
THE POLITICS OF NEURODIVERSITY

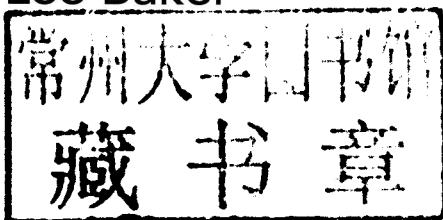
**Why
Public Policy
Matters**

Dana Lee Baker

The Politics of Neurodiversity

Why Public Policy Matters

Dana Lee Baker



BOULDER
LONDON

Published in the United States of America in 2011 by
Lynne Rienner Publishers, Inc.
1800 30th Street, Boulder, Colorado 80301
www.rienner.com

and in the United Kingdom by
Lynne Rienner Publishers, Inc.
3 Henrietta Street, Covent Garden, London WC2E 8LU

© 2011 by Lynne Rienner Publishers, Inc. All rights reserved

Library of Congress Cataloging-in-Publication Data

Baker, Dana Lee, 1973–

The politics of neurodiversity : why public policy matters / Dana Lee Baker.
p. cm.

Includes bibliographical references and index.

ISBN 978-1-58826-754-2 (hc : alk. paper)

1. People with mental disabilities—Government policy—United States.
2. People with mental disabilities—Civil rights—United States.
3. Discrimination against people with disabilities—United States.
4. Discrimination against the mentally ill—United States. I. Title.

HV3006.A4B253 2011

323.3—dc22

2010027704

British Cataloguing in Publication Data

A Cataloguing in Publication record for this book
is available from the British Library.

Printed and bound in the United States of America



The paper used in this publication meets the requirements
of the American National Standard for Permanence of
Paper for Printed Library Materials Z39.48-1992.

5 4 3 2 1

The Politics of Neurodiversity

Disability in Society

Ronald J. Berger, series editor

Brain Injury Survivors: Narratives of Rehabilitation and Healing

Laura S. Lorenz

The Politics of Neurodiversity: Why Public Policy Matters

Dana Lee Baker

Love, Sex, and Disability: The Pleasures of Care

Sarah Smith Rainey

Borderlands of Blindness

Beth Omansky

*For Alan, Kal, and Maggie,
much adored and admired representatives
of the shining future of neurological difference*

Preface

The Politics of Neurodiversity presents a taxonomy of agendas shaping modern disability policy: cause, care, cure, and celebration. These distinct agendas create tensions that both help and hinder the development of effective disability policy in modern democracies. By taking the reader through the implications of each of these tensions, the book conveys a comprehensive framework from which to study the politics and policy of neurodiversity and neurological differences.

Neurodiversity is an emerging area of disability studies. More important, however, awareness of neurodiversity and neurological differences is an increasingly prevalent characteristic of modern societies. The concept emerged in autism-related activism during the 1990s and has been a developing topic of academic scholarship since 2003. Although some still reserve the term “neurodiversity” exclusively for autism and related differences, in recent years its use has expanded to include the full spectrum of neurological differences. I employ this inclusive approach to the concept and draw from several projects focused on questions surrounding social and political implications that I conducted in recent years.

Writing from the perspective of political and policy analysis, I employ theories of issue definition and agenda setting to explore how the efforts of policy entrepreneurs dedicated to these agenda types interact with one another. I also seek to lay the groundwork for improved relations between stakeholders representing different agenda types. Ideally, such consideration results in increased potential for collaboration and improved understanding of the necessity of variation in political philosophy and policy goals within modern disability policy subsystems.

The Politics of Neurodiversity begins with two introductory chapters detailing the politics of neurodiversity and neurological differences. The

first chapter focuses on the concept of neurodiversity using the foundation of a constructivist understanding of disability. The chapter also discusses the distinctions between difference, impairment, disability, and handicap employed in the development of modern public policy. The second chapter describes the four primary goals of political activists and policy entrepreneurs working in the disability policy arena (cause, care, cure, and celebration). The next six chapters of the book examine the nature and implications in all possible pairings of agenda types. The concluding chapter revisits the concept of neurodiversity and its implications for disability scholarship and society.

