They Aren't Like Me, They are Bad, and They are to Blame: A Theoretically-Informed Study of Stigma of Hoarding Disorder and Obsessive-Compulsive Disorder

Gregory S. Chasson, Arryn A. Guy, Sage Bates, & Patrick W. Corrigan

Author Note

Gregory S. Chasson, Department of Psychology, Illinois Institute of Technology; Arryn A. Guy, Department of Psychology, Illinois Institute of Technology; Sage Bates, Department of Psychology, Illinois Institute of Technology; Patrick W. Corrigan, Department of Psychology, Illinois Institute of Technology.

Correspondence concerning this article should be addressed to Gregory S. Chasson, Department of Psychology, Illinois Institute of Technology, 3424 South State Street, 201 Tech Central, Chicago, Illinois 60616; 312.567.5936 (Telephone); 312.567.3493 (Fax).

Email: gchasson@gmail.com

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Abstract

There are no systematic investigations of public stigma of hoarding disorder (HD), and although there have been some studies on the public perception of obsessive-compulsive disorder (OCD), such research has not examined three theoretically informed facets of stigma: *difference* ("They aren't like me"), *disdain* ("They are bad"), and *blame* ("They are to blame"). The current Internet study evaluated these three facets of stigma in a general sample of 591 adults by comparing ratings of public perception for HD, OCD, serious mental illness (SMI), substance use disorders (SUD), and those in jail. Results indicate that HD is mostly associated with a neutral or negative public perception across all stigma facets, but OCD is associated with mostly positive or neutral public perception. Across all stigma ratings, HD was viewed more negatively than OCD. Comparison of ratings across conditions and the three facets of stigma suggest a nuanced picture in which HD and OCD demonstrate differences in public perceptions compared to jail, SMI, and SUD, some in the positive direction and some in the negative. In addition, among those who scored in a clinically elevated range of HD symptom severity, one facet of public stigma (i.e., a proxy for self-stigma) was negatively correlated with an index of treatment-seeking willingness, implicating stigma as a potential factor in the treatment ambivalence commonly associated with HD treatment.

Keywords: hoarding disorder; obsessive-compulsive disorder; stigma

They Aren't Like Me, They are Bad, and They are to Blame: A Theoretically-Informed Study of Stigma of Hoarding Disorder and Obsessive-Compulsive Disorder

Both Hoarding Disorder (HD; pathological difficulty discarding possessions others find useless or valueless, resulting in clutter) and obsessive-compulsive disorder (OCD; recurrent intrusive thoughts, images, or urges that elicit distress and safety behaviors that function to decrease that distress) have received increased attention in the public spotlight in recent years, most notably through non-profit advocacy and media portrayals. Non-profit organizations, like the International OCD Foundation (IOCDF), endeavor as part of their mission to reduce stigma for OCD and related conditions (IOCDF, 2017). On the other hand, characterizations of mental health conditions, like OCD, in the media are often associated with higher levels of stigma (e.g., Fennell & Boyd, 2014; Hoffner & Cohen, 2017). Many forces may therefore act on the stigma of OCD and HD, but very little empirical research has quantified or systematically investigated stigma for these two conditions.

Mental health stigma is a complex construct. The scientific literature includes considerable theory building (see National Academy of Science [NAS], 2016, for an overview), as well as empirical work on the nature (e.g., Corrigan, Bink, Fokuo, & Schmidt, 2015), measurement (NAS, 2016), and reduction (e.g., Corrigan, Morris, Michaels, Ragacz, & Rüsch, 2012) of stigma, so much so that it has generated federal attention. Indeed, the National Academy of Science (2016) was commissioned by the US Department of Health and Human Services to publish a consensus report highlighting the construct of mental health stigma and its profound consequences. One such consequence is discrimination, which can emerge from stigma, and can influence policy decisions (Skitka & Tetlock, 1992). For example, evidence

suggests that mental illness stigma is inversely related to monetary allotment during hypothetical budgetary decisions concerning human welfare programs (e.g., HIV/AIDS services; programs for women, infants and children; Corrigan, Watson, Warpinski, & Garcia., 2004).

The construct of stigma can be bifurcated into two entwined components: self-stigma and public stigma. *Self-stigma* occurs when individuals internalize prejudice of their condition, whereas *public stigma* refers to endorsements by the general population of stereotypes and prejudices about people with a certain condition (Corrigan, Druss, & Perlick, 2014; Corrigan & Watson, 2002). Public stigma itself is not a unitary construct and is composed of multiple facets, and using a single facet to operationalize *stigma* can be problematic (e.g., two facets might reflect opposite patterns) (Haslam & Kvaale, 2015). Pertinent to the current study, three major theoretical facets of public stigma include *difference* ("They aren't like me"), *disdain* ("They are bad"), and *blame* ("They are responsible") (Corrigan, Bink, et al., 2015). When these facets, which are prejudicial stereotypes, are accepted by the public and internalized by the individual with the condition, it becomes self-stigma (Corrigan, 2015; 2016). When public stigma is internalized as self-stigma, it can influence treatment-seeking behavior when it elicits label avoidance—people with a mental health condition aim to prevent discrimination and loss of opportunity from psychiatric labels by not going to clinics or settings where such labels are assigned (Corrigan, 2004). Thus, stigma is an important factor to examine when studying treatments for mental health conditions, such as HD and OCD.

There is a minimal amount of research on stigma of OCD, and to our knowledge, only one study highlighting HD stigma. In a sample of adults from the general population, Coles, Heimberg, and Weiss (2012) presented participants with a vignette depicting OCD, and 14.7% endorsed the belief that the character in the vignette should not mention the symptoms to avoid

stigma. With undergraduate samples, Simonds and Thorpe (2003) and Cathey and Wetterneck (2013) found higher levels of stigma for vignettes depicting harm OCD and sexual intrusion OCD compared to other manifestations of the disorder. Studies with mental health practitioners have similarly found that stigma ratings are higher for contamination, harm, and sexual intrusion OCD (Steinberg & Wetterneck, 2017), and in one study, only 18% of psychiatrist reported that OCD patients are admirable (Kusalaruk, Saipanish, & Hiranyatheb, 2015). Belloch, del Valle, Morillo, Carrio, and Cabedo (2009) found that 35% of an OCD sample reported delaying treatment-seeking behavior because of shame from the content of the OCD symptoms, and 31% because of fearing a label of *mentally ill*. Similarly, an online survey of 351 individuals with OCD indicated that more than 50% reported that shame was an important barrier to seeking treatment and about 40% reported that social judgment from others was a barrier (Marques et al., 2010). However, it appears that only one study has examined public stigma in OCD (i.e., Coles et al., 2012), and none have examined the aforementioned three theoretical facets of *difference, disdain,* and *blame.*

