply unaware of stigma. Qualitative research, however, has shown that people with ID are in fact aware of the public stigma of their disability and cope with its social consequences in their everyday lives (Jahoda, Cattermole, & Markoya, 1988; Jahoda & Markova, 2004; Rapley, Kiernan, & Antaki, 1998). In a study by Ali, Strydom, Hassiotis, Williams, and King (2008), the most frequently endorsed statements by individuals with ID about their personal experiences of stigma and discriminatory behavior included the following: "people talk down to me" (60%), "people on the street look at me in a funny way" (61%), and "people treat me like a child" (46%). Moreover, two thirds of the individuals in their study reported that they stayed away from other people because they perceived them as not nice toward them. These reports are echoed in descriptive findings from other studies, with recurrent reports from people with ID experiencing teasing and anxiety when attempting to join mainstream activities or obtain employment (Cooney, Jahoda, Gumley, & Knott, 2006; Jahoda & Markova, 2004; Szivos & Griffiths, 1990).

Heterogeneity of ID

Efforts to understand stigma toward ID are further complicated by considerable heterogeneity in ID types and level of functional limitations. ID encompasses a variety of disorders and conditions, ranging from rare genetic disorders to self-inflicted or accidental origins. Clearly there is also a broad range of functional abilities and limitations in the MI population, but the implications of more extreme variations in cognitive functioning is arguably specific to the ID population. For example, although the experiences of individuals with severe psychosis or thought disorder may seem to be relatively inaccessible, some level of communication typically remains possible; on the other hand, for individuals with the most

profound forms of ID, functional limitations may be so great that communication barriers cannot be overcome and decipherable forms of communication may not be possible. Another characteristic that differs within this population is the extent to which individuals' disabilities are "visible" and hence, unlike many individuals with MI, do not allow them to "pass" as "normal."

Some types of ID, for instance, are associated with clear craniofacial or musculoskeletal differences. The implications of these differences are potentially important inasmuch as physical "abnormality" alone, even in the absence of mental disability, is a frequent source of stigma (Kaney, 2001; Strauss et al., 2007). Levinson and Starling (1981) found evidence to support an interaction between SES level and visibility of disability on mothers' perceptions of stigma—that is, families from lower SES reported greater stigma when their child had visible (as opposed to invisible) signs of ID. Findings by Usitalo (2002) point to high levels of stigma in adolescents with craniofacial conditions even in the absence of any intellectual or physical disability. In contrast, Varughese and Luty (2010) found that stigmatizing attitudes toward ID were reduced when participants were shown a picture of a man with Down's syndrome (vs. a brief description). Even though images of individuals with Down's syndrome often appear in ad campaigns related to ID, this represents only one of the many etiologies of ID.

Impact of Stigma on Individuals With Intellectual Disabilities

Social stigma has the potential to affect many key areas of life. These areas include social equality and inclusion, autonomy and choice making, health disparities, internalization, and pride and advocacy.

Social Equality and Inclusion

In terms of life goals, the WHO (2001) emphasizes full participation in community life for people with disabilities. However, from a historical perspective, power has been used to subject individuals with ID to such atrocious acts as forced institutionalization and sterilization. These types of systemic discrimination are recognized as structural stigma. In addition, more subtle forms of discrimination exist. For example, cognitive inaccessibility of public information for individuals with ID results in an "invisible barrier" to full inclusion in social life (see Yalon-Chamovitz, 2009). Individuals with ID are also widely excluded from key developmental experiences such as higher education, and recent lawsuits over the discriminatory treatment of college students with ID (e.g., Fialka-Feldman v. Oakland University Board of Trustees, 2010) highlight the extent to which such exclusion both depends on false stereotypes and further entrenches social role devaluation.

