



# Visibility, respectability, and disengagement: The everyday resistance of mothers with disabilities



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## ABSTRACT

This article presents findings from 42 interviews with mothers who have physical and/or sensory disabilities in the USA and Canada. While much of the stigma literature emphasizes disempowering forms of coping, findings demonstrate these mothers frequently employ strategies of everyday resistance to challenge stigma, including visibility politics, respectability politics, and disengagement. The author explores how these mothers employ varying combinations of resistance strategies, depending upon the social context and intersecting aspects of their identities. Finally, the author illuminates how stigma demands hidden labor from these mothers, no matter the resistance strategies they choose.

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## 1. Introduction

Mothers with disabilities face unique forms of stigma, generated by intersecting cultural beliefs about disability, gender, and motherhood. While nondisabled women often confront a moral imperative to become mothers (Kohler Riessman, 2000), women with disabilities face an imperative of childlessness. Culturally defined as incompetent and dependent themselves, disabled women are viewed as inappropriate and even dangerous in the role of caregiver. What's more, the methods these mothers employ to care for their children are often viewed as deficient, particularly when held up against the measuring stick of intensive mothering (Hays, 1996). Finally, these mothers are perceived to stand in the way of a culturally imagined "progressive future" without disability, as women with genetic disorders threaten to pass their disabilities to their children.

Consequently, disabled women are likely to experience heightened surveillance by social service and medical professionals (Frederick, 2015; Malacrida, 2009; Prelliltensky, 2003; Thomas, 1997), and they are more likely to have their parental rights terminated than non-disabled mothers (Lightfoot et al., 2010;

Rivera Drew 2009). These mothers must also contend with prejudice and discrimination from medical and social service professionals, members of the public, and at times from their own families (Frederick, 2015; Malacrida, 2009; Prelliltensky, 2003; Thomas, 1997). Women with disabilities experience this profound marginalization, even as research suggests disabled parents are no more likely to maltreat their children than non-disabled parents (Preston, 2012). Yet, despite profound cultural pressure to abstain from motherhood, women with disabilities are found to devote as much time to caregiving as nondisabled women (Shandra and Penner, 2016). How do women with disabilities resist stigma as they mother? And what personal costs do they endure as they confront and manage negative cultural values about their role as mother? I explore these research questions through 42 interviews with American and Canadian mothers who have sensory and/or physical disabilities.

### 1.1. Stigma: from shame to everyday resistance

Stigma is the dominant concept social scientists employ to account for the prejudice and discrimination leveled against people with disabilities. Stigma research has documented the many ways cultural devaluation of disabled people manifests, including prejudicial treatment by individuals, discriminatory institutional

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practices, and internalized shame, or what is termed self-stigma (Link and Phelan, 2001; Major and O'Brien, 2005; Pescosolido and Martin, 2015). Most social science research on disability oppression is located in the broader literature on stigma, and this field has cultivated a language all its own with little cross-fertilization with research on other forms of inequality (Phelan et al., 2008).

While agency and resistance are prominent themes in research on other oppressed groups, the stigma literature has tended to portray disabled people through a “tragic lives” paradigm (Oliver, 1990; Scambler, 2009), which leaves little room for explorations of more empowering forms of agency (Shih, 2004; Thoits, 2011). This pattern dates back to Erving Goffman's seminal formulation of stigma, which failed to account for the possibility that some stigmatized individuals reject the cultural devaluation of their identities (Kohler Riessman, 2000). Stigma research continues to be preoccupied with measuring levels of self-stigma, causing some to reject stigma as a victim word (Pescosolido and Martin, 2015; Shih, 2004; Thoits, 2011). These patterns in the literature persist, despite evidence that those with visible stigmas do not suffer from diminished self-esteem, and despite unresolved contradictions in research examining self-esteem among those with mental illnesses (Major and O'Brien, 2005; Thoits, 2011).

A few scholars are examining forms of stigma resistance, that is, how marginalized individuals challenge stigma. Researchers in this new but growing area are paying increased attention to those groups of stigmatized individuals who resist dominant cultural values about their groups (Shih, 2004; Sibitz et al., 2011; Thoits, 2011). Scholars have explored more empowering forms of internal identity work, including “resistant thinking” and “reframing” (Kohler Riessman, 2000; O'Donnell et al., 2011), “deflecting” (Shih, 2004; Thoits, 2011), and positive group identification (Buseh and Stevens, 2007). These scholars have also explored resistant interactional strategies, including “coming out” (O'Donnell et al., 2011; Poindexter and Shippy, 2010; Saguy and Ward, 2011), “speaking up” (Buseh and Stevens, 2007; Kohler Riessman, 2000); and creating safe spaces (Buseh and Stevens, 2007; O'Donnell et al., 2011). Some have challenged fundamental tenets of stigma, arguing classic stigma-management strategies like passing and avoidance, largely pathologized in the literature, can be important forms of stigma resistance. For example, Kalei Karuha (1999) finds that the queer people of color she interviewed employed passing in various situations, not due to shame, but to protect themselves from harm and to preserve their time and energy. Other studies find that strategies of “strategic avoidance” (Kohler Riessman, 2000) and “calculated concealment” (Simi and Futrell, 2009), performed in moments when the threat of harm is high, can actually strengthen people's oppositional identities (Einwohner, 2006). This article seeks to build on the small but growing interest in forms of stigma resistance.

