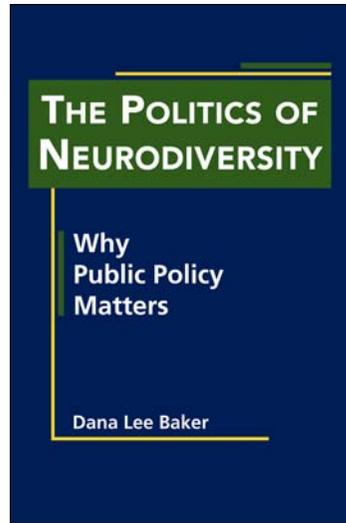


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The Politics of
Neurodiversity:
Why Public Policy Matters

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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 homogeneity (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

described as having a neurological difference as a result of engaging in a set of behaviors observed as characteristics of having a neurological difference that is in turn defined by those behaviors.

While substantial progress has been made in identification of morphological or mechanical factors underlying neurological differences, for the most part unambiguous and fully reliable explanations of relationships between actual differences in brains and assignment of particular diagnoses remain tenuous if not absent. Furthermore, it is important to understand how our limited understanding of brain function invokes the question of voluntariness into the public and political discourse surrounding neurological differences. For example, as David Smukler points out, “although individuals are identified as autistic on the basis of their behavior, it has long been assumed that autistic behavior has its origin in mental function . . . people do not simply ‘act autistic’ . . . they ‘are autistic’” (2005, 13). This assumption, combined with the remaining ambiguity surrounding neurological explanations, creates tension between different disability policy stakeholders as well as among the rest of the general public. Even so, progress continues in locating pharmaceutical and therapeutic interventions that alleviate the unwanted atypicalities attributed to neurological differences. As a result of perceived and realized potential of this progress, demand for public policy focused on neurological differences has risen dramatically across industrialized nations over the past several decades.

Another factor better understood over time is that neurological differences are not categorically the same as disease. This tends to complicate the development of policy addressing neurological differences, even to the point of opening up basic questions about the necessity of such policy. Furthermore, this realization comes as part of a larger shift in prevalence of the disability paradigms that introduced the concept of cultural relativity into disability. In recent years, conceptions of disability have come to be understood as highly variable across cultures and time (Longmore 2003). Conditions treated as completely disabling in some cultural settings go unnoticed or even create advantages in others (Grinker 2007). Understanding disability as influenced by sociocultural context clarifies the role that development of politics within the disability policy subsystem² plays in public efforts to support and encourage social justice. This means that disability becomes an unavoidably public issue, arguably especially in the case of the so-called invisible disabilities, such as many of those believed to be associated with neurological differences.

A Continuum of Understandings of Disability

Conception of disability is socially relative and, therefore, at least somewhat unique to time and place. However, understandings of disability can be classified for the purposes of empirical analysis or more global discussion of politics found in disability policy subsystems. For the purposes of this book, understandings of disability are described as existing along a continuum from purely essentialist to purely constructivist. In going forward with such a discussion, it is of course vital to understand that these two defining conceptions of disability frame a wide variety of possible understandings of disability rather than creating a simplistic binary of two opposing philosophical camps.

A continuum is by definition a spectrum where little—if anything—in the real world is purely black or white. One should hardly expect that most people involved in the political and public discourse surrounding neurological difference and neurodiversity would consciously or explicitly self-identify as either purely constructivist or purely essentialist. This classification scheme is employed not only because it can most fully describe recent innovations in understandings of disability as compared to more traditional interpretations, but also because of the emphasis placed on the social and political aspects of constructions of understandings of disability. Employing this continuum makes the most sense for a sustained examination of the politics of neurodiversity and neurological difference, but not, for the most part, for the classification of individuals involved in the discourse.

Essentialist Understandings of Disability

Essentialist understandings consider disability to be entirely located within an individual who has a culturally relevant functional difference.³ In such mind-sets, making up for disadvantages resulting from a human functionality considered atypical becomes the responsibility of the individual or his or her family. Assignment of responsibility takes place in this way because the person's mind, body, or spirit is understood to be the cause of the difficulties.⁴ Whether articulated as a curse, punishment of ancestors, irresponsibility, stupidity, immorality, or laziness, explanation for the presence of disability more often than not becomes attributed to actions of the individual with the functional difference or to those of his or her family. In addition, as frequently noted in disability studies literature, essentialist

understandings of disability usually blame the so-called victim of disability for associated social, economic, political, occupational, or legal disadvantages.

Under a purely essentialist understanding of disability, society incurs no fundamental moral responsibility to mediate effects of disability. Compassionate societies might intervene on behalf of families including individuals with disabilities using charitable or medical strategies. However, such measures represent normative choices about social preferences as opposed to the fundamentals of justice expected of healthy governance, particularly in a democracy. One commonly referenced piece of evidence of historical dominance of essentialist understandings of disability is the rumored etiology of the word “handicapped,” which supposedly describes a person with a functional difference holding their cap in their hand and begging more upstanding citizens for money. Another is the extent to which US president Franklin Delano Roosevelt and those surrounding him worked to hide his use of a wheelchair (Fleischer and Fleischer 2000).

