

## Enabling Disability: Rewriting Kinship, Reimagining Citizenship

*Rayna Rapp and Faye Ginsburg*

In trying to portray my son in the literary model known as a novel, I have passed through . . . stages. In the case of a person like him with a mental disability, it isn't the individual himself but rather his family that has to pass from the "shock phase" to the "acceptance phase." In a sense, my work on this theme has mirrored that process. I have had to learn through concrete experience to answer such questions as how a handicapped person and his family can survive the shock, denial, and confusion phases and learn to live with each of those particular kinds of pain. I then had to find out how we could move beyond this to a more positive adjustment, before finally reaching our own "acceptance phase"—*in effect coming to accept ourselves as handicapped, as the family of a handicapped person.* And it was only then that I felt the development of my work itself was at last complete. (Oe 1995: 46, emphasis added)

In 1963, when the Japanese novelist Kenzaburo Oe's son Hikari was born with a dangerous brain tumor, Oe and his wife chose to have it removed, a process that, along with a range of other kinds of supports, enabled the infant Hikari to survive, but with a profound disability. Since then, the family has had to re-create itself and its narrative. In his book, *A Healing Family*, Oe describes his family's capacity to embrace Hikari.

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**Public Culture**

*Healing* is used here in two senses that draw our interest as researchers. The word's immediate referent would seem to be the capacity of parents and siblings to help heal the wound of difference for the affected boy. But Oe also emphasizes the work the family has undertaken to heal the wound of difference dealt to its own kinship narrative and practice. Oe, who won the Nobel Prize in literature in 1994, has written several other books chronicling the transformations in their familial universe inaugurated by the birth of Hikari. His works have helped his family and, at a remove, his readers, to imagine an unanticipated cultural future that could give meaning and possibility to the reshaped habitus of daily life with a disabled family member.<sup>1</sup> Oe's compassionate and frank story of how his family came to embrace "being handicapped" is representative of a kind of shift in consciousness—disability consciousness—suggestive of a more expansive sense of kinship across embodied difference that, we argue, is essential to the growing public presence of disability in contemporary postindustrial democracies.

The proliferation of publicly circulating representations of disability as a form of diversity we all eventually share—through our own bodies or attachments to others—offers potential sites of identification and even kinship that extend beyond the biological family. In the United States in particular, such public representations of the connections (and disconnections) of disabled people and their families across embodied difference have helped to introduce a sense of public intimacy that, we argue, is crucial to redeeming the ADA promissory note of a polity "beyond ramps" (Russell 1998). The simultaneous emergence of the U.S. disability rights movement along with the escalation of reproductive and neonatal technologies has intensified cultural awareness of a range of broader issues. These increasingly both shape and destabilize contemporary kinship practices as well as debates among disability rights activists, feminists, bioethicists, and health service providers.

Such concerns engage questions about medical ethics and the complexities of reproductive choice; concrete dilemmas about how to organize the practical logistics of care for disabled children; political and distributive queries about what citizens are owed; and conceptual questions about how disability is figured discursively. While such issues are often made the subject of public policy debate, they come already anchored in the daily and intimate practices of embracing or reject-

1. Oe's writings point to the impossibility of individual solutions—even at the level of narrative—to what are cultural and social dilemmas. In a kind of parallel process, Oe has also written movingly on the aftermath of Hiroshima, an assignment he began the same year Hikari was born. This project enabled him to cope with the incomprehensibility of his son's condition by placing it in an even more inexplicable context of social suffering.

ing kinship with disabled fetuses, newborns, and young children. We suggest, then, that disability criticism should encompass not only the public arenas of law, medicine, and education, or the phenomenology of embodiment. It also needs to engage the intimate arena of kinship as a site where contemporary social dramas around changing understandings and practices of reproduction and disability are often first played out. Although the term *kinship* is conventionally associated with the private or domestic sphere, we stress the cultural work performed by the circulation of kinship narratives through various public media as an essential element in the refiguring of the body politic as envisioned by advocates of both disability and reproductive rights.