Seclusion from society continues to be evident in the services available for individuals with ID. Currently, the most recognized services include segregated day programming, sheltered workshop experiences, and residential environments. Beyond physical inclusion, the deinstitutionalization movement failed to provide services that allowed for social inclusion opportunities. For example, national statistics indicate that only 21% of working-age adults with ID are employed and 76% of those employed are working in facility-based services (Braddock et al., 2005; U.S. Bureau of Labor Statistics, 2010). Research has identified that a prominent barrier to community-based employment is the existing social belief that the majority of adults with ID are "unemployable" in the community setting (Parent, Hill, & Wehman, 1989; Shaw, MacKinnon, McWilliam, & Sumsion, 2004). Echoing this, findings from a multinational study by Siperstein, Norris, Corbin, and Shriver (2003) indicated that over one third of the public reported believing that individuals with ID should work in special workshops as opposed to competitive, community-based employment, and the vast majority of participants in the study believed that youth with ID should be educated in special schools, separate from other students.

Autonomy and Choice Making

Khan (1985) labeled the power that is exercised to protect people with ID as "paternalistic control" and reflects the assumption that people without ID, such as parents, siblings, legal guardians, and other caregivers, know what is best for individuals with ID. In such contexts, stigma, particularly in close associates, may be motivated by benevolence, born out of an effort to protect individuals thought to be innocent, childlike, and vulnerable (Glick & Fiske, 1996; Jackman, 1994). Perceptions of ineptitude or literal dis-ability also drive paternalism and benevolence. One of the most damaging consequences of this common response to individuals with ID is the low expectations that follow, and even adults with ID are often viewed as incapable of making decisions for themselves. These diminished expectations also lead to subsequent discrimination in the form of not offering choices or opportunities to people with ID because they are believed to be incapable of handling such decisions, managing their lives, or participating in the full range of social activities, including intimate relationships.

These circumstances have prompted a relative surge in research related to the promotion of empowerment and self-determination (Wehmeyer, 1992, 1998; Wehmeyer & Palmer, 2003) for individuals with significant disabilities, as well as a considerable increase in the number of self-advocacy groups (including People First and Self-Advocates Becoming Empowered); yet, this literature has paid surprisingly little attention to the processes and mechanisms responsible for instigating and maintaining these attitudes nor the relationship between public and family stigma, self-internalization, and disempowerment. Researchers in MI, conversely, have paid close attention to the relationship between autonomy in making choices about treatment and recovery and both external and internal stigma (Angell, 2012; Kreyenbuhl, Nossel, & Dixon, 2009).

Health Disparities

The U.S. Surgeon General's report (2002) *Closing the Gap: A National Blueprint to Improve the Health of Persons with Mental Retardation* draws attention to another important area in which individuals with ID face diminished access and poorer outcomes. This report not only acknowledges that significant health care disparities exist for individuals with ID, but also that these disparities occur within the context of a society that has neglected to implement changes in health care policy and delivery that ensure availability and access to adequate medical care for these individuals. Myriad factors contribute to such inequalities including genetics, social circumstances, environmental conditions, health pro-

motion, and medical care access (Krahn, Hammond, & Turner, 2006). This model of the determinants of health and health status disparities for individuals with ID illustrates the role that social factors, such as stigma, play in poor health outcomes faced by this population.

Public stigma related to ID on the part of health care providers is one factor potentially contributing to the inadequacy of the health care system when it comes to serving individuals with ID. The limited existing research studying the attitudes of general health providers toward people with ID suggests more negative attitudes than would be expected from "caring" professionals, particularly when education and training related to this patient group is lacking (Lewis & Stenfert-Kroese, 2010; Ouellette-Kuntz, Burge, Brown, & Areault, 2010; Slevin & Sines, 1996; Yazbeck, McVilly, & Parmenter, 2004). Such negative attitudes coupled with limited training reduce the number of medical professionals who are willing and able to provide care to individuals with ID, resulting in poorer health outcomes for this population. For example, a national survey by Krauss, Gulley, Sciegaj, and Wells (2003) found that more than one fifth of children with ID had problems accessing necessary care from specialty doctors in the preceding year.