Essentialist understandings of disability sometimes are described as “medical” models of disability. This description does not originate with and is rarely used by health care professionals. Instead, this nomenclature is predominantly employed by disability studies scholars, progressive program managers, and disability rights activists. The nomenclature invokes medical practices involving systematic removal of individuals with specified differences from interaction with the rest of the general population to institutional facilities. It also raises the specter of adverse medical procedures such as forced sterilizations performed in the name of eugenics throughout much of the Western world well into the twentieth century.⁵ Institutional facilities and adverse medical practices developed prolifically during the late nineteenth and early twentieth centuries, with the supposed purposes of protecting public health and providing prolonged medical care to a historically neglected population. Though at least initially well intentioned, in practice institutional conditions were all too often conducive to abuse. The medical model terminology also highlights a pronounced expectation of professionals engaged in medical treatment to assume full control over their patients, whether strictly medically necessary or not.

Constructivist Understandings of Disability

At the other end of the continuum lie constructivist understandings of disability. Most scholarship considers such conceptions of disability to be the result of recent historical innovation of progressive democracies as tied to

a larger history of expansion of human and civil rights (Gross and Hahn 2004; Ishay 2008). A purely constructivist understanding of disability locates the source of disability entirely in the social and political infrastructures surrounding the individual who has the functional difference. Constructivist understandings of disability begin with the axiom that all human beings have differences in functionalities affecting their ability to interact absolutely successfully with any society's infrastructures. Generally speaking, infrastructures include enough flexibility to allow individuals to participate in society without extraordinary or individualized assistance.

In disabling circumstances, however, a public infrastructure becomes too rigid to include all people living in the society. As a result of this created rigidity, individuals with levels of functionality outside the limits of the established norm become disabled (or even handicapped). Constructivist understandings of disability are sometimes referred to as "social" models of disability, particularly when referenced in opposition to understandings described as the medical model or when referring to disability policy in industrialized nations other than the United States.⁶ In such discussions, social models describe inclusion whereas medical models connote exclusion. As Gillian MacIntyre explained, "broadly speaking, in many spheres there is a growing rhetoric of commitment to the social model of disability and this is echoed in policies of inclusion for people with disabilities" (2008, 13).

A key observation of constructivist understandings of disability recognizes society's infrastructures as including more than physical infrastructures. This distinction's importance to the politics of neurodiversity and neurological difference arises because disability is stereotypically perceived as physical disability in the industrialized world. After all, an image of an individual in a wheelchair commonly symbolizes all disability in these societies. As a result, social and political infrastructures can become reflexively and exclusively understood as physical infrastructures such as buildings and roads. However, constructivist disability theory highlights historical patterns of disabling limitations incorporated into a variety of basic elements of a society, such as legal, political, ethical, attitudinal, fiscal, health, occupational, and educational infrastructures.

In the extreme, constructivist understandings of disability envision society as uniquely responsible for the creation of disability. Disability results from "what people decide matters" (Smukler 2005, 12). If a society deliberately includes and carefully plans supports for all individual differences, then no one, so the reasoning goes, would become disabled, re-

ardless of how much they might differ from the human norm in any functionality. These theoretical premises support the conclusion that public policies addressing challenges relating to human functional differences should seek to change infrastructures and not directly target individuals perceived as having a disability. As a result, constructivist understandings of disability can lead to (over)simplification of disability policy subsystems. As Tom Shakespeare (2006) explained, social models of disability provide a unified goal for disability policy activism in the form of barrier removal. This simplification helped tremendously during earlier days of the self-conscious disability rights movement because it established a joint call to action for an otherwise diffuse and frequently disempowered group. However, as the policy subsystem matured, this simplification became more limiting, particularly with regard to issues related to neurological differences.

The Continuum of Understandings of Disability in the Real World

Continuums tend to be bounded by archetypes that are approached but never actually manifest, in even the most extreme of cultural or political circumstances. The continuum of disability paradigms involves no exception to this general rule. The existence of charitable interventions as well as studies demonstrating traditional societies that are more inclusive of individuals with disabilities suggest at least tacit acceptance of disability predating the innovation of constructivist understandings. In fact, research conducted over the past several decades has demonstrated improved outcomes for individuals who have some functional differences in traditional environments. For example:

World Health Organization (WHO) studies on schizophrenia conducted in the 1970s . . . showed that even though schizophrenia occurred with similar frequency all over the world, people with schizophrenia in developing countries did better over time than those in the industrialized countries . . . they needed less care and fewer medicines, and they have fewer traumatic, psychotic episodes. (Grinker 2007, 10–11)

Furthermore, as Tom Shakespeare (2006) pointed out, proponents of medical models of disability are virtually impossible to locate and certainly not consciously active as such in mainstream policy debates of most nations. While understandings of disability, perhaps particularly in some of the more traditional health care settings, may at times approach the essentialist end of

the continuum, prevailing public and political discourses lack real world examples of pure essentialism.