The efforts of families to “rewrite” kinship are crucial to creating a new cultural terrain in which disability is not just begrudgingly accommodated under the mandates of expanded post-1970s civil rights legislation, but is positively incorporated into the social body. Likewise, rejection of the disabled from the familial and social body continues to occur, occasionally played out in the public media as scandals of exclusion<sup>2</sup> and in more intimate arenas as the conventional limits of kinship are sustained rather than transcended.

When we began to explore the world of disability—both as parents of disabled children and as anthropologists interested in reproduction, kinship, and social activism—we were struck by narratives like Oe’s and their proliferation in a world in which constructions of the body and identity are increasingly mediated by biomedical technologies.<sup>3</sup> We were particularly interested in contradictions between, on the one hand, burgeoning genetic knowledge and the neoeugenic

2. For example, national attention was riveted on the upper-middle-class Kelso family of suburban Philadelphia in December 1999, when they abandoned their ten-year-old son, Steven, with his diapers, medications, toys, and medical records at the Du Pont Hospital for Children in Wilmington, Delaware. Their nursing schedule had fallen apart over the holidays, and the parents claimed they could no longer cope with the intensity of their child’s needs. While stories of abandonment are not uncommon, this one made public headlines in part because the mother had been a prominent volunteer on the Pennsylvania Developmental Disabilities Council.

3. The recent explosion of U.S. writing on disability, building on the groundbreaking work of scholars/activists who have been writing since the 1970s, is reflected in such developments as the dramatic growth of the Society for Disability Studies, the launching of book series such as *Corporealities: Discourses of Disability* (edited by David T. Mitchell and Sharon L. Snyder for the University of Michigan Press), and the creation of university-based disabilities studies programs, such as the one at the University of Illinois at Chicago. All are founded on a commitment to the centrality of disabled people both as researchers and subjects (see, e.g., Charlton 1998, *Nothing about Us without Us*). In anthropology, the efforts of pioneers such as Robert Edgerton (1993, first published 1967) and Henri-Jacques Stiker (1999, first published 1982) have been joined by an emerging scholarship focusing on issues ranging from stigma (Ingstad and Whyte 1995), to cultural communities of difference (Groce 1985), to the phenomenology of differently abled bodies (Frank 2000; Murphy 1987).

**Public Culture**

practices it has fostered; and, on the other, the expansion of more inclusive democratic discourses—in particular, that of disability rights. To explore this tension, in this essay we foreground the domains of kinship and reproduction as key social sites at which many disabilities are initially assigned cultural meaning in the United States. We focus in particular on contemporary dilemmas surrounding pregnancy and the care of newborns and children with disabilities, which in turn underscore questions concerning the social location of caretaking and its political economy.

We locate our work at this nexus not only because reproductive choices—and the role played in them by the possibility of disability—are increasingly implicated in the new genetic knowledge, but also because the parent-child relationship is a nexus at which dramatic alternatives are articulated: dependency versus autonomy; intimacy versus authority; the acceptance of caretaking versus its rejection; normative cultural scripts versus alternative, more inclusive “rewritings.” Clearly, the “passions and interests” (cf. Hirschman 1977) at work here can divide the points of view of children and parents. These potential divisions can be particularly acute in the case of children with disabilities, whose bodily and sensory (and, eventually, social and political) experiences may be profoundly different from those of their parents. Recent debates about cochlear implants for deaf children or facial surgery for children with Down syndrome highlight divisions over the value of mainstreaming technologies. Such issues divide families who differ over what constitutes “the best interests of their children.” Although conflicts between the perspectives of parents and children are typically associated with the separation and self-definition that intensify at adolescence, we focus here on dilemmas that emerge much earlier—indeed, from the embryonic stage or before.

**Rewriting Kinship**

The birth of a child who is, in one sense, profoundly different from other family members can pose an immediate crisis to the nuclear and extended family. In addition to providing medical support for the affected child, families face the task of incorporating unexpected differences into a comprehensible narrative of kinship (Landsman 1999, 2000; Layne 1996). The birth of anomalous children is an occasion for meaning-making, whether through the acceptance of “God’s special angels” or the infanticide of offspring deemed unacceptable. And in millennial America, new technologies have made the domain of kinship and reproduction—the locus classicus of anthropology—particularly charged with cultural contradictions surrounding questions of bodily difference.