Structural stigma also limits the ability of individuals with ID to obtain adequate health care. In a managed care, fee-for-service system in which physicians increasingly link the amount of time spent with each patient with dollars earned, the greater health care needs of individuals with ID create a conflict. Health care needs go unaddressed for these individuals because the payment system is not designed to allow for increased appointment time, accessible information, or specialized assessment measures that may be required for individuals with ID during medical appointments (Krahn et al., 2006). Additionally, general practitioners and psychiatrists report a lack of training opportunities available to them to build skills necessary to serve individuals with ID (Lennox, Diggens, & Ugoni, 1997; Werner, Levav, Stawski, & Polakiewicz, 2012), alluding to the fact that stigma may exert itself at the institutional level as well, with medical schools failing to offer the education necessary for providers to deliver adequate care to this population.

Important shifts in the health care system necessary to reduce such disparities would include increasing the number of health care professionals willing to accept individuals with ID as patients and possessing the proper training to attend to this population's unique health care needs and identifying and funding specialty health care programs designed to meet these individuals' needs. The Special Olympics' Healthy Athletes initiative began in 1997 and aims to reduce health care disparities by conducting research to identify gaps and barriers to care and by increasing access and availability of specialized dental, vision, and hearing care for their athletes (Special Olympics, 2013). Addressing stigma-related barriers to care will be an important part of reducing disparities.

Internalization of Stigma

In addition to social barriers impacting individuals with ID as a result of stigma, the internalization of stigma can have specific negative psychological effects on the lives of individuals with ID. A study by Szivos-Bach (1993) suggests that young students with ID who reported greater perceived stigma also had the lowest self-esteem. Caine and Hatton (1998) also discuss the concern that individuals with ID are at a greater risk of developing mental health problems compared with the general public, attributing this risk to the impact of stigma.

In the MI literature "label avoidance" has been viewed as a harmful effect of stigma, whereby individuals who might benefit from mental health services choose not to pursue them in order to sidestep the negative social and institutional consequences of such labels (Corrigan, 2004). Thus, an individual with prodromal psychosis might avoid seeking help in an effort to not associate him or herself with devalued "crazy people" and to avoid the insult to his or her self-image and self-perception. Although ID is usually present from birth, it is possible that such "label avoidance," nevertheless, manifests in the lives of individuals with ID in negative ways. This may be particularly true for individuals with milder form of ID, who can "pass" as nondisabled, rather than suffer the consequences of being labeled the "R-word" or even thinking of themselves in such socially devalued terms. Individuals may avoid associating themselves both with any ID-specific service or peers with ID. Attempting to pass may have benefits, but may also lead to excessive stress or anxiety about discovery and potentially increase exposure to negative stigma from potential social partners (Jahoda et al., 2010).

Finally, self-stigma may have enormous consequences for social integration. Given the stereotype that individuals with ID cannot form friendships with "normal" people, individuals may believe that they should not even try to engage nondisabled persons or to participate in activities that characterize "engaged" social life—that is, expressing political opinions, participating in neighborhood organizations and forums, asking questions in secondary or postsecondary settings, and so forth. Self-stigma may also lead to self-foreclosure on sexual relationships or, conversely, unsafe sex, or even sexual victimization (Gill, 2009).

Pride and Advocacy

The disability rights movement has been historically dominated by individuals with physical and sensory disabilities, but self-advocacy of individuals with ID has surged over the last two decades (Hayden & Nelis, 2002; Miller & Keys, 1996). Groups like People First, Self-Advocates Becoming Empowered, and Kids as Self-Advocates (KASA) have expanded significantly over the past two decades, with individual groups advocating for policy change and building the capacity of their peers. Young people affiliated with these groups in particular have increasingly embraced the slogan "disabled and proud" and view their identity as explicitly positive (e.g., Fialka-Feldman, n.d.).

In spite of these positive trends, it seems likely that stigma leads many individuals with ID to dis-identify with their peers or feel shame rather than pride (Jahoda et al., 2010). By better understanding the impact of different forms of stigma and the process by which they are internalized, researchers may be better poised to collaborate on interventions that promote positive identity and the rejection of negative stereotypes and thus to promote greater sociopolitical involvement and self-advocacy.

In the preceding sections, we have reviewed the potential impact of stigma on individuals with ID. As should be clear, research on stigma toward this population remains extremely underdeveloped, particularly relative to the literature in the MI field. We next

suggest some possible reasons for this incongruence and consider future steps.