Similarly, most disability theorists, activists, and progressive program managers include some essentialism in their thinking about disability. First, even constructivist understandings of disability recognize agency on the part of individuals with functional differences in their choice to identify as an individual with a disability. In *Make Them Go Away: Clint Eastwood, Christopher Reeve, and the Case Against Disability Rights*, Mary Johnson (2003) describes reasoning drawn from David Pfeiffer to explain this choice as follows:

To name a person as “disabled” is to give them an inferior position. In our society people identified as disabled are second-class, third-class, or even worse-class citizens . . . We live in a constant state of discrimination . . . Identifying oneself or another person as a “person with a disability” is an ideological act . . . There is no other way to describe it . . . Which is why not everyone with a functional difference will identify as disabled. (198)

Of course, the degree to which this choice exists depends on the specific functional difference and on how this affects the individual’s interaction with the surrounding society. Under most modern circumstances, it would be more difficult for a person with Down syndrome than for a person with attention-deficit disorder not to identify as having a disability, due to the general belief that disability is visually obvious. Nevertheless, in the end, such deliberative decisionmaking can only take place at the essential core of the individual, rather than happening entirely in surrounding social contexts.

Furthermore, particularly in more recent constructivist thinking, some human differences are recognized as different ways of being human. As such, specific differences in functionality become core components of select individuals’ identity and essential to their unique understanding of self. The deaf community can be understood as an example of this aspect of essentialism found in more constructivist understandings of disability.⁷ Often, writings about this essentialist element of largely constructivist understandings of disability point to the origins of the disability rights movement, in more or less exclusively physical functional differences, as contributing to the neglect of disability as a potentially desirable component of individual or community identity by early disability theorists and the efforts of activists. The fact that many of the most famous and persuasive early activists were people who acquired their disabilities as teenagers or young adults (Pelka 1997) might also have contributed to this impression. As is discussed

later in this book, this essential component of disability sometimes involves using disability-first (or disability-alone) language wherein people with disabilities refer to themselves as, for example, “autistic individuals” or “autistics” as opposed to employing people-first language.

A Taxonomy of Atypical Functionalities Based on Outcome of Interactions

Modern conceptions of disability fall somewhere toward the middle of the continuum, with some tendency to favor the constructivist end. Conceptions of disability employed in modern public arenas depend on events and circumstances, not diagnosis. Depending on responses to a given functional difference at a particular point in time, interactions between levels of functionality and social and political infrastructures result in four possible outcomes: difference, impairment, disability, or handicap. Literature about disability inconsistently employs distinctions between these categories, particularly outside of mainstream disability studies literature.

This book employs the taxonomy as follows, with distinctions between categories depending on the degree to which a society considers varying levels of particular functionalities as being relevant to participation in society at a given moment in time. It is important to note that the taxonomy describes events and experiences as opposed to static descriptions of particular conditions or functional differences. An individual experiencing an atypical level of a human functionality may find him- or herself in any of the four categories over the course of a day depending on the specifics of the interactions between the individual’s functional differences and social and political infrastructures. For the most part, however, because of the consistency of influence of a given sociocultural context, ongoing interaction of an atypical functionality and surrounding infrastructures will produce a stable categorical outcome. In other words, while it is inappropriate to state in this taxonomy that a person with schizophrenia will always be considered to have a disability in modern society, because of a failure to consider the immediate effect of flexibility limitations of the surrounding society’s infrastructures, this can nevertheless be reasonably assumed likely, given the observed tendency of modern society’s infrastructures to be insufficiently flexible to incorporate the functional atypicalities associated with schizophrenia. Furthermore, in considering interactions between functional atypicalities and society’s infrastructures, it is important to remember that only

the most extreme of constructivist interpretations would require society's infrastructures to become infinitely flexible and accommodate any and all needs or behaviors associated with functional atypicalities. The general call for increased flexibility responds to a long history of exclusion, not an effort in pursuit of anarchy.

Difference

Of the four categories, difference is the most innocuous and generic. Every human being embodies and experiences functional atypicalities. This book employs *difference* as the generic category to reference individuals, in the absence of connection to a relevant event. In the absence of context, nothing beyond difference exists. Also, types of functionalities considered differences may go completely unnoticed in the society in question. For example, the functional atypicality currently called dyslexia presumably went mostly unnoticed in preliterate societies and even in societies where there was no expectation that the general population read or write with any kind of regularity (Armstrong 2010).