Acknowledgments

First and foremost I thank my family, spread vibrantly across Canada and the United States. I feel privileged to be part of it. My grandparents, aunts, uncles, and cousins have each helped in their own way to make this book a reality. In my immediate family, I thank my son, Kal, not only for being the bravest person I know, but also for teaching me a great deal about recognizing the possibilities and limitations of social constructions. He has also patiently served as private barista, making me countless, nearly flawless mochas. Kal's sister, Dawn, was the baby in my baby vs. book race, thereby providing necessary constraint on the time it could take her mother to complete this book. Her lovely spirit motivated me from before her birth and has continued to help keep things on track as she and this book now toddle off into the world. My mother, Mary Ellen Baker, gave daily support and encouragement, as well as great insight into living neurodiversity. My father, Don Baker, not only inspired my interest in health care policy but is the best source I have found for insight into interpreting organizational and political realities. As a physician, my sister, Catherine Baker, has often served as a reasoned sounding board for assertions about the roles of health care providers in the politics of neurodiversity. As a best friend, she has provided more support, encouragement, and laughter than one person can possibly deserve. Her husband, Jim Howard, has also given me helpful insight into the world of medicine, as well as ongoing good humor. Caring for my niece, Madeline Howard, provided balance in the earliest days of writing this book, and her evolving personality has given me great joy throughout the writing process. My brother Alan Baker served as my introduction to neurological difference. The effects of his companionship and reflections are deeply woven into this text. Last, but never least, I thank my brother Brian Baker, whose desire to work for justice always inspires my own.

My enthusiastic thanks go out to professional contacts and colleagues who have generously supported me in the creation of this book. Andrew Berzanskis's assistance as editor has been consistent, reassuring, and often inspiring—really all that anyone could ever wish for in an editor of one's first book. Ronald Berger, as editor of the *Disability in Society* series, provided encouragement and valuable suggestions from proposal right through to final draft, for which I am eternally grateful. Allison Smith, who is also the best of friends, gave generously of her time by reading and providing terrific feedback on an early draft of the book. I owe a great debt of gratitude to the anonymous reviewers whose comments enriched both the experience of writing and the book itself. My much missed friend and sometimes co-author Trudy Steuernagel and her son Sky deserve my ongoing gratitude for early encouragement of my academic interest in autism policy, which will be ever manifest in remembering that their story of neurodiversity amounts to much, much more than how it ended. My friend and fellow academic Sara Maurer blessed me with unfailing moral support. Finally, I thank Guy Adams at the University of Missouri–Columbia for taking the time to mentor me in the research process as a young academic.

Working for the Department of Political Science and Criminal Justice at Washington State University (WSU) is an honor and a privilege, particularly because of the people with whom I have the pleasure of working. In particular I recognize the “hard core” faculty in the Program of Public Affairs, who are all both dear friends and wonderful colleagues—Laurie Drapela, Carolyn Long, Adam Luedtke, Mark Stephan, Paul Thiers, and Darryl Wood. I also thank Clay Mosher of WSU's Sociology Department for bringing the series to my attention and for his advice about authoring books. Amy Wharton has served as a fabulous mentor and professional exemplar. Furthermore, the program simply would not function without the dedicated assistance of our professional staff, which at the time of this writing included Marie Loudermilk, Ginny Taylor, Linda Campbell, Annette Bradstreet, and Shari Clevenger.

I have had the great fortune to come to know practitioners whose sincerity and hard work have allowed me to glimpse just how beneficial well-conceived and expertly implemented policies surrounding neurological difference and neurodiversity can be. Diane Wiscarson brilliantly negotiates the fine line between representation and alienation, thereby making manifest conditions in which students who might otherwise be cast out can learn and thrive. Susan Cone, one of the best educational administrators in the business, creates an environment of open communication and committed inclusion in one of the toughest of locations (a public junior high

school). Kathryn Murdock daily achieves what conventional wisdom often discerns impossible, by providing superb legal representation to a public school district while never losing sight of the individual rights and needs of children who are different. Tom Adams, as vice principal of Columbia River High School, exhibits the patience of a saint and a commitment to creative solutions, which I enthusiastically admire and have sought to reflect. Dan Delepine's talent for working with neurodiversity in teenagers provides a stunning example for anyone lucky enough to come into contact with him. Finally, the Connections Team in the Clark County Juvenile Justice system—especially Terri Chapman, Michelle Karnath, Rick Mason, and Dawn Young—continually demonstrate that unfailing belief in even the most momentarily challenging of youth creates both a world of difference and, ultimately, a different world.

Contents

<i>Preface</i>	ix
<i>Acknowledgments</i>	xi
1 Why Public Policy Matters for Neurodiversity (and Vice Versa)	1
2 Competing Disability Policy Agendas: Cause, Care, Cure, and Celebration	27
3 Securing Civil Rights vs. Providing Care	45
4 Securing Civil Rights vs. Finding a Cure	87
5 Securing Civil Rights vs. Celebrating Diversity	115
6 Providing Care vs. Finding a Cure	145
7 Providing Care vs. Celebrating Diversity	167
8 Finding a Cure vs. Celebrating Diversity	191
9 Finding Common Ground	215
<i>References</i>	225
<i>Index</i>	235
<i>About the Book</i>	239

1

Why Public Policy Matters for Neurodiversity (and Vice Versa)

In early 2010, President Barack Obama nominated Ari Ne'eman to the National Council on Disability (NCD), along with seven other people. Unlike the other nominees (and all others who have served on the NCD since its inception), Ari Ne'eman has autism. The seven other nominees were relatively quickly confirmed. Ari Ne'eman was not. In the US Senate, an anonymous hold was put on the motion to allow the vote on his confirmation.