Disproportionate Research and Considerations

It is not immediately apparent as to why there is such a notable disparity between the amount of attention paid to the stigma of MI compared with ID. There may be several possible reasons for this gap. First, this may simply be due to the lower prevalence of ID. National estimates in the United States suggest that approximately one in four adults experience a mental health disorder in a year (Kessler, Chiu, Demler, & Walters, 2005), whereas studies looking at ID report prevalence rates between 1% and 2.5% (Gillberg & Soderstrom, 2003). Related, it could be argued that another reason MI stigma has received more focus and attention is due to the scale of its influence as a public health concern. Whereas ID is by its definition a lifelong disability acquired by birth or in the early developmental years, MI can conceivably impact any member of the general public personally at any life point. Further, in spite of the functional disability MI can lead to, it is generally viewed by clinicians and researchers as potentially reversible or curable (prompting multibillion dollar expenditures into the development of new drugs and treatments). Additionally, although service disengagement may be a problem for individuals with ID, as mentioned above, disengagement (or "noncompliance") ostensibly has very different implications in MI inasmuch as it involves the refusal of treatments that are often very effective. If drugs and treatments existed that substantially altered the course of ID, it is likely that much more attention would be paid to both continued development and research into any factors surrounding nonadherence (such as stigma). Thus, although label avoidance may cut across populations, the extent to which ID stigma directly impacts the health of the general population is presumably considerably more limited.

Second, it appears that at some level stigma toward ID may be viewed as something stagnant and potentially impossible to change. From anecdotal conversations with service providers in the ID field, stigma appears to be something individuals who work with this population are well aware of, but see it as a perpetual barrier that, although they certainly strategize to adapt and work around it, is not going anywhere anytime soon. Thus, a focus on stigma may unintentionally overemphasize the negative aspects of disability. To be sure, this view is also common in the MI field. In fact, some stigma change efforts have found limited to no success in changing public attitudes (Corrigan, Morris, Michaels, Rafacz, & Rusch, 2012); however, strategies incorporating education and contact have demonstrated positive results (Allport, 1954; Corrigan et al., 2001, 2012; Stefan, 2001). It seems plausible then, that at least some of the pessimism stems from perceptions of the relative stability of ID (as mentioned above) as compared with MI. Although stories of mental health recovery continue to grow in number (including the *New York Times* recent "Lives Restored" series, and the memoirs of prominent individuals such as Elyn Saks and Kay Jamison), there is seemingly no equivalent of "recovery" in the context of ID.

Third, in the context of the ID literature, stigma overlaps with other well-studied constructs—including *attitudes, community integration, self-determination*, *accessibility*, and *advocacy*—that arguably approach individuals' lives from a more explicitly "positive psychology" or strengths-based perspective. As Daly and Silver (2008) underscore in the context of research on social exclusion versus social capital, however, negative social phenomena often elicit more research into their causes and positive social phenomena their consequences. Recently, more attention has been given to the causal mechanisms of inclusion in the social integration literature (e.g., Novak & Ryan, 2010). Arguably then, in tandem with these efforts, research on stigma would be valuable to further our understanding of the causal mechanisms of exclusion (and hence inclusion), rather than merely focusing on the positive consequences of social integration and empowerment when they can be achieved.

Related to this, it is also possible that stigma has been avoided by some in the ID field in effort to minimize the negative impact of social inclusion. Fears related to stigma have been used to support sheltered and segregated employment, schooling, and recreational activities. Because some studies have indeed shown a relationship between physical integration into mainstream activities and experiences of stigma (Jahoda et al., 2010; Siperstein et al., 2007), there may be concern that reverting to more segregated or institutionalized practices will decrease "exposure" to stigma. It will be important to reconcile these concerns by focusing on the development of effective stigma change strategies and proactive interventions to facilitate social acceptance.

