



Negotiating intersex: A case for revising the theory of social diagnosis



Tania M. Jenkins^{a,*}, Susan E. Short^b

^a Department of Sociology, University of Chicago, 1126 East 59th Street, Chicago, IL 60637, USA

^b Department of Sociology, Brown University, Box 1916, Maxcy Hall, 112 George Street, Providence, RI 02912, USA

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ABSTRACT

The theory of social diagnosis recognizes two principles: 1) extra-medical social structures frame diagnosis; and 2) myriad social actors, in addition to clinicians, contribute to diagnostic labels and processes. The relationship between social diagnosis and (de)medicalization remains undertheorized, however, because social diagnosis does not account for how social actors can also resist the pathologization of symptoms and conditions—sometimes at the same time as they clamor for medical recognition—thereby shaping societal definitions of disease in different, but no less important, ways. In this article, we expand the social diagnosis framework by adding a third principle, specifically that 3) social actors engage with social structures to both contribute to, and resist, the framing of a condition as pathological (i.e. medicalization and demedicalization). This revised social diagnosis framework allows for the systematic investigation of multi-directional, dynamic processes, formalizing the link between diagnosis and (de)medicalization. It also responds to long-standing calls for more contextualized research in (de)medicalization studies by offering a framework that explicitly accounts for the social contexts in which (de)medicalizing processes operate. To showcase the utility of this revised framework, we use it to guide our analyses of a highly negotiated diagnosis: intersex.

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The past decade has seen a surge of sociological attention dedicated to diagnosis. Mildred Blaxter originally called for a “sociology of diagnosis” as early as 1978, and Phil Brown reiterated that call again in 1990, but it was not until around 2009 that sociologists began delineating the contours of this new subfield. Since then, there has been an explosion of scholarly works and meetings dedicated to diagnosis both as a label and a social process inherent to the practice of medicine and the classification of diseases (see for example Davis, 2015; Jutel, 2009, 2011, 2015; Jutel and Dew, 2014; McGann et al., 2011).

In the context of growing sociological interest in diagnosis, Brown et al. (2011) proposed their theory of social diagnosis to account for the relationship between larger social structural factors, and individual or community health. Social diagnosis, they argued, is social because (1) it diagnoses the social, political, economic and cultural structures that frame and contribute to disease and illness; and (2) it is conducted by various social actors (‘social diagnosticians’), including, but not limited to, clinicians, social scientists and lay people (Brown et al., 2011). For example, a social

diagnosis of the recent lead poisoning crisis in Flint, Michigan might involve an appraisal of the political, economic and infrastructural factors that led to the crisis, as well as a careful examination of the various social actors (such as politicians, lay people and scientists) who contributed both to the poisoning itself and to raising awareness. In this way, social diagnosis serves as a framework for identifying the social determinants of health which, in addition to individual pathologies, lead to disease.

The relationship between social diagnosis and (de)medicalization, however, remains undertheorized, even though medicalization and demedicalization are central to diagnosis (Jutel, 2009; Jutel et al., 2014). Medicalization is the process by which a condition becomes recognized and treated as a medical problem, whereas demedicalization is the process by which a problem loses its medical definitions and solutions (Conrad, 1992). Scholars increasingly recognize that processes of medicalization and demedicalization can occur simultaneously (making it difficult to entirely separate one process from the other) and that conditions can thus be characterized as more or less medicalized as social actors and forces change (Ballard and Elston, 2005; Bell, 2016; Conrad, 2013; Halfmann, 2012; Sulzer, 2015). Yet, while social diagnosis emphasizes how social actors “contribut[e] to the creation of ... diagnosis,” (p. 941) and “collectively work to politicize ...

* Corresponding author.

E-mail addresses: tmjenkins@uchicago.edu (T.M. Jenkins), susan_short@brown.edu (S.E. Short).

illness through social movements,” (p. 940) thereby working towards medicalization, it does not account for the myriad ways social actors also work towards demedicalization by *resisting* the pathologization of symptoms and conditions—sometimes at the same time as they clamor for medical recognition. In other words, it overlooks the *multi-directionality* of social processes that can shape diagnosis. For its part, the medicalization literature has called for more research on the social contexts in which (de)medicalization takes place (Ballard and Elston, 2005; Bell, 2016; Clarke et al., 2003; Conrad, 2013)—a central feature of the social diagnosis framework. Social diagnosis can therefore contribute to, and benefit from, studies of medicalization by shedding light on the social context in which social actors and structures can not only *contribute to* diagnoses but also *push against them*, thereby shaping the contours of diagnosis in different but no less important ways.