To our knowledge, only one study has examined self-stigma in HD, and no studies have investigated public stigma. In the London field trial for HD, one item about stigma—*would you find it stigmatizing to receive such [a] label [of HD]*?—was asked of 29 adults from the community with a confirmed diagnosis of HD (Mataix-Cols, Billotti, de la Cruz, & Nordseltten, 2013). Of those 29 participants, 17 reported that an HD label was *not too stigmatizing* or *not all stigmatizing*, and 12 reported it was *somewhat stigmatizing* or *very stigmatizing*. The researchers followed up this item with an open-ended, qualitative question to probe the reason participants answered the stigma item as they did. Themes of responses about stigma included fears that others might misunderstand the HD label, that such a label might limit social acceptance by

others, and that labels like this might elicit privacy violations. Not all qualitative responses reflected concerns about stigma; some comments highlighted that a label of HD could increase support seeking outside of the family, as well as advance understanding of HD (e.g., increase awareness of the condition). This was an important first step in understanding the self-perception of HD among individuals with the condition, but the public perception of HD remains poorly understood. It is also unclear if self-perception of HD among those with the condition correlates with treatment-seeking willingness. Indeed, stigma in general acts as barrier to patients engaging in mental health treatment (NAS, 2016), and thus, the impact of stigma on treatment seeking for HD and OCD is an important area of research given the high levels of refusal and dropout—two potential markers of low treatment-seeking willingness—associated with HD and OCD services. Evidence from extant cognitive-behavioral therapy for HD studies suggests that 48% of patients refused or dropped out from treatment (Muroff, Bratiotis, & Steketee, 2011). Similarly, the most evidence-based treatment for OCD is exposure and response prevention, but approximately 25% of participants refuse this treatment and another 25% drop out once initiated (Jenike, 2004). For example, one possible factor that may contribute to lack of treatment engagement is poor insight, a common correlate of individuals with HD (Tolin, Frost, Fitch, & Steketee, 2010). Thus, factors that obstruct treatment engagement in those with HD and OCD are important to investigate, and stigma may be a fruitful example of one of these factors.

The current study recruited an online sample to answer questions about public stigma of HD and OCD, as well as other comparison groups with a history of negative public perception: severe mental illness (SMI; i.e., those with psychosis), those in jail, and substance use disorders (SUD) (Corrigan et al., 2017). SMI is a useful comparison. Prior research has shown that public believes individuals with SMI are violent, irresponsible, and childlike, and that they cannot make

their own decisions (Corrigan & Penn, 1999). Similarly, for comparison purposes, SUD and jail conditions are commonly included as negative anchors in research because they are strongly stigmatized groups (Corrigan et al., 2010; Corrigan et al., 2017; NAS, 2016). Also, because mental illness stigma is indirectly associated with monetary allotment as part of hypothetical budgetary decisions about human welfare programs (e.g., HIV/AIDS services; programs for women, infants and children; Corrigan, Watson, Warpinski, & Garcia., 2004), as another indicator of stigma, we have included a hypothetical budget decision measure—as a proxy for public funding beliefs—that examines if participants would choose to underfund HD and OCD services relative to other human services.

For those participants who surpassed a clinically significant cutoff score on severity measures of HD and OCD, we also calculated the degree to which stigma ratings—as a proxy measure of self-stigma—correlated with a rating of treatment-seeking willingness. Although previous investigations have examined stigma of OCD, only one investigation has done so with adults from a general population (i.e., not clinical or student samples), and none for HD stigma (i.e., the London field trial examined HD self-stigma in participants with HD). Therefore the current study would expand research in this important population—a sample of the public to reflect public perception. In addition, this is the first study to test stigma of HD and OCD based on all three theoretically informed dimensions of the construct: *difference*, *disdain*, and *blame*.

We hypothesized that stigma ratings for HD across all three dimensions would be more severe, and OCD stigma ratings less severe, than ratings for comparison conditions, based on the recent negative depictions of HD and less (but not absent) negative OCD characterizations in the media, which is a common source of exposure to these conditions for the public. Specifically, in the last decade, several reality television shows have emerged that follow the experience of an

adult with HD symptoms as family members or strangers clear out the clutter and organize the home (e.g., *Hoarders, Buried Alive*). Many of the non-fictional depictions of HD are negative (i.e., they carry a negative name, depict extreme cases of HD, show highly distressing interventions, and dramatize interpersonal antagonism). By contrast, although reality television depictions of OCD have been aired (e.g., VH1's *The OCD Project* and A&E's *Obsessed*), the dosage of these shows on public perception is considerably smaller compared to HD shows. For example, combined, *Hoarders* and *Buried Alive* were broadcasted for 190 episodes over 19 seasons, whereas *The OCD Project* and *Obsessed* combined for 20 episodes for less than two years. On the other hand, the fictional portrayals of OCD tend to be viewed positively when the content of the media is qualitatively coded (Siegel, 2015) and rated by adults in the general population (Hoffner & Cohen, 2015). Nonetheless, there is a mixed perception by individuals with OCD and anxiety disorders (Fennell & Boyd, 2014; Hoffner & Cohen, 2017), as media portrayals of OCD can be stigmatizing. We also hypothesized this direction of an effect because of the concerted effort of OCD advocacy groups, like IOCDF and the Peace of Mind Foundation, to combat OCD stigma in the public; this type of advocacy is less robust for HD.

Although the study was primarily designed to evaluate public stigma, for those participants who scored in a clinically elevated range of HD and OCD symptoms, we also tested an exploratory hypothesis in which ratings of stigma of HD and OCD—in this case a proxy for self-stigma—would correlate negatively with an index of treatment-seeking willingness. We also explored moderation analyses to test if participant familiarity with respective conditions (e.g., through lived experience in the self or family member) influenced stigma ratings, as familiarity tends to reduce negative perception (Angermeyer et al., 2004).

Method

Participants

Participants in the final sample included 591 adults recruited online in the United States. The sample was 49.7% male and 86.49% non-Hispanic White, with an average age of 37.03(*SD* =11.42) years. Additional demographic information is presented in Table 1.

Design

The current study adopted a within-subject design in which participants rated multiple facets of stigma across five different groups: individuals in jail, and those with HD, OCD, SMI, and SUD. Data were collected using Qualtrics survey software, and participants were recruited via Amazon's Mechanical Turk (MTurk), a crowdsourcing website that enlists participants who complete surveys for compensation, which totaled $3.40 per participant for this study based on 20-minutes to complete the measures. MTurk filtering features were utilized to recruit only individuals who connected to MTurk from the US and reported being at least 18 years of age. MTurk has grown as a source for human subjects research over the last few years. Previous research has shown that studies using human subjects recruited from Mturk yielded high internal consistency (α coefficients ranging from .73 to .93) (Buhrmester et al., 2011). Other research has replicated popular behavioral research with relative success (Crump et al., 2013). The internal validity of online research, specifically the lack of effortful responding, has been called into question by some researchers (Huang et al., 2015). Thus, threats to internal validity were reduced by including three items as validity checks throughout the questionnaires—for example, "For this question in the substance use disorder section, please select eight as the response." In addition, participants were informed of the existence of these validity checks as part of the consenting procedure as a way to encourage valid responding. The attention check items resulted in removing 20 participants (approximately 3.3% of the total respondents) for missing at least

one of the validity check items, yielding the study *N* reported above. As another check of valid responding, survey completion times were examined. The distribution of completion times was normal in shape with no negative statistical outliers (i.e., *Z* score < 2.0—nobody in the final sample responded extremely quickly as a marker of invalid responding). Approval for conducting the research was obtained from the Institution Review Board of the university of the authors.

