

## Introduction

# Living With the Label “Disability”: Personal Narrative as a Resource for Responsive and Informed Practice in Biomedicine and Bioethics

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**Abstract.** *What is it like to live with the label “Disability?”* NIB editorial staff and narrative symposium editors, Jeffery Bishop and Naomi Sunderland developed a call for stories, which was sent to several list serves, shared with the 1000 Voices Project community and posted on *Narrative Inquiry in Bioethics*’ website. The request for personal stories from people who identify with the label “disabled” asked them to: consider how the label “disability” interacts with other aspects of their life in health care settings; does the term “disability” reflect their actual embodied experiences of impairment or does it fail to do justice to their particular experience of impairment; describe the kind of experiences that are possible because of the impairment(s); discuss how the label has affected their “authentic voice”; and many other concepts about what effects the label has on their lives. These authors share deeply personal experiences that will help readers understand their world, challenges, and joys. Thirteen stories are found in the print version of the journal and an additional five supplemental stories are published online only through Project MUSE. The stories are complemented by four commentary articles by Elizabeth R. Schiltz; Lorna Hallahan; Nicole Matthews, Kathleen Ellem, and Lesley Chenoweth; and Jeffery Bishop, Rachelle Barina, and Devan Stahl. These scholars come from the disciplines of law, social work, media studies, medicine, and bioethics from Australia and the United States. Together, the symposium’s storytellers and commentators offer striking and informative insights into the everydayness of living with disabilities.

**Key Words.** Acceptance, Accommodate, Affliction, Ambivalence, Autonomy, Bioethics, Disability, Disability Culture, Ethics, Identity, Marginalization, Narrative, Negative Emotions, Stigmatize, Valued Difference

This narrative symposium presents 13 people’s stories in the print version (another five supplemental stories are available in the online version) of living with the label of disability. The stories are complemented by four commentaries by scholars across the disciplines of law, social work, media studies, medicine, and bioethics from Australia and the United States. Together,

the symposium’s storytellers and commentators offer striking and informative insights into the everydayness of living with disabilities—insights that may confront the abstractions of both modern biomedicine and bioethics.

Mainstream biomedicine—i.e., medicine that uses knowledge of biological and physical systems as a basis for clinical practice—has for a long time

understood disability to be a “problem” anchored in the bodies of people with impairments. As such biomedical practitioners, researchers, and governments have invested much in seeking to alleviate, fix, or eliminate the causes and sources of disabled bodies. While this approach to disabled or “impaired” bodies has had differing outcomes for many individuals and families, it has also focused our collective attention on disability as being primarily a physical “affliction.” This biomedical approach to disability has also contributed to negative social stereotypes surrounding people’s personal capacities and lives that can have little to do with the daily realities of living with a disability.

In biomedical contexts, the practice of “bioethics”—i.e., the practice of exploring the moral and ethical aspects of medical research and interventions—has often been concerned with mediating between what *can* be done medically and scientifically with what *should* be done according to other—sometimes contending—values, perspectives, and concerns. Bioethicists for example have argued successfully that medical and related practitioners must obtain “informed consent” before manipulating bodies and strive to uphold patients’ autonomy, dignity, and privacy. Bioethicists have also, on occasion, actively supported attempts to prevent differently embodied persons from coming into being at all through genetic screening and abortion (see for example Savulescu, 2001; 2002; 2007). As this symposium’s commentators Matthews, Ellem, and Chenoweth point out though, the issues that many bioethicists have focused on rate little to no attention from people with disabilities themselves when they are discussing the key issues that affect their interactions with health and medical practitioners and their broader lives. Hence, while valuable ground has been made toward alternative approaches to bioethics by feminist and narrative ethicists such as Margaret Urban-Walker (2007) and Jayne Clapton (2009), many prominent bioethicists still appear to have misunderstood or ignored the lived and embodied realities of disability (Scully 2008).

In response to this disconnect, this *Narrative Inquiry in Bioethics* symposium explores what it is like for people to live with, alongside, and at times in opposition to the label “disability.” We have focused

on the disability label in the symposium as a shared social phenomenon that is familiar both to people who identify as having a disability and people who do not. While both groups simultaneously experience shades of both ability and disability on a daily basis (i.e., we are all abled and disabled in some way), only one experiences the social, political, and moral phenomenon of being self or otherwise *labeled* as a person with a disability. The other group, while perhaps not privy to the inner lived experience of being labeled as a person with a disability, may learn much by *listening to* and reimagining his or her own life and practices through the stories of the other. The narratives included in the symposium hence depict the everydayness of impairment in health and medical related settings and, as such, offer critical resources for reframing how we might respond to disability.

The symposium editors distributed a call for stories via several international networks including the online 1000 Voices Project, which “aims to collect, display, and analyse 1000+ life stories from people with disability from around the world” ([www.1000voices.edu.au](http://www.1000voices.edu.au)). The editors also sent the call for stories directly to groups that work with and advocate for persons living with disability in Chicago, Philadelphia, St. Louis, and Atlanta. We took a deliberately broad conception of “disability” to acknowledge that, for many, disability is simply a form of difference—albeit a potentially highly politicized one. This moved the symposium away from a biomedical conception of disability as a form of physical illness or impairment toward what is generally referred to as the “social model” of disability (Hughes and Patterson, 1997). Responding storytellers were hence able to self-define whether they experience disability or not based on their own criteria and experiences.