When remarked upon by a society, differences invoke no change in social standing or individual potential. Differences also include variations in human form not known to involve any functional atypicality. For example, in Western societies, interaction between eye color and surrounding social and political infrastructures rarely (if ever) produces anything but passing curiosity. Eye color, therefore, almost always falls into the category of difference.

Impairment

Impairment occurs in situations in which the difference is noted by surrounding society and deemed potentially inconvenient enough, for either the individual or the society, to be worthy of possible correction or assistance. Left-handedness, for example, was in the past often associated with impairment when residual superstition considered this difference to be unseemly (if not evil) and even a possible threat to the health of the individual. Under these circumstances, teachers routinely sought to teach left-handed children to write with their nondominant hand. In contrast, in modern societies under most circumstances, near- and farsightedness have come to be considered impairments given the importance attributed to "perfect" or "corrected" vision. As used in this book,

the term “impairment” does not automatically imply reduced social status or ability to become included in society other than at the level of minor inconvenience reflexively accommodated by infrastructures and the general population.

Disability

Disability happens with impairment of major life functions. This definition commonly appears in modern political discourse on atypical functionalities and is written into policies in disability policy subsystems, particularly in North America. Most public and political discourse surrounding atypical functionalities focuses on disability and disabling circumstances. Accordingly, disability represents the major focus of this book.

Major life functions include those activities considered fundamental to full-fledged membership in a given society. Societies completely define major life functions, which tend to change over the course of history and can vary dramatically in different cultures. In modern democracies, for example, ability to become gainfully employed outside the home is routinely perceived as a major life function for adults who have no other prevailing responsibilities, at least between the ages of eighteen and sixty-five. A century ago, however, such a capacity was considered crucial only for men lacking independent wealth. In fact, at some points in history, paid employment implied an impairment, which more fortunate members of society, particularly women, assiduously avoided as a point of pride. Although diagnosis incompletely defines disability, it is disability, of all the categories of atypical functionality, that tends to depend on formal, public definition. It is most exclusively experienced by those given a diagnosis explicitly established as legitimate within a given society. Goals of most progressive disability policies include reduction of conditions that unnecessarily turn impairments into disability.

Handicap

Finally, handicap refers to interactions between human differences and society that inevitably produce lowered social status. In the past, a variety of conditions equated disability inherently and irrevocably with poverty, thereby creating handicap. For example, as James Trent explained in *Inventing the Feeble Mind: A History of Mental Retardation in the United States*: “Between 1880 and 1950 mental retardation had largely been seen

as a problem of lower-class teenagers and adults. Not infrequently, that group was regarded as a threat to the social order. During the heyday of the eugenics scare (1908–1920), Americans began to see poor, immigrant and working-class retarded teenagers and adults as the nation’s primary ‘menace’” (1994, 265–266). Often such attitudes resulted from an essentialist belief in fault or failure on the part of the handicapped individual as a root cause of the individual’s difficulties.

Modern societies generally consider handicapping circumstances universally inappropriate. Handicapping infrastructures, such as the condition of most public transport systems, continue to exist, but are not generally considered a desirable part of civilization and are not deliberately endorsed by the general public or promoted by policymakers.

Movement Between Categories of Atypical Functionality

Examining political discourse surrounding neurodiversity requires distinguishing between difference, impairment, disability, and handicap as employed in the development of modern public policy. Furthermore, it is useful to consider which basic policy tools best facilitate movement between categories in the desired direction. Table 1.1 shows this basic schema.

Table 1.1 Categories of Atypical Functionality

| Basic Social Construction | Category | Basic Policy Tool |
|-------------------------------|------------|--|
| | Difference | |
| If relevant in society ↓ | ↕ | ↑ With mitigation (medicine, therapy, or device) |
| | Impairment | |
| If a major life function ↓ | ↕ | ↑ With reasonable accommodations |
| | Disability | |
| If lower status is presumed ↓ | ↕ | ↑ With protection of equal rights |
| | Handicap | |

Understandings of Disability in Political Discourse Diversify Policy Agendas

The general philosophical trend in popular understandings of disability as reflected in culture and policy is typically understood as moving away from the essentialist dominance culminating in the Western world toward the beginning of the twentieth century. Current sensibilities dictate employing a flexible understanding of atypical functionality as a fundamental component of supporting social diversity. Nevertheless, since effects and implications of interpretations of functional atypicalities in political discourse are as much successively added as replaced over time, an overarching effect of this change involves diversification of types of policy agendas found in disability policy subsystems.