Procedures

After signing consent, participants completed the sections in which they were asked to rate stigma items for the various conditions (e.g., SMI, OCD, HD). Each condition had identical items measuring the different facets of stigma (i.e., *difference*, *disdain*, and *blame*), stigma items for each condition were clustered together, and the presentation order of clusters was randomized across participants to reduce order effects. Participants then completed a hypothetical resource allocation measure (described below), a series of demographic and clinical and family history questions, and measures of HD and OCD symptom severity, which each triggered an additional item about treatment willingness for HD and OCD, respectively, if scores fell in a predefined clinical range.

Measures

Stigma. Each condition (e.g., SMI, OCD, HD) was rated on seven stigma items based on three theoretically derived and empirically based facets of stigma (i.e., *difference*, *disdain*, and *blame*; Corrigan, 2000; Corrigan 2002). *Difference* contained three items measuring similarity, likeness, and comparability, all of which characterized how much the rater believed individuals with the respective condition were like them. Here is an example item for the *Difference* facet: *How like or unlike do you think is a person with obsessive-compulsive disorder compared to*

everyone else in the general population? Disdain contained three items measuring badness, respect, and favorability—items that reflected negative or positive judgments about the character of people with the respective condition. Here is an example item for the *Disdain* facet: *How good or bad do you think is a person with hoarding disorder compared to everyone else in the general population?* The *Blame* facet was based on one item measuring responsibility for the condition: *How responsible do you think a person with serious mental illness is for his or her condition?* Prior research supports this single item as a reliable and valid index of blame (Corrigan et al., 2000; Corrigan et al., 2002). All items were coded so that higher scores reflected more negative perception. The three *difference* items were averaged to yield a single index for this stigma facet, and a similar procedure was carried out for the three *disdain* items. Internal reliability estimates for the derived *difference* and *disdain* scores are presented in Table 2 and ranged from .60 to .86, with the lower scores calculated for *disdain* only. The appendix illustrates how each of the conditions (e.g., OCD, SUD) was described to the participants.

Resource Allocation Measure (RAM). Stigma was also measured indirectly through a budget allocation measure. Participants were given a list of ten human services or programs: women, infant and children program; family planning; healthy kids program; HIV/AIDS services; organ transplant act; SMI services; jail and social services; addiction services; hoarding and clutter programs; and services for OCD. They were then asked to allocate a hypothetical $100 million to these programs in whatever pattern they wished. Similar RAM tasks have been used in other research as a measure of the association between stigma and policy decisions (Skitka & Tetlock, 1992). Please see the appendix for the instructions provided to participant for the RAM.

HD Symptom Severity. Participants completed the Saving Inventory-Revised (SI-R; Frost, Steketee, & Grisham, 2004), a widely-used 23-item measure of hoarding severity with strong psychometric properties, including internal consistency and construct validity based on strong convergent, discriminant, and factorial validity (Coles, Frost, Heimberg, & Steketee, 2003; Frost et al., 2004). The SI-R requires participants to endorse items using a 5-point Likert scale from none (0) to almost all/extreme/very often (4), with higher scores reflecting higher HD symptom severity. The measure is summed to create a total score, as well as three subscales: acquisition, clutter, and difficulty discarding. A total score 41 or higher has been identified as a reasonable clinical cutoff threshold (Frost et al., 2004), and scores at this level or higher triggered an additional item measuring a participant's willingness to seek HD services. For the current sample, SI-R $\alpha = .95$.

OCD Symptom Severity. The Dimensional Obsessive-Compulsive Scale (DOCS; Abramowitz et al., 2010) was used in the current study to measure OCD symptom severity. The DOCS is a 20-item self-report adult OCD severity scale in which each item measures OCD symptoms *over the last month* on a 5-level scale from lowest (0) to highest (4) severity, thus yielding a scale that ranges from 0 to 80, with higher scores reflecting more severity. The 20 items are composed of five subgroups of four items, with the subgroups approximately mapping on to the empirically derived OCD symptom dimensions (i.e., contamination, symmetry, responsibility, and unacceptable thoughts). The DOCS has demonstrated strong psychometric properties, including convergent validity with another measure of OCD severity; discriminant validity based on correlations with measures of depression, anxiety, and stress; factorial validity supporting the empirically derived and theoretically consistent subscale structure; criterion-related validity based on differences between OCD, other anxiety disorder, and student groups;

internal consistency and temporal stability; and diagnostic utility (Abramowitz et al., 2010). A total score 18 or higher has been identified as a reasonable clinical cutoff (Abramowitz et al., 2010), and scores at this level or higher triggered an additional item measuring a participant's willingness to seek OCD services. For the current sample, DOCS $\alpha = .94$.

Demographic, Family, and Clinical History. A series of questions measuring an assortment of participant demographic, family history, and clinical items were constructed for the study. In addition to demographic information, participants were asked about their own personal experience with various conditions. Personal experience was defined as the endorsement of yes/no items asking if a participant had ever been diagnosed with or personally experienced one of the clinical conditions in the study (e.g., SUDS, OCD). For example, "*Are you or have you ever been diagnosed with hoarding disorder?*" or "*Are you or have you ever been to jail?*". A similar item was asked for personal experience of having a loved one with a respective condition.

Treatment-Seeking Willingness. An item measuring the degree to which a participant would be willing to pursue treatment for HD or OCD was adapted from the following question from the Recovery Assessment Scale-Revised, "I am willing to ask for help.**"** Extensions were added to this item stem: "for my clutter, hoarding, or saving difficulties" or "for my obsessive and compulsive difficulties" for HD and OCD, respectively. This item stem is part of the aforementioned scale that has demonstrated strong psychometric properties (Corrigan, Giffort, Rashid, Leary, & Okeke, 1999; Corrigan, Salzer, Ralph, Sangster, & Keck, 2004).

Data Analyses

In order to compare the participants' views of *difference*, *disdain*, and *blame* across SMI, SUD, Jail, OCD, and HD, the researchers conducted within-subjects ANOVAs for each domain

across all clinical conditions. Two sets of post hoc tests of marginal means were employed in order to identify significant differences across clinical conditions in ratings of stigma; the first set compared HD to the other conditions, and the second compared OCD to the other conditions. We also explored diagnosis of or personal experience with a particular clinical condition as a moderator of stigma ratings by re-running the ANOVAs while including interaction terms between condition and each yes/no familiarity item (one such interaction term per model). This familiarity variable was operationalized based on endorsing *Yes* or *No* to aforementioned items measuring clinical history of a diagnosis for oneself or a family member (i.e., OCD or HD diagnosis depending on the model; see *Measures* above) and not based on clinical cutoffs on the DOCS or SI-R. Correlation analyses were used to evaluate stigma and treatment-seeking willingness. Within-subject ANOVAs were also employed to test differences in budget allocation across human services and programs based on RAM responses. As with the stigma item analysis, two sets of post hoc tests of marginal means were employed in order to identify significant differences across clinical conditions in budget allocation for various human services and programs; the first set compared HD services to the other human services and programs, and the second compared OCD services to the other human services and programs. Type I error rates for all regression analyses were controlled using a False Discovery Rate Procedure (Benjamini & Hochberg, 1995), yielding a critical *p*-value of .030. Correlation analyses were not included in the error rate procedure.