The National Council on Disability was created as part of Title IV of the Rehabilitation Act of 1973. According to the agency's website:

NCD is an independent federal agency and is composed of 15 members appointed by the President, by and with the advice and consent of the Senate. It provides advice to the President, Congress, and executive branch agencies to promote policies, programs, practices, and procedures that guarantee equal opportunity for all individuals with disabilities, regardless of the nature or severity of the disability and to empower individuals with disabilities to achieve economic self-sufficiency, independent living, and inclusion and integration into all aspects of society. (National Council on Disability 2010)

Given this mission and Ne'eman's status as the founder of the nationally recognized Autistic Self-Advocacy Network (ASAN), this hold appears surprising at first glance. After all, one of the key reasons for ASAN's existence is to promote independence among a rapidly growing group of people recognized as having a disability.

However, as described by Amy Harmon in the *New York Times* in March 2010: "Mr. Ne'eman is at the forefront of a growing movement that

describes autism as a form of ‘neurodiversity’ that should be embraced and accommodated, just as physical disabilities have led to the construction of ramps and stalls in public restrooms for people with disability. Autism, he and others say, is part of their identity” (Harmon 2010). Ne’eman, like many modern disability activists, sees challenges relating to disability as resulting primarily from discrimination and from a failure to effectively support celebration of different ways of being human.

As much as issue stakeholders who are focused on the interests and experiences of individuals with autism might otherwise be thrilled at the prospect of having the voice of an individual with autism serve in such a high-profile, national-level capacity, when it came to the question of Ne’eman’s service, many hesitated or even publicly balked at the proposition. In an online newspaper titled *The Age of Autism*, Kim Stagliano (2010) wrote:

I know of no one opposed to self-advocacy for those who are able, despite the cries within the Neurodiversity community that we in the treatment community are “anti-autism.” The reality is that many of our loved ones cannot self-advocate due to the severity of their autism. We use treatments in order to elevate our children’s functioning to a place where they too can self-advocate. We bristle when we’re told that our children do not deserve treatments and research that could move them “up” the spectrum.

Stagliano went on to argue that when it comes to disability policy, limited resources should be focused on those whose disabilities appear to be most severe from the perspective of the general population. According to Stagliano, the most important challenges relating to disability are tied to an absence of a cure for distressing conditions.

Others, such as the director of Autism Society of America, Lee Grossman, described those who are working to create better policies and programs for autism as “battle-hardened” (Harmon 2010) and sometimes turning on one another rather than working together in their pursuit of different agenda types. Grossman believes that this hardening has come about because “we have this community out there frustrated and bewildered and reaching out for any assistance” (Harmon 2010). The struggle between the various agendas gets in the way of otherwise positive efforts to reframe conversations about disability, such as Ne’eman’s nomination.

The Senate ultimately and unanimously approved Ne’eman’s nomination in late June 2010. At the time of this writing, though, the identity of the responsible senator or senators, the exact reason for the hold on Ne’eman’s nomination, and the reason the hold was ultimately removed re-

main unknown. What is clear from this event is that the politics surrounding neurological difference are far from simple.

Connecting Policy and Neurodiversity

Diversity means strength. From our basic biology to international relations, a narrow attraction to sameness weakens the human experience. Nevertheless, even our thinking about diversity tends toward homogeny (Gregory 2006; Spinner-Halev, Bowman, and Sanders 2005). At the beginning of the twenty-first century, consideration of diversity in industrialized nations habitually involves organized celebration of the coexistence of individuals with differences conceived in terms of relatively observable characteristics such as race, ethnicity, gender, or sexual orientation. Often, consideration of diversity is limited to racial or ethnic differences.

Diversity is more than skin deep, however. In recent years, human understanding of neurology has progressed beyond its infancy. Part of this expansion in basic knowledge has involved development of increasingly sophisticated taxonomies of neurological differences. Our evolving understanding of the human brain, combined with the engagement of a greater proportion of the population of industrialized nations in knowledge- or service-based work, has stimulated increasing public notice of neurological differences.