Interactions between these agenda types shape development of policies and programs addressing all aspects of functional differences. Furthermore, ongoing dynamics between policy agendas have amplified influence on neurological disabilities. First, as already mentioned, understanding of the brain has developed considerably in recent years, creating increasingly sophisticated neurological taxonomies. Second, existence of neurological difference often requires a sustained and pervasive degree of belief in the absence of fully objective proof, particularly for those who are not intimately related to the individual with the difference. Third, children are much more frequently diagnosed with neurological differences than ever before. As a result, policy agendas focused on neurological differences may become conflated with modern parenting goals. Also, public representations of individuals with neurological differences most often focus on children, complicating creation of policy that addresses neurological differences across the lifespan. Furthermore, explicit acceptance of multiple agendas helps in the necessary escape from technocratic tendencies involving the expectation that scientific discovery alone will solve political challenges. As Roger Pielke explained, “We often expect science—the systematic pursuit of knowledge—to provide insight into the nature of problems, decision alternatives, and their consequences with respect to desired outcomes . . . with respect to decisions, this technocratic impulse suggests that the reduction of scientific uncertainty necessarily leads to a reduction of political uncertainty” (2007, 35).

Finally, neurological differences include a plethora of distinct conditions, many of which manifest quite differently in different people. This diversity means that individuals with neurological differences, even those who

share diagnoses, may have radically divergent public goals, policy preferences, and programmatic needs.

What Is Neurodiversity?

Neurodiversity describes a relatively novel concept. Whereas neurological difference involves individual experiences, which may or may not meaningfully interact with the infrastructures in which the person resides, neurodiversity comprises questions of political and communal identity (Baker 2006). Neurological difference can, given the opportunity and individual choice, remain a private matter. However, neurodiversity—like any kind of politicized diversity—is inherently public (Chambers 2003). After all, regardless of the degree of uniqueness or atypicality of an individual’s functionality, no one person or homogeneous group can be diverse alone. Even so, according to Andrew Fenton and Tim Krahn, “neurological diversity is the norm in the natural world” (2007, 3) because it is observed as present (and tolerated) in animals, including the great apes.

The concept of neurodiversity primarily originated in the thinking of adult members of self-aware autistic communities founded during the final decades of the twentieth century (Fenton and Krahn 2007). The term relatively quickly expanded to include all those with neurological differences (Ward and Meyer 1999; Nadesan 2005; Fenton and Krahn 2007; Armstrong 2010). As Fenton and Krahn explain, “the current scope of the term includes not only lower functioning autistics (LFAs) but also those diagnosed with such neurological or neurodevelopmental disorders as attention deficit-hyperactivity disorder, bipolar disorder, developmental dyspraxia, dyslexia, epilepsy, and Tourette’s syndrome” (2007, 1). This list of examples is of course designed to illustrate the expansive umbrella of modern neurodiversity rather than a catalog of all possible neurological differences. Some examples of neurological differences, with their clinical descriptions and selected population characteristics, are shown in Table 1.2. Currently, the concept is widely used to include all differences of the human brain that are not considered typical (see, for example, Antonetta 2005).

Some argue for limiting the conception of neurodiversity to include only those individuals who have autism spectrum differences, particularly because of the specific policy agendas of some of the early activists. While such restriction of the conception of neurodiversity is undoubtedly

Table 1.2 Examples of Neurological Differences

| Neurological Difference | Clinical Description (based on DSM-IV TR and Draft DSM-V) | Key Population Characteristics |
|---|--|---|
| Attention-deficit hyperactivity disorder (ADHD) | Involves recognized and marked inattention, impulsivity, and hyperactivity generally noted as present before age seven, manifesting in two or more locations and including clear evidence of clinically significant impairment in social, school, or work functioning for at least six months. | Roughly 3–5 percent of school-aged children are expected to have ADHD. An estimated 4 percent of adults have ADHD. Observed as being more common in males than females. |
| Autism and Asperger syndrome | Involves a combination of qualitative impairment in social interaction and communication; restricted repetitive and stereotyped patterns of behavior, interests, and activities; and delays or abnormal functioning in social interaction, language as used in social communication, and/or symbolic or imaginative play with onset prior to age three. Though it appears in the DSM-IV, Asperger syndrome will likely be eliminated from the DSM-V. | Much more prevalent in current generation of young people (approximately 1 in 166). About four times more common in males than females. |
| Bipolar disorder | Involves experiencing a combination of at least one manic or mixed manic episode, depression, and times of typical mood. The defining characteristics of mania include heightened mood (either euphoric or irritable); flight of ideas and urgency of speech; and increased energy, decreased need for sleep, and hyperactivity. | Approximately 1.5 percent of the general population is expected to experience bipolar disorder over the course of their lives. Bipolar disorder is believed to be equally common among males and females. |

(continues)