In this article, we revise the social diagnosis framework and forge a relationship between social diagnosis and (de)medicalization. In its original formulation, social diagnosis recognized two principles: 1) extra-medical social structures frame diagnosis; and 2) myriad social actors, in addition to clinicians, shape diagnostic labels and processes. In this revision, we add a third principle: 3) social actors engage with social structures to contribute to *and resist*, sometimes simultaneously, the framing of a condition as pathological (i.e. medicalization and demedicalization). Thus, a social diagnosis of Flint, Michigan using the revised framework would not only examine the political, economic and social factors and actors that contributed to the public health crisis, it would also be sensitive to the social forces and structures that *resisted* recognizing the situation as a crisis, including government officials and the laws protecting them (Phillips, 2016). Through this revision, we make explicit diagnostic resistance as a component of social diagnosis. Further, we situate (de)medicalizing processes in a framework that emphasizes social determinants of health and health behaviors, and the interplay between social actors and social institutions, structures, and ideologies (Braveman et al., 2011; Short and Mollborn, 2015), thus forging a connection between medical sociological subfields which promotes the examination of (de) medicalization in context.

To illustrate the revised framework, we conduct a social diagnosis of intersex, a site which renders visible the complex ways in which social actors shape and contest the pathologization of a condition. Intersex broadly refers to a variety of conditions that can present at birth or later in life whereby an individual's chromosomes, hormones, or sexual organs differ from the 'norm' in a way that does not correspond to "typical definitions of male and female" (ISNA, 2008b). These individuals are usually given an umbrella diagnosis of "disorders of sex development," or DSD, which is then further classified into one of over 20 DSDs to guide management and prognosis (Consortium, 2006). Social actors disagree, however, about whether sexual variation of this kind should be pathologized, despite considerable agreement (even among some doctors) that the construction of intersex as a diagnosis reflects a quandary of social categorization (Davis, 2015). Intersex is therefore a prime example of the kind of push-and-pull that makes medicalization more a question of scale than of discrete categories—a diagnosis in which structure is responsive to process—making it an appropriate case to illustrate the advantage of a revised theory of social diagnosis.

A brief note about terminology: throughout the paper we use the term 'intersex.' We acknowledge the appearance of consensus among medical professionals to use different terminology, namely "Disorders of Sex Development" (Alm, 2010), but we reflexively choose not to use the medical language of "disorders." We recognize that not all scholars prefer the term intersex and that some intersex individuals do not prefer the term DSD (Davis and Murphy,

2013; Dreger and Herndon, 2009). We use the term intersex consciously, acknowledging its limitations (Holmes, 2009) and understanding that what 'counts' as intersex is also contested (Dreger and Herndon, 2009)—and socially constructed (ISNA, 2008b).

1. Medicalization and diagnostic resistance

1.1. Multidirectional processes of medicalization and demedicalization

Recent debates in medicalization studies emphasize the inherent complexity, dynamism and multi-directionality of medicalization as a *process* or "continuous value," rather than a binary either/or state (Clarke and Shim, 2011; Conrad, 2013, p. 197; Halfmann, 2012, p. 186). Demedicalization is an inherent and simultaneous part of this process, with medicalized categories contracting and expanding, resulting in *degrees* of medicalization (Conrad, 1992, 2013; Halfmann, 2012). As biomedicine has advanced, scholars have adapted their studies of medicalization to include biomedicalization, a term that describes transformations in medical phenomena and the remaking of new identities using technoscientific medicine. This perspective also recognizes "the increasingly complex, multisited, multidirectional processes of medicalization," (Clarke et al., 2003, p. 162) by examining our growing reliance on technoscientific means to *transform*, rather than merely control, medical phenomena (Clarke and Shim, 2011, p. 173).

Medicalization may be multi-directional, but only a small portion of studies examine the aspect of social *deconstruction* of disease (Crossley, 2004), partly because counter-efforts to medicalization rarely amount to "organized social resistance" (Conrad, 2013, p. 208) in the way that medicalization efforts sometimes do (see Barker, 2002). Contesting medicalization refers to "challenging the aspects of the creation and application of medical diagnostic categories and treatments," (Conrad and Stults, 2008, p. 324) and can include resistance towards being labeled as sick (Cheung and Delfabbro, 2016), reluctance to using medical therapies (Malacrida, 2004), and debates over whether a condition should be considered problematic (Grinker and Cho, 2013). Medical professionals can also resist diagnoses, as with the British Psychological Society's critiques of the DSM-5, which, in their view, pathologizes "natural and normal responses" to experiences "which do not reflect illnesses so much as normal individual variation" (British Psychological Society, 2011, p. 2). Diagnostic resistance is thus a significant, if less exposed, social force that can occur alongside the well-known engines of medicalization like biotechnology and consumerism (Conrad, 2005).

1.2. Decontextualized: bringing structure back in

As with most studies of medicalization, however (Ballard and Elston, 2005; Bell, 2016; Clarke et al., 2003; Conrad, 2013), resistance remains decontextualized. Few studies systematically analyze the ways in which social structures contribute to or support these social processes (Crossley, 2004). Conrad (2013) and Bell (2016), for example, have respectively lamented the absence of research on the political economy of (de)medicalization, and the paucity of scholarship on disparities therein. Yet social structures are important sources of *inertia*—or resistance to social change—that lend stability to social practices and can perpetuate inequalities. Insurance companies, for example, can provide "inadvertent" resistance to medicalization by refusing to pay for certain conditions, such as fertility treatments (Bell, 2016; Conrad, 2013). Federal funding structures can also impact a condition's

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