A wide variety of contemporary cultural productions testify to this intensification. It is our argument that such public storytelling—whether in family narratives, memoirs, television talk shows and sitcoms, movies, or, most recently, through Web sites and Internet discussion groups—is crucial to expanding what we call the social fund of knowledge about disability. In opening up the experiential epistemology of disability, as shaped by and shaping the intimate world of nonnormative family life, such forms of public culture widen the space of possibility in which relationships can be imagined and resources claimed. We underscore the significance of this burgeoning public circulation of intimate disability stories, expanding the arguments of others regarding the place of intimacy in constituting subjectivities of all sorts. As Lauren Berlant writes in her introduction to the special issue of *Critical Inquiry* on intimacy,

Rethinking intimacy calls out not only for redescription but for transformative analyses of the rhetorical and material conditions that enable hegemonic fantasies to thrive in the minds and on the bodies of subjects while, at the same time, attachments are developing that might redirect the different routes taken by history and biography. To rethink intimacy is to appraise how we have been and how we live and how we might imagine lives that make more sense than the ones so many are living. (Berlant 1998: 286)

In the expanded domain of “public intimacy” linked to disability, different forms of embodiment are represented within the context of domestic routines and subjectivity. If this is true of information-sharing magazines such as *Exceptional Parent* and the slick and upbeat activist publication and Web site *WeMedia*, it is no less characteristic of academic writings by scholars who may themselves be disabled (Asch 1989; Charlton 1998; Fries 1997; Handler 1998; Hockenberry 1995; Kuusisto 1998; Linton 1998; Mairs 1996), or caring for disabled family members (Beck 1999; Bérubé 1996; Featherstone 1980; Finger 1990; Jablow 1982; Kittay 1999; Seligman and Darling 1989). We suggest that such representations—what we call disability narratives—are foundational to the integration of disability into everyday life in the United States, a process that is in turn essential to the more capacious notions of citizenship championed by the disability rights movement. As authored by disabled people and/or their family members, these narratives offer revised, phenomenologically based understandings that at times also anchor substantial analyses of the social, cultural, and political construction of disability. The dissemination of such intimate insights among a broader public has helped to mobilize an extraordinary and rapid transformation

**Public Culture**

since the 1970s in the way such notions as rights, entitlement, and citizenship are conceived—a transformation that is shaping public policy in areas such as health care, education, transportation, and access to built, aural, and visual environments.

Of course, not all disability narratives are so inclusive. A very different discourse about disability has emerged around the proliferation of reproductive technologies, in particular prenatal testing for detectable fetal anomalies. Certain assumptions are foundational to these processes. While U.S. genetic counselors are trained to express neutrality about the choices a pregnant woman and her partner may make around amniocentesis testing, the very existence of such a technology and the offer of such tests under the terms of consumer choice are premised on the desire for normalcy and fear of unknown abnormalities (Parens and Asch 2000). As anthropologists, our task is to understand how these neo-eugenic technologies come to make cultural sense despite the emergence of more inclusive discourses of disability in other cultural domains. Prenatal screening, for example, is attractive to cost-accounting health care bureaucracies in which market forces increasingly stratify the “choices” made available to different constituencies as medical care becomes subject to the spreading hegemony of neoliberal practices and ideologies. The attractiveness of prenatal screening to cost-conscious health bureaucracies is a case in point: with the administration of medical care increasingly under the sway of hegemonic neoliberalism, market forces come to dictate what choices are available to different constituencies.