Table 1.2 continued

| Neurological Difference | Clinical Description (based on DSM-IV TR and Draft DSM-V) | Key Population Characteristics |
|--------------------------------------|---|---|
| Mental retardation | Involves significantly sub-average intellectual functioning as demonstrated by an IQ of approximately 70 or below on an individually administered IQ test, and concurrent deficits or impairments in present adaptive functioning. | Believed to be the most common developmental disorder, though exact prevalence is unclear. In the United States, it has been found to be more common in males than females. |
| Posttraumatic stress disorder (PTSD) | Involves development of characteristic symptoms following an extreme traumatic event directly involving death, injury, or threat to oneself or others. Characteristic symptoms include intense fear, helplessness, or horror (or in children, the response must involve disorganized or agitated behavior); persistent reexperiencing of the traumatic event; persistent avoidance of stimuli associated with the trauma and numbing of general responsiveness; and persistent symptoms of increased arousal. | Prevalence naturally depends on the proportion of the population exposed to extremely traumatic events. Recorded rates among high-risk populations (such as military veterans) have been as high as 58 percent. |
| Schizophrenia | Involves a combination of delusions; hallucinations; disorganized speech manifesting a formal thought disorder; grossly disorganized or catatonic behavior; blunted affect; lack or decline in speech or motivation; and marked social and occupational dysfunction. | About 1 percent of the general population is expected to experience some kind of schizophrenia during the course of their lives. Males are more likely to have early onset schizophrenia than are females. |

politically useful in certain contemporary circumstances, philosophically isolating individuals with autism while simultaneously implying that other neurological conditions are not worthy of inclusion makes less sense in academic and philosophical considerations of this concept.

Nevertheless, it is important to understand that the roots of neurodiversity lie in the discourse and activism surrounding autism. Neurodiversity rose to the top of some systemic agendas in response to largely negative publicity and public discourse surrounding perceived growth in autism incidence at the end of the twentieth century. Most of this discussion tended to describe autism as an epidemic and therefore focused almost exclusively on finding a cure for autism. Although the incidence of autism is currently estimated at 1 in 150 children, this kind of alarmist thinking led to statements such as the following, which appeared in the *Market Wire* on August 4, 2004, in an article titled “GEM Media, Inc. & Spectrum Publications Launch NY Spectrum Magazine”: “at this rate, no family will be left untouched by autism with statistical estimates reaching 1 in 7 children diagnosed with autism by the year 2012.”

Some adults with autism began to fear increased intolerance of their way of being if not outright eradication of their lifestyles and preferences (Fenton and Krahn 2007). Fundamentally, neurodiversity asserts that neurological differences can be understood and experienced as much as a source of community and communal identity as can differences more routinely associated with politicized diversity, such as race, ethnicity, gender, religion, and sexual orientation. Groups dedicated to neurodiversity evolved to help promote this interpretation of living fully with neurological difference in the face of potentially overwhelming messages to the contrary.

In recent years, neurodiversity groups have become increasingly active. To date, these organizations operate predominantly online. Goals of neurodiversity-oriented organizations tend to include promoting positive understandings of autism, redirecting autism research funding away from its primary focus on treatment, countering public rhetoric describing autism as a disease (or as being otherwise fundamentally undesirable), and, to some degree, opposing efforts to find a cure for autism (Bumiller 2008). Neurodiversity advocates also contend that “neurological diversity is the norm in the natural world” (Fenton and Krahn 2007, 3) rather than a pathology or result of a possibly overly liberal acceptance of personal choice in the modern world. Organizations and groups engaged in neurodiversity activism or advocacy consciously employ language, theoretical constructs, and strategies inspired by those used to promote and support

other forms of diversity over the course of the twentieth century. They also emphasize the unique contributions to society of individuals with neurological differences, autism especially. Often these discussions mention famous historical figures retroactively diagnosed with autism, at least by activists.

Identification Involves Choice

Just as happens with other characteristics more commonly associated with diversity, not everyone with a neurological difference identifies with neurodiverse communities. Furthermore, questions surrounding identification and outing of individuals with neurological differences parallel those found in, for example, gay and lesbian communities. A fundamental tenet of this book is that neurodiversity includes the right of individuals to choose not to publicly identify as having a neurological difference while simultaneously not supporting any social and political infrastructures that either universally encourage (or force) “passing” as neurologically typical, or incorporate negative consequences for publicly identifying as having a given neurological difference.

In addition, given the complexity of modern individual identity, neurodiversity as discussed in this book also protects the preferences of those who do not consider their neurological identity as a core element of personal identity while still identifying with neurodiverse communities. Public identification as an individual with a neurological difference incurs no extraordinary communal or political obligation. Someone with a neurological difference has the same right as any other person to create an identity more centered on personal characteristics than on neurological differences.

Basic Characteristics of Neurodiverse Conditions

One of the challenges in discussing neurodiversity involves defining who (and in some sense, what) this category should include. As mentioned previously, articulation of neurodiversity originated in thinking about individuals with autism spectrum differences. Limiting neurodiversity only to those with autism and related differences, however, resembles limiting ethnic diversity to discourse about individuals of African American descent. While it may be that this group comes most immediately to the minds of casual thinkers about ethnic diversity, clearly this perception misrepresents the realities of racial and ethnic diversity experienced in today’s societies. Diversity is, after all, a condition of a society or community and never of an

individual human being or homogeneous group, regardless of how exotic the particular group seems to other members of the general population.