Results

Descriptive Data and Preliminary Analyses

Descriptive results for each clinical condition across stigma domains are illustrated in Figure 1 and provided in Table 2. With respect to the valence of the stigma item ratings,

participants rated OCD neutrally to positively, but for HD, mostly neutrally to negatively. Means and standard deviations for budget dollars allocated in the RAM are presented in Figure 2. Both HD and OCD services were allocated a small amount of the hypothetical budget of $100 million, at 4 and 5%, respectively.

Items that measured a participant's familiarity with each condition indicated some variability in how much a participant had been exposed to HD and OCD. Personally having a formal diagnosis of OCD was reported in 1.4% of the sample, and 30.4% indicated that a close family or friend was diagnosed with OCD or suspected of having OCD although not formally diagnosed. Although no participants reported having a formal diagnosis of HD, 39.4% reported having too much clutter in their home or that others believe they have too much clutter. Slightly more than 31% reported that a close family or friend was diagnosed with HD or suspected of having HD although not formally diagnosed.

Correlations among stigma domains within clinical condition are presented in Table 2. As an indicator of convergent validity for the stigma items, ratings were correlated with each other within clinical condition for *difference* and *disdain*. This was not the case for correlations for those two stigma indices with *blame*.

Correlation analyses between stigma indices and dollar allocation on the RAM were also carried out. There were no significant correlations between OCD stigma items and hypothetical dollar amount of allocation for OCD services. There were, however, two small but significant correlations between HD stigma items and dollar amount for HD services—*blame*, $r = -.121$, $p < .001$, and *disdain*, $r = -.087$, $p = .034$—indicating that participants allocated fewer hypothetical dollars for HD services the more they negatively percieved HD, and vice versa.

Hypothesis Tests

Separate within-subjects ANOVAs were completed for *difference*, *disdain* , and *blame* across five clinical groups (i.e., SMI, SUD, Jail, OCD, and HD). There was a significant effect for clinical condition for *difference*, $F(4,588) = 70.81$, $p < .001$, Partial $\eta 2 = .107$; *disdain*, $F(4,588) = 270.02$, $p < .001$, Partial $\eta 2 = .314$; and *blame*, $F(4,588) = 70.81$, $p < .001$, Partial $\eta 2 = .107$. Post hoc tests of marginal means comparing HD to the other conditions, as well as OCD to the other conditions, are illustrated in Figure 1 and detailed in Table 3. There were significant differences in stigma ratings between HD and other clinical conditions. HD was viewed as more different from the general population than SUD, Jail, and OCD, but less different from the general population than SMI. On the other hand, HD and SMI were viewed with similar levels of *disdain* compared to the general population, less than Jail and SUD, but more than OCD. Those with HD were seen as having more *blame* for their condition compared to individuals with SMI and OCD, but less than Jail and SUD. Effect sizes for the HD comparisons were mostly medium-to-large or large (Table 3).

Similarly, a second set of post hoc tests of marginal means revealed significant differences in stigma ratings between OCD and other clinical conditions (Figure 1 and Table 3). OCD was viewed similarly to those who have been to jail on *difference* from the general population, but they were viewed as more different compared to SUD and less different than HD and SMI. OCD was viewed with significantly less *disdain* and *blame* compared to all other clinical conditions, except individuals with OCD were seen has having more *blame* compared to SMI. With a couple of exceptions, effect sizes for the OCD comparisons were mostly large (Table 3).

Using data from the RAM, we then examined the differences in budget dollars earmarked for different types of human services and programs. The within-subjects ANOVA across the ten

human services or programs was statistically significant, $F(9,582) = 206.35$, $p < .001$. $\eta^2 = .76$. Post hoc comparisons indicated that fund allocation for HD and OCD services was statistically significantly lower than for all other human services and programs, but there was no significant different in allocation amount between HD and OCD services.

Moderation analyses were then conducted to test the hypothesis that a participant's familiarity with a specific clinical condition would decrease stigma ratings for that respective condition. Personal experience with SUD and OCD did not moderate domain ratings for public stigma, but personal experience with SMI ($n = 96$), Jail ($n = 70$) and HD ($n = 159$) moderated ratings for public stigma. For participants who had been diagnosed or treated for an SMI, those with SMI were viewed more favorably across all three stigma facets, $F(6, 585) = 3.62$, $p < .03$, $\eta^2 = .01$. Compared to those who have not been to jail, participants who reported having been to jail had more favorable ratings on the three facets, $F(6,585) = 6.60$, $p < .001$, $\eta^2 = .03$. For participants who reported that a family member or close friend has exhibited hoarding or clutter difficulties, individuals with HD were viewed more favorably in terms of *difference* and were viewed less favorably for *disdain* and *blame*, $F(2,589) = 10.26$, $p < .001$, $\eta^2 = .03$.

Additionally, in participants reaching clinical cutoff scores for OCD and HD symptoms, correlations between treatment-seeking willingness and ratings on stigma items are presented in Table 2. Among participants who reached the HD symptoms clinical cutoff ($n = 24$), treatment willingness was negatively associated with *disdain* ($r = -.48$, $p < .001$), but not significantly related to *difference* and *blame*. Mean HD stigma ratings for the group with elevated HD symptoms was as follows: *disdain* = 5.92(1.37), *difference* = 5.51(1.79), and *blame* = 4.66(2.30). Among participants who reached the OCD symptoms clinical cutoff ($n = 78$), there were no associations between OCD treatment willingness and ratings of stigma. Mean OCD

stigma ratings for the group with elevated OCD symptoms was as follows: *disdain* = 4.84(1.28), *difference* = 4.81(1.61), and *blame* = 3.25(2.19).

Discussion

We surveyed an internet sample to investigate public stigma of HD and OCD compared to other groups with a history of negative public perception. We hypothesized that stigma ratings across three theoretically based dimensions would be higher for HD compared to SMI, Jail, SUD, and OCD. Although the results for HD were mixed, the valence of the stigma ratings leaned in the negative direction, and HD had a statistically equivalent level of *disdain* as SMI—a highly stigmatize condition (Corrigan & Penn, 1999). In addition, participants allocated significantly fewer hypothetical dollars to HD programs compared to other causes, except for OCD programs, and dollar amounts for HD services decreased as *disdain* and *blame* for the condition increased, suggesting that HD stigma is associated with less generosity in funding by the public. Though, there were some exceptions to the general pattern that HD was more stigmatized than other conditions. For example, *disdain* and *blame* ratings for HD were significantly lower than for Jail and SUD. These findings are not surprising, given that individuals in jail and with SUD elicit negative judgments from others that tie into moral models of conduct (e.g., addiction viewed as a sin; see Klostermann & Kelley, 2012, for a discussion). Taken together, the overall pattern of findings indicates that HD is associated with negative public perception, more so than other conditions like OCD, and that this stigma may manifest in the public's view of how money should be allocated in policy decisions about service priorities.