In the United States, and increasingly throughout the postindustrial world, the anxieties that accompany pregnancy are, we argue, exacerbated by the individualized and privatized nature of medical decision-making. When it comes to information about the forms of medical and community support that might be available to the family of a child with a stigmatized difference, the access of prospective parents is limited. They are often unaware of the social fund of knowledge that would help them make a more knowledgeable choice (Ginsburg and Rapp 1999). This de facto segregation is apparent in narratives elicited by researchers from pregnant women and their supporters about their attitudes and aspirations regarding prenatal testing (Browner 1996; Kolker and Burke 1993; Press and Browner 1995; Rapp 1999; Rothman 1986). Unlike the stories discussed earlier, few encounters with prenatal testing are rendered as public narratives. While the social science literature suggests that awaiting the results of an amniocentesis is quite stressful, the stress turns out to be ephemeral for those who receive normal diagnoses of their fetuses. They retrospectively experience the test as a nonevent; amniocentesis is quickly subsumed within the schedule of

now-routine health procedures whose presumed outcome is a “normal” baby. By contrast, most of those whose diagnosis is positive choose to end the pregnancy. Such events generally pass unmarked, as is the case with most abortions in the West (for the counterexample of Japan, see Hardacre 1997). Writing about abortion, especially under circumstances such as these, when the pregnancy was initially desired, is fraught with personal and political risk. Those few pregnant women who have breached the veil of privacy surrounding prenatal testing and abortion tend to circulate their stories only in specialized medical contexts (Green 1992; Brewster 1984; but cf. Rapp 1999). In describing their decision-making processes, they tend to emphasize the limits of caretaking within an available family structure and concern for a child’s potential suffering.

Some people say that abortion is hate. I say my abortion was an act of love. I’ve got three kids. I was forty-three when we accidentally got pregnant again. We decided that there was enough love in our family to handle it, even though finances would be tight. But we also decided to have the test. A kid with a serious problem was more than we could handle. And when we got the bad news, I knew immediately what I had to do. At forty-three, you think about your own death. It would have been tough now, but think what would have happened to my other kids, especially my daughter. Oh, the boys, Tommy and Alex, would have done okay. But Laura would have been the one who got stuck. It’s always the girls. It would have been me, and then, after I’m gone, it would have been the big sister that took care of that child. Saving Laura from that burden was an act of love. (Rapp 1999: 247)

Such stories provide an illuminating, if stark, comparison to the more established and more acceptable genre of disability narratives. The themes shaping these different genres of narratives about disability reveal the crucial role that kinship plays in social exclusion, on the one hand, and as a site for the transformative cultural work that can help resituate disability in contemporary American social life, on the other. Clearly, disability stories are complex and variable. The parenting literature, for example, is fraught with the tensions between efforts to normalize the experience of disability and the need for advocacy and special resources to accommodate those who cannot enter mainstream American society through the same pathways or trajectories as most others.

These tensions are themselves a reflection of the way that consumer capitalism is shaping the experience of reproduction in the United States. Perhaps the starkest examples are provided by the contemporary trend of increasingly aggressive medical intervention, with the new reproductive technology of prena-

**Public Culture**

tal testing conjuring up a familiar specter from dystopian science fiction: that of designer babies for the market (McGee 1997). At the same time, large numbers of compromised babies are able to survive thanks to advances in medicine and in therapeutic regimens such as occupational therapy and infant stimulation programs (Landsman 1999, 2000). These diverging sociomedical practices, which are increasingly part of normal obstetric and neonatal medicine, embody a doubled telos of modernity and technology. The practices of genetic testing, and other genetic research, seem to promise perfectibility for those who choose and can afford cutting-edge interventions (although what “perfectibility” might mean in practice is highly contested, as we discuss below). Concomitantly, other new technologies, medical and otherwise, offer another promise of expansive democratic inclusion and improved quality of life for those marked by difference from a hegemonic norm of embodiment (Blair 2000).

Suppressed in these narratives of modernity, which stress individual choice and achievement, is the crucial place of kinship and gender in structuring these possibilities. Specifically, this double telos places pregnant women under the very American pressure of “choice.” Many women, and especially women with first pregnancies, imagine themselves entering the workplace of contemporary mothering in one of two ways. Most plan to control the balance between participation in wage labor and the domestic economy. They use prenatal testing hoping never to face a pregnancy whose outcome would demand more caretaking than they feel they could provide; selective abortion haunts this dilemma. This model of rationality fits easily with the one that has emerged with genetic counseling, which assumes the power of individuals, no matter how constrained, to make rational choices that will “improve the quality” of their lives. A minority of women approach these tests differently, without intent to abort. They view the test as a technology for appropriate preparation should they need to provide specialized support for the birth of a child with a serious disability. In both cases, the assumption endures that infant and child care are primarily the responsibility of the individual mother, with support from other kin and recourse to the marketplace, if finances permit.