However, expansive definitions of concepts such as neurodiversity run the risk of death by diffusion. No two human brains are identical. To the extent that neurodiversity includes everything, then it might come to mean nothing. Managing this expansion represents an ongoing challenge for neurodiversity advocates and activists. For example, as Fenton and Krahn (2007) point out:

This defense of the normalcy of cognitive, and so neurological diversity, must respond to worries about over inclusiveness—i.e., by regarding as normal the neurological structures that underlie the behavior of autistic individuals we run the risk of including maladaptive cognitive and neurological traits . . . a partial response can note that what qualifies as maladaptive, or adaptive, is context sensitive. (3)

For the purposes of this book, neurodiversity refers to atypical functionalities found in individuals who have identifiable neurological differences and to their interactions with individuals considered neurologically typical in the context of public infrastructures built around a presumption of neurotypicality. For the most part, this implies that communities referred to as neurodiverse include only those that incorporate individuals who have been formally diagnosed (or could be, given access to professionals) with a disability believed to involve a significant brain-based difference compared to what is currently considered the human norm.

Defining neurodiversity in this way somewhat complicates matters, as most writing about disability, particularly outside disability studies, does not aggregate atypical functionalities in this way. Most discussion of brain-based disabilities considers these conditions to be of at least three primary types: mental illness, developmental disability, and brain injury acquired through either accident or disease. Some people, even those with other neurological differences, dislike being identified in tandem with the other types, for reasons ranging from simple discomfort and outright discrimination against individuals with other types of differences. This is arguably particularly the case for mental illness and psychiatric disorders, since acceptance of these differences as disabilities has historically lagged behind acceptance of the other two types. For example, as pointed out in the entry for the Americans with Disabilities Act in *The ABC-CLIO Companion to the Disability Rights Movement*, “there were various attempts in the House to derail or weaken the bill, including efforts to limit its protections for people with HIV/AIDS and psychiatric disabilities” (Pelka 1997, 20). How-

ever, for the purposes of examining public and political discourse surrounding neurological differences, it is important to include and consider all of the ways in which brains (or minds) are understood as differing. Failing to do so would artificially truncate the political conversation and present an incomplete picture of the dynamics of neurodiversity.

The prevailing taxonomy of neurological difference grows out of an importance placed on whether or not the observed difference is attributed to theoretical differences in brain chemistry, to a critical difference in the morphology of the brain itself, or to an identifiable event that (usually irrevocably) changed a once neurologically typical brain. This traditional distinction matters in the contexts of politics and policy. Often, policies and publicly funded programs are made and designed separately to target individuals with differences in these three categories. For example, in state governments in the United States, programs for individuals with mental retardation are often separated from programs for those with mental illness. This policy division echoes the strongly essentialist understandings of disability that dominated political discourse in the past, particularly the associated importance assigned to reasons for differences as a mechanism for assigning blame for the disabling outcome.

Nevertheless, more modern policies and programs have become increasingly generalist in their orientation, particularly as a result of extreme budgetary constraints and recognition of the prevalence of dual diagnoses (individuals falling into two or more of the traditional categories). Furthermore, the politics of neurodiversity in and of itself does not naturally become overly concerned with the mechanism or origin of differences in functionality, only with the unusual implications that result from these differences interacting with infrastructures. Arguments presented in this book, then, make little distinction between mental illness, developmental disability, or traumatic brain injury. This interpretation will be problematic for some readers. As Fred Pelka explains, “critics of cross-disability organizing maintain that no amount of awareness and sensitivity can alter genuine differences in philosophy and agenda between the various constituencies in the disability community” (1997, 82). Such distinctions are especially relevant to issue activists, but less so for more generalist issue stakeholders engaged in the public and political discourse surrounding neurodiversity (especially those directly involved in policy formulation and development, as this inherently involves compromise between different political philosophies). Furthermore, as Simi Linton points out, disability scholars habitually consider disabilities in a cross-disability context because “we may drool, hear voices, speak in staccato syllables, wear catheters to collect our urine,

or live with a compromised immune system . . . we are all bound together not by our collective list of symptoms but by the social and political circumstances that have forged us as a group” (1998, 4). The scholarly literature also points to such grouping forces. For example, in an article about the widespread presumption of incompetence of autistic children in US schools, Douglas Biklen and Jamie Burke point out that “the tradition in American education to assume incompetence of students who have severe communication impairments extends beyond autism, and includes those with other developmental disabilities, such as Down’s syndrome, Rett Syndrome, Cri-Du-Chat, and others” (2006, 167). In this book, references to and descriptions of experiences of individuals with neurological differences should be read to include individuals falling into all of the traditionally employed categories unless specifically stated otherwise.