Fourth, because the extent to which individuals with ID are aware of disability labels and the associated stigma has been called into question, there may be an assumption that individuals with ID are therefore "protected" from stigma and its impact. In contrast to the consistent evidence that people with mild-to-moderate ID are aware of the stigmatized treatment they experience (Beart, Hardy, & Buchan, 2005; Jahoda & Markova, 2004; Reiss & Benson, 1984), other findings have suggested that even though ID is indeed a powerful and stigmatized identity, some individuals with ID appear to be unaware of disability labels. A study conducted by Cunningham, Glenn, and Fitzpatrick (2000) found that 41% of the participants with Down's syndrome did not demonstrate awareness of their disability label, and the authors attributed this lack of awareness in part to not meeting a certain threshold of cognitive functioning to be capable of this type of social awareness. However, Beart, Hardy, and Buchan (2005) raised some questions about that study's methodological approach, and pointed out that many participants were able to identify Down's syndrome visually but not verbally (and vice versa) and suggested that it is possible that awareness of social identity involves different aspects of cognitive functioning. Moreover, individuals who may be unaware of (or choose to not identify with) a particular label may still indeed be conscious of negative attitudes and treatment targeted at them.

Finally, it is important to note that the word "stigma" has been criticized by some for its implication that stigma is inherent to the individual (e.g., Maio, 2004; Sayce, 1998). This concern should not be ignored; however, we underscore that "stigma" is not a personal characteristic of individuals, but a "mark" placed upon them by society. The stigma models in the MI literature emphasize the process and types of stigma incorporating a focus on the cognitive, affective and behavioral responses of society. Efforts to move forward with research looking at the stigma of ID should clearly avoid victim-blaming and stress that people with ID do not

have but are subjected *to* stigma; society, not the affected individual, is the locus of the problem.

Future Research Directions

The ultimate goal of research looking at stigma toward ID is to establish effective, concrete intervention strategies, and the stigma models used in the MI literature allow for a multilevel approach to addressing stigma change. Drawing on the framework described by Corrigan and Watson (2002), we propose that the first stage of research should involve identifying the common stereotypes of ID. Despite the public attitudes and beliefs that have been documented, at this point in time, the specific stereotypes associated with ID remain unclear. This could be best achieved by using a mixed-methods research design, using qualitative approaches to include various stakeholder perspectives, including individuals with ID, family members, service providers, and members of the general public, as well as incorporating quantitative measures tapping into the general public's perceptions of ID. Focusing on *public* stigma at the outset will help guide further inquiry given that stigma is explicitly conceptualized as a directional process moving from public attitudes and behaviors down to the levels of self and family (Larson & Corrigan, 2008; Phelan, Bromet, & Link, 1998) and will pave the way for the study of its impact on individuals and families. It will also be useful in guiding (and evaluating) stigma change initiatives. To be certain, we are not advocating that researchers spend substantial time and effort in this phase merely to describe the problem. Rather, we suggest that building on the existing measures and studies on public attitudes, a systematic approach to documenting salient stereotypes is imperative to informing a multilevel understanding of stigma and intervention strategies.

Second, more research is needed to look at overlap and potential collaboration with attitudes research. Much of the existing theoretical and empirical work focusing on tripartite models of attitudes (e.g., Eagly & Chaiken, 2007) has direct application to increasing our understanding of the stigma dimensions of prejudice and discrimination. Intraattitudinal structure and phenomena have important relevance for understanding attitude formation, whereas theoretical conceptualizations of stigma call attention to the cognitive and social processes of self-stigma and structural stigma. Together these lines of research have the potential to substantively inform intervention approaches targeting multilevel stigma change.

Third, there are additional constructs that appear directly connected to stigma. For example, *self-determination* has also been a key construct gaining much recognition in the ID field in response to the limited opportunities for choice making due to lowered expectations of the public toward this population (Wehmeyer, 1998). Clearly, there is a link between public stigma, prejudice, and discrimination and these limited opportunities. Future lines of research may examine the impact of increased opportunities for self-determination on self-stigma. In addition, constructs such as *community integration* or *community participation* appear to have a complex relationship with stigma. For example, segregation of this population may be rooted in discrimination, yet increased social integration has been associated—at least in some studies (e.g., Cooney et al., 2006)—with increased experience of stigma through greater exposure to public stigma, possibly because of both explicit behavioral discrimination and general ignorance regarding how to interact with individuals perceived to be dissimilar. Thus, the role of stigma as both a barrier to and effect of more full integration is a line of inquiry requiring further development.