Familiarity with HD moderated stigma ratings. Participants reporting familiarity with a friend or loved one with HD symptoms indicated that individuals with the condition are less different from the general population compared those reporting no familiarity, suggesting less

stigma. On the other hand, this HD familiarity also coincided with more *disdain* and *blame*, suggesting more stigma. The reason for this specific pattern among participants familiar with HD is unclear and requires further research. Whereas high ratings of *disdain* and *blame* coincide with standard interpretations of mental health stigma, the low *difference* subscale is anomalous. There are several possible explanations for this, all of them speculative and suggestive of future research. First, it may be the case that individuals with some familiarity with HD are more likely than participants unfamiliar with HD to recognize the familiality of the disorder, as reinforced by genetic findings for HD (Hirschtritt & Mathews, 2014) (e.g., "my mother has HD tendencies, and so does my sister"), and therefore believe that HD tendencies are not so uncommon (i.e., low *difference* scores). Second, and related to the first possibility, high levels of familiality may indicate more chances to experience HD behavior in the family, which may artificially inflate perceptions of the normalcy of HD tendencies (i.e., perceived base rate of HD is higher, meaning it is assessed as more common, and therefore HD is rated with lower *difference*). Third, HD appears to be dimensional and not taxonic in nature (Timpano et al., 2013), and perhaps participants familiar with HD are more aware of these natural individual differences in the general population, eliciting a belief that individuals with HD are not that different from those with HD tendencies in the general population (i.e., low *difference* scores). Regardless of the best interpretation, these results reinforce the idea that familiarity is an important moderator of stigma ratings (Angermeyer et al., 2004), but further research is needed to explore this interaction with public perception of HD. No such familiarity interactions were uncovered for OCD.

The reasons for public stigma for HD are not clear, but there are some possibilities, albeit preliminary in nature given the lack of empirical research. Recent reality television shows—often bearing a name with a negative connotation (e.g., *Buried Alive*)—have capitalized on

depicting severe HD symptoms in highly antagonistic and stressful situations. There are no shows, particularly with non-fictional characters like in OCD depictions, that largely portray common positive aspects of individuals with HD (e.g., creative, environmentally minded) or that emphasize strengths in their struggles. In addition, although non-profit organizations have devoted some resources to HD (e.g., IOCDF), the emphases for resource allocation and mission messaging are generally devoted more to OCD proper and less to OCD-related conditions, like HD. To our knowledge, there are no well-established foundations devoted exclusively to HD.

Similar to the mixed pattern of ratings of HD stigma, evidence for the hypothesis that OCD of stigma would be lower than for the comparison groups also yielded a variable picture. Based on the valence of the ratings, OCD was generally viewed in a neutral or positive way, suggesting that public stigma of OCD is not highly pronounced. The public rated OCD with significantly less *disdain* and *blame* compared to all other conditions, except that SMI was viewed with less responsibility than OCD. Indeed, comparisons between HD and OCD indicate that the former is viewed by the public with significantly more *difference, disdain*, and *blame* across all indicators of these dimensions. The evidence for low public stigma for OCD, however, was not entirely consistent. For *difference*, OCD was statistically comparable to ratings for people in Jail but viewed as more dissimilar than individuals with SUD. In addition, like HD, OCD programs from the RAM were earmarked with less hypothetical dollars compared to other causes. Thus, the mixed results for OCD suggest that, despite the relatively neutral or positive scores for OCD perceptions on most ratings, work is still needed to address some public stigma facets in OCD.

The reasons for these generally encouraging findings for OCD are not clear. One possibility includes the recent influx of fictional OCD characters in the media that have a largely

positive perception, especially to viewers without OCD or anxiety (Hoffner & Cohen, 2015; 2017; Siegel, 2015). Not mutually exclusive, another possibility is that non-profit organizations centered on OCD (e.g., IOCDF, Peace of Mind Foundation) have made progress in fighting negative public perception of the condition based on their mission statements, some of which to their credit explicitly mention fighting stigma (e.g., IOCDF, 2017). Organizations that endeavor to fight negative public perception of OCD might consider adapting strategies and increasing resources to address specific facets of stigma that still linger, without eliminating attention to facets that seem more neutral or positive given that public perception is not static over time.

As another explanation for the pattern of results, one recent theoretical account of public stigma may align well with the results of the current investigation. Haslam and Kvaale (2015) highlight the multifaceted nature of stigma and suggest that a perceived biogenic etiology—that is, whether or not the cause of a condition is perceived as biological (versus non-biological)—influences the degree to which the public views the condition as controllable and essentialist (i.e., a universal category and not a social construction). The degree of perceived controllability and essentialism of the condition seems to have a differential impact on the various stigma indices. For example, blaming the sufferer for his condition may decrease as biogenic explanations increase, but other prejudicial stereotypes tend to increase, such as *difference*. Applied to results of the current study, both HD and OCD demonstrated a pattern in which stigma ratings for *difference* and *disdain* were higher than ratings for *blame*. This pattern was also found in the SMI condition, but not with the Jail or SUD conditions, both of which are less likely to be associated with a biogenic explanation (e.g., public perception of SUD moving away from an *illness* explanation; NAS, 2016). Overall, this may indicate that public stigma of OCD and HD conforms to perceptions of a biogenic etiology, suggesting less blame by the public, but

possibly increased prejudicial beliefs coinciding with an essentialist and uncontrollability perspective. Future research on OCD and HD stigma would benefit from explicitly measuring perceptions of biogenic etiology to explore these ideas further.

Among those participants who scored in the clinically significant range of HD and OCD based on cutoff scores, we expected an inverse relationship between ratings of stigma (as a proxy for self-stigma) and treatment-seeking willingness. This expectation was supported for HD but not OCD. For those who reported clinically elevated levels of HD symptom severity, HD *disdain* was statistically significantly inversely rated to treatment-seeking willingness, and this is particularly noteworthy given the small sample size and therefore low statistical power. Nonetheless, a larger *N* would be helpful for ruling out sampling error in this modest sample size of individuals with elevated HD symptoms. *Blame* also exhibited an effect size in the same inverse direction with treatment-seeking willingness, although low statistical power may have precluded a significant point hypothesis test. Thus, this exploratory analysis with a diagnostically unconfirmed clinical subgroup suggests that HD stigma may obstruct willingness to seek treatment. In addition, those who surpassed the HD clinical cutoff viewed the condition negatively, based on their HD *difference* and *disdain* stigma ratings. These results complement the work of Mataix-Cols et al. (2013), who carried out the London field trial of HD, and found mixed evidence for self-stigma—59% reported no or low stigma from an HD label, whereas 41% indicated an HD label was *somewhat* or *very* stigmatizing. The current study suggests that this self-stigma of hoarding may be negatively associated with treatment-seeking willingness, although additional research with larger and clinically diagnosed HD samples is warranted before drawing firmer conclusions. Ultimately, however, this finding may shed some light on the

treatment ambivalence, dropout, and refusal so common in services provided to those with HD (Muroff et al., 2011).