The caretaking of a disabled infant requires different and expanded resources than can be provided by most kin groups without additional forms of support. The complexities of mobilizing the necessary medical, therapeutic, and social support reveal the limits of kinship within a gendered nuclear family structure. It is through this revelation, we suggest, that some begin to reimagine the boundaries and capacities of kinship and to recognize the necessity of broader support



for caretaking. On occasion, they are motivated to rewrite kinship in ways that circulate within larger discursive fields of representation and activism.

### The Limits of Kinship

Despite a quarter century of activism, policy innovation, and the substantial provision of public services, in the United States, the securing of care for disabled members rests with the family. A vast gap remains between the rhetoric of public inclusion that mandates everything from universal design to inclusive classrooms and the battles that still have to be fought on a daily basis to ensure their availability—battles which not everyone can or will fight. As the mother and the aunt of a child with significant disabilities point out in the article “Uncommon Children”:

Laws attempt to provide parity in society for disabled individuals, but do they go far enough? Underfunded and understaffed public schools may be hard-pressed to meet sophisticated or extensive needs. Parents of “special ed” children become angry at the lack of responsiveness while parents of typical children grow resentful of monies seemingly diverted from regular ed. The very people who need to work together to meet these complex challenges are often pitted against each other.

We expect parents of children with disabilities to “rise to the occasion,” but some don’t or can’t. As a nation we were recently horrified by the Kelsos, who left their profoundly disabled ten-year-old at a Delaware hospital with a note saying they could no longer care for him. Certainly, they did the wrong thing. But their desperate act should not be dismissed lightly as simply aberrant. (O’Connell and Foster 2000: 18)

When we step back from this impassioned description of a grim social landscape, we recognize this narrative as grounded in a potentially productive tension between a capacious view of liberal democracy, in which law and social services are expanding to accommodate the needs of people with disabilities, and the reality of the daily tasks of caretaking, which remain in the household, dependent on family—and overwhelmingly female—labor. At the same time, biomedical technology holds out utopian promises that elide the dilemmas of caretaking while raising others about perfectibility, exemplified in a variety of sometimes controversial supports to people with disabilities, from cochlear implants for the hearing-impaired to computer resources for “fast-forwarding” learning-disabled students. Technology has also delivered a rapidly expanding panoply of reproductive

**Public Culture**

choices. Reliable and inexpensive birth control, infertility treatments, and safe and legal abortion have greatly enhanced women's ability to control the circumstances of mothering. The prenatal diagnosis of disabling conditions in fetuses is surely part of this technological modernity. The common choice to abort based on such diagnoses suggests the limits of the expansion described above and the implicit recognition that much of the labor of caretaking, especially in infancy and childhood, still falls on mothers.<sup>4</sup> In a sense, technologies such as amniocentesis are allowing pregnant women and their partners to construct the limits of kinship on their own terms, however constrained. Realistically, many fear that the social support that they would need for a disabled child might be difficult to obtain. This was true in many of the narratives of working-class women who chose amniocentesis, who had vivid images of what a chronically ill child might do to their lives. One woman explained her decision to have prenatal testing this way:

With my other two, Lionel worked nights, I'm on days, we managed with a little help from my mother. When Eliza was three, my mother passed on, then my sister, she helped me out as much as she could. With this one, we're planning to ask for help from a neighbor who takes in a few kids. I couldn't keep a baby with health problems. Who would baby-sit? (Rapp 1999: 145)

Such stories poignantly illustrate how close to the edge many parents feel when they imagine the juggling of work and family obligations should disability enter an already tight domestic economy. Such stories can also mask deep-seated prejudices against the imagined "courtesy stigma" incurred by those close to people with "spoiled identities" (Goffman 1963). Yet it is important to highlight the material pressures under which many families with two working parents find themselves and that serve as the matrix in which the decision to use prenatal testing is made.