Fourth, the current dearth of psychometrically adequate scales based on stigma conceptualization in the area of ID makes it difficult to examine and consolidate findings. In a recent review, Werner, Corrigan, Ditchman, and Sokol (2012) reviewed 25 scales measuring public, self, and family stigma in the ID field and evaluated them in terms of their psychometric properties. They found that many of the measures reviewed did not appear to be appropriate or feasible for individuals with ID to complete, particularly individuals with more severe disabilities. Moreover, the heterogeneity of this population is an important consideration. The challenge of finding ways to make measures appropriate for use with individuals with varying cognitive levels and/or communication styles is an important consideration in the development of new evaluation and measurement strategies. Jahoda and colleagues (2010) suggest that using a variety of data collection strategies (including longitudinal observation and in-depth interviews with both target individuals and their families) is essential to gaining insight into the meaning of stigma for these participants, finding the absence of such detailed longitudinal work as a matter of concern in the mainstream social psychological literature.

Finally, we advocate for the inclusion of individuals with ID throughout the research process. Stigma work has been criticized for not incorporating the perspectives of individuals themselves (Link & Phelan, 2001). Community-based participatory research (CBPR) has been a core feature of much of the MI stigma research. CBPR is research that is conducted with community members as active and equal partners in all aspects of the research process (Wallerstein & Duran, 2006). Movement to include individuals with ID in the research process has been less widespread. There are indeed barriers to these efforts, such as accessibility of research discourse; however, CBPR and inclusive research practices have been successfully conducted in partnership with individuals with ID (see Abma, Nierse, & Widdershoven, 2009; Dowse, 2009; McDonald, Kidney, & Patka, 2013; Walmsley & Johnson, 2003).

Implications

Recognition of the presence of stigma faced by people with ID has several implications for clinical practice and policy. The United Nations Convention on the Rights of Persons with Disabilities (2006) explicitly calls for the prevention of discrimination through increased awareness raising efforts to combat stereotypes and prejudice toward individuals with disabilities. At the structural level, public policies stressing equal rights and social inclusion should be supported. Equipping public service personnel with adequate training around working with individuals with ID will make services (e.g., health, education) and public information more accessible to this population. Methods of protest (framing stigma as a social injustice), education (providing facts about the group), and contact (enhancing interactions between group members and the public) to address public stigma change have been well studied in the MI literature (e.g., Corrigan & Penn, 1999; Corrigan et al., 2002), with contact generally yielding the strongest results. The importance of contact (number, frequency, and quality) has also been shown to impact attitudes and social integration

of people with ID (e.g., Morin, Rivard, Crocker, Boursier, & Caron, 2013; Novak & Ryan, 2010). Other research has suggested that people's expectancies and emotions aroused by future encounters with people with ID appear to have a stronger influence on willingness to engage in future contact even over frequency of previous contact (van Alphen, Dijker, Bos, van den Borne, & Curfs, 2011). Finally, it is important that clinical professionals working with clients with ID (and/or their families) recognize the clients' individualized experience, perceptions, and internalization of social stigma and the extent to which ID is an identity associated with shame, pride, or indifference. For clients with more severe ID or limited verbal abilities, approaches incorporating observation or visual communication (e.g., photo journalism) may be beneficial for exploring their perspectives.

Despite some advances in the promotion of inclusive practices, people with ID and MI continue to remain socially excluded and encounter stigma, discrimination, and major barriers that restrict their full inclusion in community life. Although research efforts to conceptualize, measure and address MI stigma have been relatively well developed, stigma has not received the same attention in the ID field. Models developed in the MI field have reflected a multilevel conceptualization of stigma, focusing on psychological paradigms as well as macrolevel causes and mediators of stigma. These models have applicability in guiding the study of ID stigma at the public, individual, and family levels; informing the development of psychometrically sound and accessible measures; and ultimately providing a framework for targeted stigma change efforts.

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