Layout of the Book

This book presents the taxonomy of agendas shaping modern disability policy from the perspective of policy analysis, with particular emphasis on theories of issue definition and agenda setting. Although the primary focus of the book is neurological difference and neurodiversity, the chapters focused on agenda types conclude with thoughts for all disabilities. These distinct agenda types create tensions that both help and hinder the development of effective disability policy. Continuing this introduction to neurodiversity, Chapter 2 describes the four primary agenda types of political activists and policy entrepreneurs who work in the disability policy arena (cause, care, cure, and celebration).

Beginning the focus on agenda types, Chapter 3 explores the relationship between public policy agendas focusing on the civil rights and those focusing on public provision of care for individuals requiring (or perceived as requiring) specialized care as a result of manifestations of a neurological difference. The chapter begins by discussing implications over time of the deinstitutionalization of individuals with neurological differences, including the resulting intergenerational tensions. Next, the policy implications of spectrum differences (such as autism) are explored, with particular focus on issues surrounding guardianship and independence.

Chapter 4 discusses tensions between the goals of cause and cure with regard to neurological difference. The chapter begins with a discussion of policy narratives equating the two, sometimes turning the search for or application of a cure into the source of civil rights for those with neurological

differences. The chapter concludes by analyzing the attention to and influence of these two organizational archetypes in official government discourse in recent years in both the United States and Canada.

Chapter 5 focuses on the relationship between disability rights and disability culture from the standpoint of neurodiversity. Emphasis on suffering and discrimination common in early rights-based discussion of disability is first explored. The discussion then turns to an examination of efforts to celebrate disability culture as a positive right in the context of disability activism and policy focused on protection of rights of individuals with disabilities, usually constructed using a negative rights basis. The chapter concludes with an analysis of newspaper coverage of individuals with autism, demonstrating the tensions between celebration and cause as reported over time.

Chapter 6 examines policy and programmatic tensions between caring for and seeking a cure for individuals with neurological differences and how these tensions can hinder participation in society. The role of nonprofits in the relationship between these agenda types is also explored, as are the ways that investments in care and cure efforts can exist symbiotically, particularly in the public sector.

Chapter 7 focuses on tensions between caring for individuals with disabilities who are in need of direct assistance with major life functions, and celebrating the existence and accomplishments of individuals with neurodiverse conditions. The chapter discusses three central topics: the vital role of celebrating disability culture and the accomplishments of individuals with disabilities; the concern that celebrating neurodiversity tends to create a false understanding of limitations by focusing on “higher-functioning” individuals; and the parallel concern that celebrating neurodiversity sometimes tends to objectify individuals with disabilities, particularly when organized by professional caregivers. The chapter concludes with a case study of *Autism: The Musical*.

Chapter 8 explores the tensions between cure and celebration. It begins by discussing the distinctions between events designed to raise money for a cure and those designed to celebrate neurodiversity. The chapter considers the philosophical tensions between neurological difference at the individual level, which could by definition embrace individual or family choices to seek a permanent mitigation, and at the levels of community and society, which depend on the continued and public participation of members of the identified minority. The chapter closes with a discussion of the role of public policies, particularly those that rely on binary diagnosis standards, in augmenting these tensions.

Concluding the book, Chapter 9 revisits the primary implications of each of the six tensions for neurodiversity and for public policy. Recommendations for resolving the tensions within public policy in the short and medium terms are discussed. The chapter concludes by revisiting the concept of neurodiversity and its implications for disability scholarship and society.

Notes

1. See, for example, Pelka 1997 for encyclopedic descriptions of such events, including those directed at well-known cultural figures such as Helen Keller.

2. The term “policy subsystem” refers to the totality of policies and programs that address a particular area of public concern in a given society. Subsystems often overlap with regard to their claims on proposed legislation and public actions. Nevertheless, most public policies and programs fall into one or two primary policy subsystems.

3. People-first language is employed in this book unless other phrases are quoted in context or unless the discussion is referring to individuals or communities who deliberately use their disabilities as defining elements of identity.

4. Such separation of mind, body, and spirit represents a Cartesian understanding of the human condition, and has been contested by many modern neurologists. Even so, both diagnostic categories and policy instruments tend to maintain a division between disabilities rooted in a separation of mind, body, and spirit, at least for operational purposes.

5. For example, in the United States, involuntary sterilizations continued until at least 1979. The Supreme Court case that established the practice as constitutional, *Buck v. Bell* (1927), has yet to be overturned.

6. This difference in nomenclature is most likely due to a general discomfort with social(ist) policies in the United States, more than to an actual difference in understandings of disability.

7. Some members of deaf communities would not agree with this characterization because they consider deafness to be completely cultural and not a disability, regardless of the disability paradigm employed. However, as James Charlton asserted in *Nothing About Us Without Us*, “the category ‘disability’ includes people with socially defined functional limitations . . . for instance, deaf people are considered disabled even though many deaf individuals insist they do not have a disability” (2000, 8).