As we noted above, some have argued that in an upper-middle-class environment where children are increasingly regarded as commodities, genetic testing raises expectations among parents that they can "choose" to have a "perfect" baby (Browner and Press 1996; Press and Browner 1995; Corea 1985; Rothman

4. Of course, fathers have frequently been deeply involved and committed to this kind of labor and have played exemplary public roles as well (e.g., Oe 1995, Bérubé 1996). However, the high divorce rates in families with disabled children is one indication that such fathers might be more the exception than the rule. We also note the gendered nature of caretaking and the professions associated with it, such as nursing, home health care, special education, and occupational and physical therapy.

1986). A more complex scenario emerges when women of diverse class, racial, religious, and national backgrounds who were offered prenatal testing were interviewed (Rapp 1999). Whatever their cultural background, most pregnant women and their supporters are concerned not so much with perfection, but seek basic health and “normalcy,” recognizing the limits of the material circumstances within which they undertake mothering. Indeed, some were willing to live with a range of disabling conditions if they could manage it practically and if the child could enjoy life. Nonetheless, most were frightened by the stigmatizing conditions that the test might predict, about which they knew almost nothing, and whose consequences they could only imagine (Rapp 1999). Such conflicted responses are not surprising, given that the survival of disabled infants has escalated dramatically thanks to improvements in infant surgery, antibiotics, and life-support technologies. At the same time, the knowledge of what is entailed in caring for such children remains absent from mainstream discourse, underscoring a sense of social segregation and stigma. On the genetic frontier, where the use of prenatal diagnostic technologies is rapidly becoming routine, a gap exists between the medical diagnosis of a fetal anomaly and social knowledge about life with a child who bears that condition. In this gap, the use of amniocentesis and selective abortion becomes perfectly rational. This tendency to marginalize and segregate disability issues will continue, legal progress and expanded public consciousness notwithstanding, until the conditions of care are less privatized and the social fund of knowledge is increased. It is this disjunction, then, between neighboring fields of social knowledge that animates the narrative urgency of those compelled to tell what might be termed their *un-natural histories*, as they struggle to represent the difference that disability makes in the domain of kinship.

## Enabling Disability

### Changing Cultural Scripts

The cultural dialectic between perfectibility and inclusion has often animated the work of the activist individuals, families, and groups who are the crucial link between the intimate domain of kinship and the broader public sphere. The utopian promise of perfectible children has had a long-standing hold on the American cultural imagination and is particularly powerful under current technological regimes. At the same time, the ideal of equality has been the touchstone of a range of social movements that demand inclusion for those excluded on the basis of differences coded as biological deficiencies. Over the last twenty-five years, they have helped to catalyze policy initiatives that offer a potentially radi-

**Public Culture**

cal challenge to the boundaries of citizenship and the relations of obligation between (temporarily) able-bodied and dependent people across the life cycle. The IDEA, or Individuals with Disabilities Education Act (1975), followed by the ADA, or Americans with Disabilities Act (1990), are the two key pieces of post-war federal legislation that have established the framework for the civil rights for Americans with disabilities. These accomplishments have dramatically transformed both the institutional and intimate frameworks within which American families operate.

The responses of what Oe calls “disabled families” have shaped and been shaped by these historically shifting conditions. In the 1950s and 1960s, for example, many middle-class parents were commonly advised to institutionalize “non-normal” children whose survival rate was rising due to aggressive medical innovations, erasing their presence from the household and muffling their voices in family stories. Since the 1970s, however, deinstitutionalization and early-intervention programs have increasingly supported families in keeping disabled children at home. Responding to these changed circumstances, some families have begun to articulate new and public versions of domestic life with disabled children in an effort to reconfigure the discursive space defining these social fields. At the same time, a combination of forces—the *Roe v. Wade* decision legalizing abortion in 1973; the international development of prenatal genetic testing; and the rise of second-wave feminism, with its advocacy of broad-based options for women’s public and private lives—increasingly medicalized and individualized the cultural salience of reproductive choice. Twenty years on, the dilemmas of such “choices” have become a staple of public debate, as powerful medical, genetic, and prosthetic technologies extend and enable fragile lives even as prenatal screening technologies give prospective parents the option to terminate an anomalous pregnancy. Citizens of this “republic of choice” (after Friedman 1990) face contradictory options that exceed the extant frameworks for ethical deliberation. In the contemporary scenario, it is women in particular who have thus been cast as moral pioneers. These anxiety-provoking circumstances generate and are reflected in contemporary public testimony about disability, whether in the work of accomplished writers such as the Nobel Prize-winning Oe or in less prominent forms of cultural production. Such narrative engagements with unanticipated difference within the intimate culture of the family can be understood as interventions into the public sphere. They work to subvert the hegemonic discourse of perfectibility disseminated by such sites as obstetric medicine, middle-class parenting literature, and, more generally, contemporary U.S. models of personhood that valorize celebrity and individual will.