The Australian component of the symposium was strongly supported by the existing 1000 Voices disability life stories project team and existing storytellers. The editors circulated a draft call for papers to existing members of the 1000 Voices disability life stories project (i.e., people who self-identified as having a disability and who had previously participated in a public disability storytelling project) and sought their input on what topics should be covered in the symposium prior to releasing the

call for stories. The resulting call for stories invited storytellers to consider the following questions as stimuli for their story:

1. How does the label “disability” interact with other aspects of your life in health care settings, for example your gender, culture, and geographical location?
2. How does the term “disability” reflect your actual embodied experiences of impairment?
3. When does the label “disability” not do justice to your particular experience of impairment?
4. Have you accepted the label “disability” in your life? If yes, what effects has this had for you and others e.g., family, friends, health care providers, and co-workers?
5. Describe the kind of experiences you might have that are possible because of your impairment.
6. How have labels of disability affected the degree to which you feel that your “authentic voice” has been heard by others e.g., family, friends, health care providers?
7. How has the impact of the label disability changed for you over time e.g., as you have aged or as societal expectations and standards have changed?
8. How has the label “disability” been a hindrance in your life?
9. Has the label been beneficial?
10. What else might you want people to know?

The editors then selected stories to reflect a range of issues, writing styles, and self-identified types of impairment ranging from congenital conditions that people were born with through to mental and physical impairments acquired through illness, injury, or disabling social contexts and experiences. The resulting stories provide a rich and probing exploration of what it is like to strive for and find one’s own identity, independence, and personhood within sometimes disabling and sometimes supportive social systems and institutions. The stories also depict in a rare and detailed way the minute bodily (e.g., the touch of a hand) and broader institutionalized (e.g., rules and regulations) ways that other people can enable or disable differently abled people without necessarily realizing that they have done so.

The invited academic commentators on the symposium come from a variety of backgrounds. Elizabeth Schlitz is a professor of law at the University of St. Thomas in St. Paul, Minnesota, and has first-hand knowledge of the struggles of caring

for a child with Down Syndrome. Jeffrey Bishop (a physician), Rachelle Barina, and Devan Stahl are at Saint Louis University in St. Louis, Missouri, and work in the area of bioethics. Lorna Hallahan is a professor of social work at Flinders University in Adelaide, South Australia. Finally, Nicole Matthews (Cultural and Media Studies, Macquarie University) Kathleen Ellem (Human Services and Social Work, Griffith University) and Lesley Chenoweth (Human Services and Social Work, Griffith University) are part of the interdisciplinary Australian research team that facilitates the 1000 Voices Project.

Along with the storytellers, the commentators explore the space of disability as a space between bodily impairment experienced by the disabled person and the social structures that both enable and constrain the flourishing of those living with the label of disability. Matthews, Ellem, and Chenoweth suggest that these stories might challenge both bioethics and the society and provide insight into the power imbalances experienced by those living with the label of disability. Schlitz describes an ambivalence that exists in the way the authors of the stories want both to embrace and reject the label of disability, and how that ambivalence manifests itself in the laws meant to assist them. She suggests that if we destigmatize the ambivalence about disability we share both in law and society we might “open the way for more satisfactory laws, and more satisfactory support for parents negotiating the challenges of parenting children with disabilities” (Schlitz). Hallahan concludes that these stories demonstrate something important about narratives, namely that “a narrative approach to exploring ethical questions privileges the person’s telling over the abstractions so attractive (and useful) in a more conventional approaches” (Hallahan). Likewise, Bishop, Barina, and Stahl focus on the everydayness of these stories and emphasize the way in which these everyday expressions of experience of disability challenge both biomedicine and bioethics, and at the same time contribute to the identity construction of the storyteller—an identity that emerges from the embodied experience of impairment and the social structures that both enable and constrain flourishing.

Our purpose with this symposium is not to offer readers a checklist of what they should and should

not “do” in the presence of differently abled people. Rather, we are seeking to offer real, contextualized information about what it is like to live/interact on a daily basis with the label of disability. In so doing, we aim to enhance people’s sensibilities toward disability and provide professionals with relatable and practical resources upon which to draw in their daily work. Moreover, in moving toward a social model of disability, something interesting happens in our understanding of social labels, embodied disability, and personal identity. These stories show us that disability and identity are part of a fluid movement shaped by bodily finitude, surrounding social practices and contexts, and the telling and listening of one’s own and each other’s stories. Each author and commentator in this symposium tells a story of movement. Sometimes the stories are about moving from a state of health to a new state of impairment. Sometimes the narratives are stories of oscillating between a desire to claim the label disability and a desire to reject it. Sometimes they are about moving toward a new way of working and seeing. In all cases though, we can find both the desire and the resource to move ourselves toward social practices and institutions that more fully and humanely responsive to the lived realities of ability and disability.

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## Personal Narratives

### Uniquely My Own: One Woman’s Experience of Living with a Physical Disability

Stephanie Birmingham

“I don’t know. You’ll have to ask her. After all, it is *her* wheelchair.” These were the words my friend said in reply to the airline employee who continued a stream of questions as if I didn’t

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\* Name changed to protect privacy.