Contrary to the findings with HD, there were no significant associations between OCD treatment-seeking willingness and stigma, and unlike with HD, analyses did not suffer from low statistical power. In addition, individuals who surpassed the clinical cutoff for OCD symptoms reported a neutral-to-positive perception of OCD across all stigma ratings. Ultimately, it is unclear why OCD stigma was unrelated to treatment-seeking willingness and viewed in a less negative way among those with elevated OCD symptoms, especially given previous research suggesting that stigma may be a treatment barrier for individuals with the condition (Belloch et al., 2009; Marques et al., 2010). Several years have passed since these studies reported findings, so it may be that public perception of OCD has shifted favorably in that time, perhaps due to efforts by OCD foundations and acceptable media portrayals of the condition. That is, more favorable public views of OCD and its treatment may reduce the process of label avoidance, which obstructs treatment-seeking behavior (Corrigan, 2004). Methodological differences may also explain the discrepancy. For example, unlike the current sample, Marques et al. (2010) targeted a clinical group, and all studies measuring OCD treatment and stigma measured these variables differently. It may be the case that individuals with a clinical diagnosis of OCD report different associations between stigma and treatment-seeking willingness compared to individuals who are not clinically diagnosed with OCD but nonetheless endorse a high rate of symptoms on the DOCS.

The results of this study provide a coherent picture of the stigma associated with OCD and HD, but there are some methodological limitations that warrant consideration and suggest a need for future research. Jail, SMI, and SUD served as useful comparison groups, but additional

groups (e.g., individuals with major depression) could be included in future research to further contextualize the level and type of stigma associated with OCD and HD. Online research studies on MTurk may reflect the public opinion of a specific population (e.g., technologically savvy, white), a study limitation that needs addressing in future research, as that *public opinion* on HD and OCD may not be fully represented by MTurk users. Indeed, compared to the US population, MTurk users tend to be younger, more educated, and less ethnically diverse (Miller, Crowe, Weiss, Maples-Keller, & Lynam, 2017). They also tend to have elevated levels of neuroticism, as well as depressive and anxious symptoms comparable to community and clinical samples (Miller et al., 2017), possibly explaining the high rates of self-reported OCD symptoms in this sample relative to epidemiologic baserates. Ultimately, replicating the findings using a non-Internet sampling procedure and one with more ethnic diversity may reinforce the generalizability of the current study and support the construct of *public opinion* of HD and OCD. However, given that MTurk users "are not necessarily paragons of mental health," (Miller et al., 2017, p. 28), the subgroup in this study that endorsed clinically elevated levels of symptoms may provide some rich but preliminary insights into how these clinical populations perceive their own OCD and HD. Nonetheless, the sample size for those with clinically elevated levels of HD undermined tests of statistical significance because of low power, and because these subsamples were drawn from a sample of the general public based on clinical cutoffs, and not based on formal diagnosis, future research with larger samples of clinically diagnosed HD and OCD participants would be an important next step. Indeed, the inclusion of formal diagnoses would also help mitigate another possible limitation, namely that the estimate of self-stigma may have been confounded by the participant's level of insight. Those with HD and OCD with minimal insight may have endorsed low levels of HD and OCD severity, excluding them from the self-

stigma calculations. However, because individuals with low insight do not believe they have HD or OCD, they cannot internalize the prejudicial stereotypes reflected in the stigma items, and hence, ratings of OCD and HD stigma would not be considered self-stigma. Nonetheless, inclusion of more objective measures of self-stigma, along with formal diagnoses, could facilitate the inclusion of participants with low insight in future research.

As another study limitation, measurement of the different facets of stigma were based on newly developed stigma items that are not yet well validated. It is important to note, however, that findings from the current study generally conformed to expectations of HD and OCD stigma, patterns of group differences between stigmatized groups were consistent with extant research and theory, and the study identified preliminary support for some psychometric properties (e.g., . convergence between *difference* and *disdain*, mostly adequate internal reliability). Though, some of the Cronbach alphas for *disdain* were low, suggesting that future research may benefit from use of different stigma measures and further evaluation of the current set of items.

An important caveat, some of the results reveal small point differences or effect sizes. With the *difference* ratings, although statistically significant pairwise comparisons indicated large effect sizes (e.g., OCD v. SMI), the average condition scores were less than one point apart on the 9-point scale, suggesting that the clinical significance of findings on *difference* should be interpreted with caution. It is important to note, however, that many of these average condition ratings fell within different anchor ranges. For example, the average OCD rating for *difference* was in the higher 4's (reflecting a positive valence), whereas the average for SMI was in the higher 5's (reflecting a more negative valence), with 5.0 serving as the neutral anchor on the scale. This provides rich information about the valence of ratings, even if the scores reflected

only a one-point swing between conditions. Similarly, with respect to the RAM findings, the low funding priority for HD and OCD exhibited a relatively small effect, and this sample does not necessarily generalize to policymakers who make decisions about fund allocation, even if those policymakers are beholden to their respective public constituents. Future research would benefit from looking at funding allocation among policymakers.

Results from the current study have several implications. Organizations that have targeted OCD stigma—perhaps with some noteworthy success thus far—could replicate this type of work with HD. This should not necessarily preclude such organizations from continuing to address the public view of OCD, as some indices of stigma still coincide with a negative view of OCD, and public opinion shifts over time. Directly addressing public stigma using evidence-based approaches is not a fruitless endeavor, as a recent meta-analysis of such programs yielded an effect size of $\eta^2 = .45$ (Corrigan et al., 2012). Fighting public stigma may additionally have an indirect positive influence on treatment-seeking willingness, given that treatment avoidance is a reaction to internalizing public stigma—i.e., self-stigma (Corrigan, 2004). Indeed, it may be important for clinicians and those at the frontlines of triaging mental health services to learn some strategies for helping ambivalent patients obviate this barrier. In addition, interventions for HD often require a multidisciplinary approach (e.g., involving mental health clinicians, law enforcement and fire personnel, housing authorities, animal control, and family members), self-stigma-reducing strategies could be helpful for a range of professional disciplines. Such strategies could include direct stigma intervention to the individuals with HD. Indeed, one such group-based program is called Honest, Open, Proud (HOP), which is based on research indicating that keeping one's disorder a secret can be harmful and that disclosing can reduce self-stigma (Rüsch et al., 2014). The HOP protocol was designed to (1) facilitate the decision of

whether to disclosure (but disclosure is not pushed or required), (2) enhance empowerment, and (3) reduce self-stigma (for a succinct overview of this evidence-based program, see Corrigan, Kosyluk, & Rüsch, 2013). HOP has shown tremendous promise in reducing self-stigma based on two randomized controlled trials (Corrigan et al., 2015; Rüsch et al., 2014).

Conclusions

This study represent the first large-scale investigation of public perception of HD and OCD using a theoretically based conceptualization of stigma. The findings highlight the public stigma associated with HD, which is notably higher than for OCD, and suggest that internalized public stigma (i.e., self-stigma) may serve as a barrier to treatment seeking for HD, shedding some light on the treatment ambivalence, dropout, or refusal so common in services provided to those with the condition. The current study suggests that we should consider adapting evidence-based public stigma and self-stigma (e.g., HOP) interventions to fight any negative perception of HD, as well as lingering stigma indices of OCD.