The cultural activity of rewriting life stories and kinship narratives around the fact of disability, whether in memoir, film, or everyday storytelling, enables families to comprehend (in both senses) this anomalous experience, not only because of the capacity of stories to make meaning, but also because of their dialogical relationship with larger social arenas. Indeed, the transformation of both emotional and technical knowledge developed in kin groups with disabled family members can foster networks of support from which activism may emerge. In other words, the way that family members articulate changing experiences and awareness of disability in the domain of kinship not only provides a model for the body politic as a whole, but also helps to constitute a broader understanding of citizenship in which disability rights are understood as civil rights (Asch 1989; Bérubé and Lyon 1998; Kittay 1999; Linton 1998).

### Mediating Disability

The creation of kinship ties between nondisabled and disabled people requires the imagining, for many families, of an unanticipated social landscape. This sense of reorientation to a place of possibility, as opposed to disappointment, is evident in the text of a flyer posted prominently in many American pediatric wards. It offers families of chronically ill and disabled children a parable of an unexpected journey to an unknown world, a counternarrative of hope in the face of the sense of crisis experienced by many families with hospitalized offspring:

#### *Welcome to Holland*

Imagine you have planned a vacation to Italy, to see the rose gardens of Florence. You are totally excited, you have read all the guide books, your suitcases are packed, and off you go. As the plane lands, the pilot announces, "Sorry, ladies and gentlemen, but this flight has been rerouted to the Netherlands." At first you are very upset: the vacation you dreamed about has been canceled. But you get off the plane, determined to make the best of it. And you gradually discover that the blue tulips of Holland are every bit as pretty as the red roses you had hoped to see in Florence. They may not be as famous, but they are every bit as wonderful. You didn't get a red rose. But you got a blue tulip, and that's quite special, too.<sup>5</sup>

5. Rayna Rapp first heard this parable, attributed to Emily Kingsley, at a Down syndrome parents' support group in 1985. It was plastered on the walls of the pediatric ward Faye Ginsburg occupied with her daughter for most of 1989. More elaborate versions have since appeared in print, at sites as diverse as the Brooklyn waiting room of a school board Committee on Special Education and the back of a newsletter for parents of disabled children.

**Public Culture**

The almost invisible yet widespread circulation of this endlessly photocopied document joins a range of popular imagery in which people with disabling conditions are becoming ever more visible in the public sphere. There is indeed often a direct relationship between the initial efforts of families to reimagine their narratives and the more public actions they undertake to help rescript narratives of inclusion at a broader cultural level. But the call to rethink kinship enacted in the posting of the Blue Tulips flyer is relatively recent and very much the product of the activism of families who have struggled against the categories imposed by medical and bureaucratic regimes.