Effects of this new awareness extend to both systemic and formal government agendas, making an understanding of the politics of neurological difference important for anyone interested in policy, politics, and public administration, as well as for those interested in neuroscience and neurology. One aspect of this political conversation is the consideration of differences in brains as an element of diversity within societies—this is the realm of neurodiversity. Furthermore, studying the politics of neurological difference, including neurodiversity, can create “renewed interest in the question of how to promote diversity in all its manifestations and to further a more inclusive society” (Bumiller 2008, 967) for those interested in sociology and other social sciences. Furthermore, since conscious engagement in diversity is a cornerstone of the twenty-first-century experience, the politics of neurological difference and neurodiversity should be intriguing to those interested in social justice in general. Finally, as with much that will be explored in this book, these principles, while being exceptionally well-illustrated in the politics surrounding neurological difference and neurodiversity, hold for all disabilities. As Marta Russell put it in *Beyond Ramps: Disabil-*

ity at the End of the Social Contract over a decade ago, “disability and disability policy—past, present and future—is a tool for all to rate our present socio/economic order” (1998, 9).

Defining Politics: Political Discourse and Public Discourse

For many people, polite conversation excludes politics. Also, declaring one’s hatred of or distaste for politics is often considered a reasonable position for a person to take, even in a democratic setting supposedly dependent on the political participation of (at least) citizens. Despite this, all human beings engage in political behavior to some degree or another. The political behavior most people engage in may be on a smaller scale than the governance of even the tiniest of formal political entities. However, from the time a child begins to formulate strategies other than utter loss of self-control to achieve his or her interests, political behavior becomes a part of the day-to-day human experience. Because the experience of human neurological differences involves many unknowns and unsettled questions, and thus creates potential for differing interpretations of norms and situations, this experience necessarily becomes politicized in modern societies.

In essence, politics is conflict management, which ideally turns into collaboration and cooperation. As Oliver Woshinsky describes, “while we may detest politics, the alternative can be worse . . . If conflict cannot be resolved politically, it often denigrates into violence . . . In the ordinary, workaday mode, *‘politics is damage control,’* says Peter Berkowitz in one of the best aphorisms I know on the subject . . . Politics provides an arena where people can vent their hostilities without actually killing each other” (2008, 22; emphasis in original). Within the politics of neurodiversity and neurological difference, it may at first glance be difficult to conceive of a potential for outright violence surrounding political debates on the subject of human difference. After all, no known society has ever reached the point of violent revolution over management of functional differences in human beings per se. Nevertheless, an extensive history of depriving individuals of both liberty and life as a response to observed differences in their minds, bodies, or spirits exists (Shapiro 1994). There have also been countless acts of interpersonal violence resulting from the clash between the infrastructures of society and society itself, perpetrated by both those considered normal and those considered atypical. Finally, there

exist long traditions of objectification of individuals on the basis of functionality.¹ Such objectification itself constitutes a form of violent oppression.

Politics involves substantial self-expression in a variety of forms by a plethora of stakeholders. Arguments in this book make a distinction between political and public discourse. As used here, the term “political discourse” refers to any statements and expressions made with formal political intent—in other words, statements made by those who deliberately engage the disability policy subsystem with the intent of promoting and supporting specific public policy and programs. Most often, political discourse comes from politicians, government officials, bureaucrats, policy entrepreneurs, and activists. In fact, some scholars of democracy have argued that policy entrepreneurs (or other policy experts) exclusively define policy options for the general public in most cases. As Roger Pielke explained about the writings of E. E. Schattschneider in the late 1970s: “democracy is a competitive system in which the public is allowed to participate by voicing its views on alternatives presented to it in the political process . . . such alternatives do not come up from the grassroots any more than you or me telling an auto mechanic what the options are for fixing a broken car . . . policy alternatives come from experts” (2007, 12). Although such thinking naturally raises questions about what constitutes expertise (including grassroots expertise), it resonates in practice in that, for the most part, innovative issue framing and policy proposals come from political actors directly engaging the policy subsystem, usually through formal roles. Though such arguments limit interpretation of the practice of democracy, they do emphasize the need to distinguish between political and public discourse.

The term “public discourse,” on the other hand, comprises a more general category including statements and expressions made by individuals or groups who are contributing to the politicized discussion surrounding neurological difference and neurodiversity, but not necessarily consciously seeking a specific change in policy. Public discourse can come from anyone in a given society, so long as the statement is intentionally made in public (rather than in private conversation or in contemplation).

Why Are Neurological Differences Public Issues?

Taxonomies of neurological difference remain somewhat theoretical because they commonly rely on behavior-based diagnoses. In other words, most definitions of neurological differences are circular—a person becomes