With regard to disability, research on stigma has largely rendered invisible the rich histories of disability groups who have organized to resist social oppression. Goffman's (1963) portrayal of disabled people rendered invisible pockets of disability organizing within the American context, present even during the time he was writing. These include the work of the League of the Physically Handicapped during the Great Depression (Longmore and Goldberger, 2000) and the legacies of alternative cultural identities and political organizing in blind and Deaf communities dating back to the 1800's (Barnartt and Scotch, 2001; Burch, 2002; Matson, 1990). Similarly, stigma research has left under-explored the oppositional identities cultivated through the Disability Rights Movement and Deaf and other disability-specific organizing since the 1970's (Barnartt and Scotch, 2001; Scotch, 2009), and the Disability Justice Movement more recently.

While disability communities have long traditions of collective

action, this article focuses on a particular form of opposition termed everyday resistance. First outlined by Scott (1985), Everyday resistance involves individual acts—verbal, cognitive, or physical—that undermine power (Hollander and Einwohner, 2004). In contrast to organized, clearly visible forms of protest, everyday resistance is imbedded in the routines of daily life and is largely hidden or disguised from the view of those in power (Johansson and Vinthagen, 2016; Scott, 1985). In contrast to stigma research, which has focused on the internal state of stigmatized people, scholars define everyday resistance in terms of the action rather than the actor's political consciousness or state of being (Johansson and Vinthagen, 2016).

Some argue everyday resistance is an important concept for understanding how social movements function in postmodern societies. Indeed, the actions of individuals in their daily context now account for much of social movement work (Buechler, 2000). Social movements have become more diffuse, political identities are cultivated through online communities, and identities have risen to the forefront of social change. Everyday resistance might also be an important concept in explorations of stigmatized groups, given that many do not experience regular contact with others who share their marginalized identities.

A few scholars have taken up everyday resistance within the stigma subfield, though largely with respect to nondisabled groups (Kohler Riessman, 2000; Simi and Futrell, 2009). Yet this concept has not disrupted the field's preoccupation with questions of internalized stigma. Disabled people's everyday resistance has been identified elsewhere however, particularly in fields with stronger traditions of exploring agency and resistance. Boster (2013) examines the ways disabled African Americans used their disabled bodies to resist at the intersection of slavery and disability oppression. Rios (2011) explores the ways Black and Latino youth in Oakland, California, subvert the meanings of devalued disability labels. Embodying exaggerated performances such as “going hyphy,” “getting retarded,” and “going dumb,” these youth transform ADHD and intellectual disability, the highly racialized disability labels with which they are disproportionately categorized in schools, into symbols of empowerment and resistance. Finally, Cassiman (2011) explores the everyday resistance strategies of poor mothers with disabilities, finding they often practice avoidance to protect themselves from state surveillance.

In addition to exploring resistance, I also pay particular attention to the physical and emotional work disabled mothers expend, even as they resist stigma. Scully (2010) argues disabled people routinely perform “hidden labor” to manage the discomfort of others. In one respect this labor involves the exercise of agency, as disabled people develop strategies to successfully manage interactions to challenge stereotypes and gain the accommodations and acceptance they desire. Scully argues, however, that these interactional management strategies are situated in contexts of asymmetrical power. In most interactional contexts the nondisabled majority has the power to define values of normalcy and to determine the rules of engagement. For this reason disabled people bear the majority of the burden for insuring the interaction goes smoothly, including performing what Cahill and Egelston (1994) call emotion work. Types of emotion work include expressing gratitude for access and assistance, controlling the information shared about their disabilities, and performing in ways that challenge negative stereotypes about disability (Cahill and Egelston, 1994; Scully, 2010). Hidden labor also involves particular forms of physical and cognitive work, as disabled people push themselves to physical limits, expend cognitive energy planning and problem-solving, and shoulder discomforts as they seek to present themselves in ways that are acceptable to the nondisabled majority. Consistent with the concept of everyday resistance, hidden labor

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