Appendix

Condition Wording

- By severe mental illness, we mean people who show symptoms of severe depression, anxiety, hallucinations, delusions, or paranoia.
- By substance use disorder, we mean people who are addicted to alcohol or other drugs.

- By jail, we mean people who have been incarcerated for less than two years, generally for a lesser crime.
- By obsessive-compulsive disorder, we mean people who are bothered by thoughts that do not make sense and keep coming back even when they try not to have them (e.g., thoughts about dirt and germs, harm coming to others), and by behaviors they need to complete over and over again (e.g., washing/cleaning, checking over and over).
- By hoarding disorder, we mean people have so much stuff and clutter in their home that they can't use rooms as intended (e.g., using the kitchen to cook, bedroom to sleep).

RAM Item Stem

The budget in your state for all human services is 100 million dollars. In this exercise, we want you to act as a legislator who must decide how to divide the 100 million dollars among the ten human service programs listed below. You can decide to give as little as nothing or as high as the entire 100 million to any individual human service. All money must be assigned, however; the total should add up to 100 million dollars. Write zero in any space to which you decide to give NO money. Assign monies to each Human Service Program in million dollar increments (for example, if you want 2 million, 27 million, 78 million just write 2, 27,78) and not fractions thereof (for example 1,500,000 or 25,300,000).

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Table 1: Participant demographics

Gender	%	Employment Status	%
Man	49.70	Full-Time	66.89
Woman	50.00	Part-Time	10.64
Prefer not to answer	0.30	Unemployed	7.09
Sexual Orientation		Other	15.22
Heterosexual/straight	88.85	Mechanical Turk worker	0.17
Bisexual	6.42	Ethnicity	
Gay	2.36	Caucasian or White	86.49
Lesbian	1.52	Hispanic/Latino	7.61
Other	0.84	Black or African American	6.42
Education Level		Asian	6.08
Some High School	0.68	Other	3.04
High School Diploma	23.48	Household income?	
Vocational or Technical Training	8.28	$0 - $25,000	21.79
Associate's Degree	18.07	$25,001 - $49,999	31.25
Bachelor's Degree	33.61	$50,000 - $74,999	21.11
Some Graduate School	3.38	$75,000 - $99,999	14.02
Graduate Degree	12.00	$100,000 - $124,999	5.74
Some college	0.51	$125,000 - $149,999	3.38
Religion		Greater than $150,000	2.70
Christian	20.61	Marital status?	
Catholic	13.68	Single	36.15
Protestant	9.29	Married	39.19
Jewish	2.03	In a long term relationship	15.88
Other	5.90	Other	8.78

Table 2. Correlations among stigma facets within clinical condition and Cronbach alphas

		M (*SD*)	1	2	3
SMI	1. Difference	5.73 (1.79)	**.84**		
	2. Disdain	5.97 (1.26)	.49**	**.60**	
	3. Blame	2.47 (1.64)	-.13**	-.10*	-
SUD	1. Difference	4.63 (1.77)	**.86**		
	2. Disdain	6.36 (1.30)	.43**	**.66**	
	3. Blame	5.59 (2.38)	-.01	.15**	-
OCD	1. Difference	4.82 (1.60)	**.78**		
	2. Disdain	4.86 (1.26)	.40**	**.71**	
	3. Blame	3.31 (2.21)	.02	-.03	-
	4. OCD Treatment Seeking Willingness	2.92 (1.03)	.21	-.09	-.15
JAIL	1. Difference	4.86 (1.87)	**.86**		
	2. Disdain	6.65 (1.37)	.48**	**.76**	
	3. Blame	6.86 (2.12)	.04	-.22**	-
HD	1. Difference	5.50 (1.79)	**.83**		
	2. Disdain	5.92 (1.37)	.49**	**.67**	
	3. Blame	4.64 (2.29)	.07	.10*	-
	4. HD Treatment Seeking Willingness	2.87 (1.12)	.02	-.48**	-.27

Note. For all stigma facets, higher scores reflect negative public perception. HD = Hoarding Disorder; OCD = Obsessive-Compulsive Disorder; SMI = Serious Mental Illness; SUD = Substance Use Disorders; JAIL = individuals who have been to jail. Cronbach alphas are bolded and provided in the diagonal.

**$p < .01$; *$p < .05$; $N = 591$, except for the Treatment Willingness correlations ($N = 24$ for HD and $N = 78$ for OCD).

Table 3. Posthoc pairwise comparisons within each stigma domain separated by HD and OCD.

		HD Comparisons		OCD Comparisons	
Stigma Facet		*t*	*d*	*t*	*d*
Difference					
	SMI	-2.97**	0.24	-11.75**	0.97
	SUD	11.10**	0.91	2.33*	0.19
	OCD	9.44**	0.78	-0.44	0.04
	JAIL	7.33**	0.60	-9.44**	0.78
Disdain					
	SMI	-0.93	0.08	-20.86**	1.72
	SUD	-7.43**	0.61	-23.57**	1.94
	OCD	19.16**	1.58	-26.92**	2.22
	JAIL	-11.51**	0.95	-19.16**	1.58
Responsibility					
	SMI	17.69**	1.46	-10.34**	0.85
	SUD	7.71**	0.64	16.95**	1.40
	OCD	-9.26**	0.76	-1.61**	0.13
	JAIL	16.74**	1.38	26.00**	2.14

Note. HD = Hoarding Disorder; OCD = Obsessive-Compulsive Disorder; SMI = Serious Mental Illness; SUD = Substance Use Disorders; JAIL = individuals who have been to jail; *d* = absolute value of Cohen's *d.*

**$p < .01$; *$p < .030$ [False Discover Rate corrected critical *p*-value]; $N = 591$.

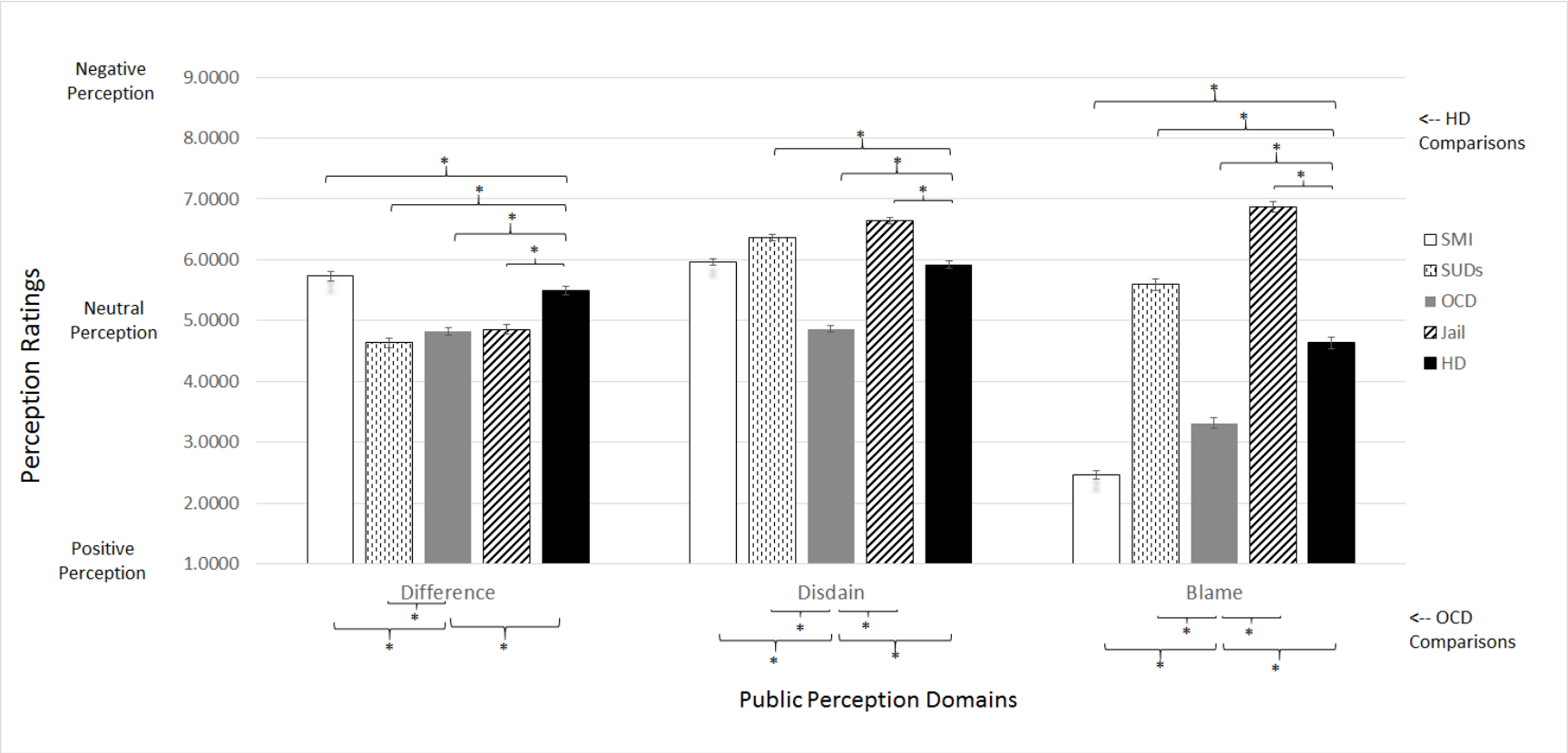

Figure 1. Means and standard errors for ratings on the stigma facets for each clinical condition and pairwise comparisons (HD compared to all other conditions above the bars and OCD compared to all other conditions below the bars). SMI = Serious Mental Illness. SUDs = Substance Use Disorders. Jail = individuals who have been to jail. OCD = Obsessive-Compulsive Disorder. HD = Hoarding Disorder. *$p < .030$ [False Discover Rate corrected critical p-value]. $N = 591$.

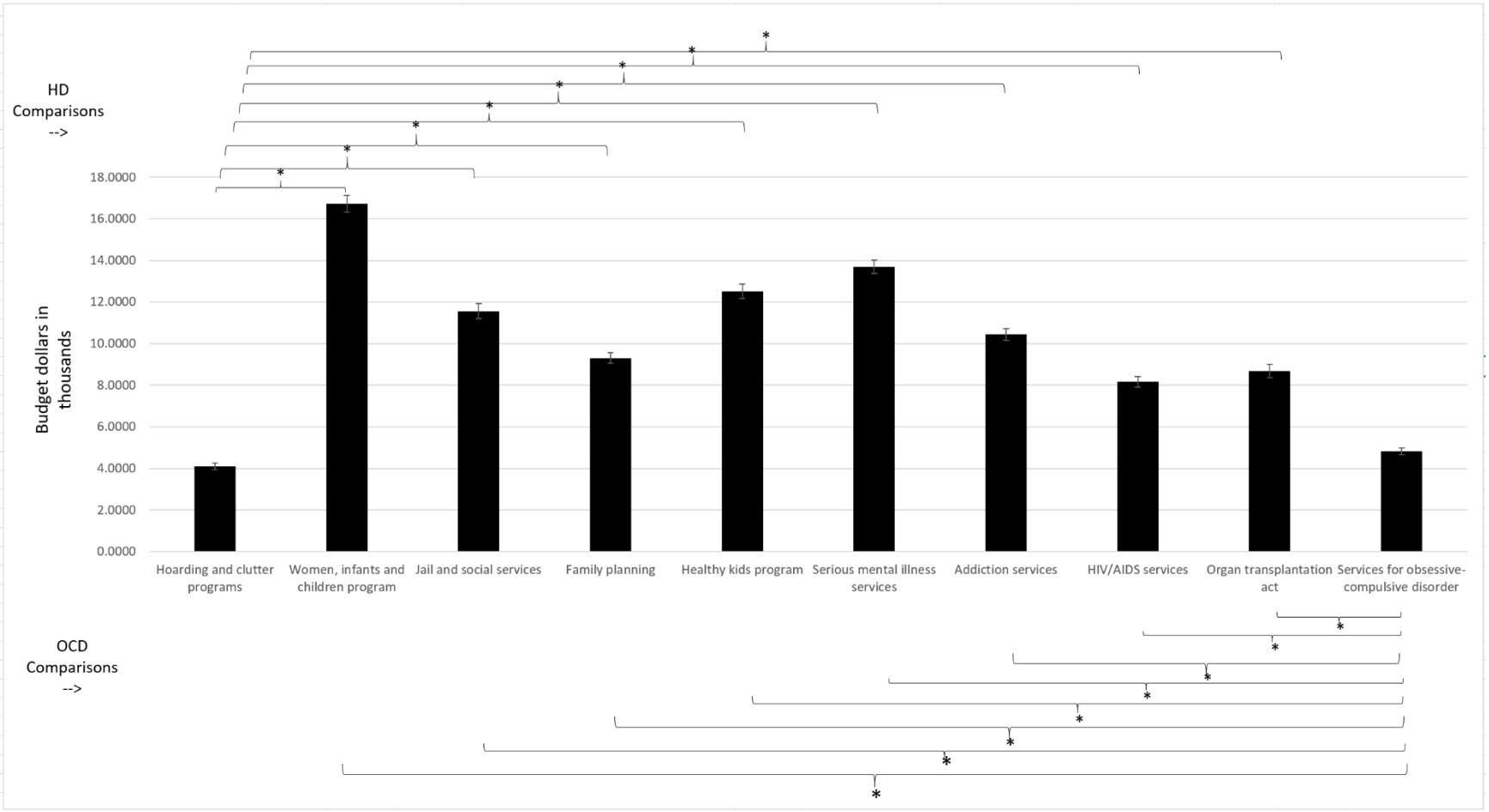

Figure 2. Means and standard errors for ratings on the Resource Allocation Measure and pairwise comparisons (HD services compared to all other services above the bars and OCD services compared to all other services below the bars). OCD = Obsessive-Compulsive Disorder. HD = Hoarding Disorder. *$p < .030$ [False Discover Rate corrected critical p-value]. $N = 591$.