The example of Down syndrome can illustrate the negotiation of such a category. Until the 1970s, many U.S. doctors would not treat the esophageal and heart problems for which newborns with DS are at increased risk, although the procedures for repair were increasingly well known. Parents of such children were encouraged to “let go,” and often had no source of knowledge with which to dispute medical experts. The result was passive infanticide, or what medical historian Martin Pernick (1996) has called the “Black Stork.” For children who survived, institutionalization was common; removal from their families was considered the responsible action to take for their care. Children with DS were regarded as incapable of emotional attachment or education. It is only since the 1970s that the conjunction of the deinstitutionalization movement, the creation of early-intervention programs for developmentally delayed infants and toddlers, and the passage of federal and state laws protecting the civil rights of the disabled have provided a social environment in which most families of DS children are now able to take them home at birth. This remarkable shift in biomedical, legal, and familial discourse and practice can be attributed in part to the direct activism of parents’ groups such as the Association for Retarded Children (now the Arc) as well as to the indirect impact of writings by the kin of DS people—and eventually by affected individuals themselves—particularly in the form of memoir. Such rescriptings present an alternative world of kinship based on a shared difference, a phenomenon common to many disability support networks (Rapp, Heath, and Taussig 2001). The following quote from two authors who recently became disability activists on behalf of their child clearly acknowledges an indebtedness to those whose narratives have created a sense of kinship that spans generations and crosses biological family lines:

Like all parents of children with Down syndrome, we owe a great deal to the authors of books like *Count Us In*—themselves young men with Down’s syndrome—and their families for having transformed the social

meaning of Down's syndrome by helping to develop what's now called "early intervention for infants with disabilities." But we also find ourselves the unwitting heirs of people and movements *we never knew we were related to*. We saunter with our Jamie publicly largely thanks to Dale Evans who, in 1953, wrote *Angel Unaware*, a best selling memoir of her daughter Robin who was born with Down's syndrome and died at age two. (Bérubé and Lyon 1998: 274, emphasis added)

Despite the progress that has been made since the publication of *Angel Unaware*, bringing a child with DS home is still an act of personal assertion in the United States; in New York state and many other places, the mother of a newborn diagnosed in the hospital is always offered fosterage or adoption placement. Although this practice is shockingly offensive to many new mothers, we should point out that it developed with "the best interests of the child" in mind. Hospital personnel know that disabled babies are at high risk of being abandoned; as they grow older and more difficult to care for, they also grow harder to place in a good home. As newborns are the easiest babies to place, social workers offer information on adoption right away. But the practice has an unintended consequence. The task of composing a normalizing narrative that can create a space of inclusion for the DS child within the family circle is immediately thrust upon the mother, who has to justify to medical personnel the otherwise unproblematic action of taking her newborn home with her.

Constructing such a normalizing narrative is an ongoing process. Down syndrome affects the full spectrum of class and ethnic differences in the United States, and parents of DS children pursue a correspondingly wide variety of strategies for expanding the reach and support of their children's lives. The established script of Down syndrome is being rewritten across a range of sites in a way that opens up a supportive universe for disabled people and their kin. The Special Olympics; infant stimulation programs; consciousness-raising and other sorts of events organized by the disability rights community; and Internet chat groups are all examples of sites that can help reconfigure community for dubious family members.

These forms of positive public mediation of disabled people play an important role in refiguring the cultural landscape for new generations of families engaging with the social fact of disability. The activism of one parent, Emily Kingsley, a scriptwriter for the children's television program *Sesame Street*, is exemplary of this process. Kingsley was told that her son "would never have a single meaningful thought" when Jason was born and diagnosed with Down syndrome. She was counseled to institutionalize Jason immediately and to "try again" (Kingsley and

**Public Culture**

Levitz 1994: 3). Instead, she wrote him into the script of *Sesame Street*, where he appeared throughout his childhood. Contrary to the dire predictions for his intelligence, at age six he was “counting in Spanish for the cameras” (1994: 4). The Kingsleys’ cultural activism opened the door for people with other disabilities—people using wheelchairs, braces, and seeing-eye dogs—to appear as part of the quotidian world of mass media that is now an integral part of the public sphere of most postindustrial countries. Jason himself went on to coauthor the aforementioned book, *Count Us In*, with his friend Mitchell Levitz, who also has DS. Later, his mother scripted a prime-time docudrama based on her family’s experiences, entitled *Kids Like These* (CBS, 1991). Of course, this ability to work in (and have access to) such media venues is not simply a matter of individual achievement, but also of the cultural capital of activist families. As Bérubé and Lyon (1998: 282) point out: “Their fame . . . depends on their good fortune: not only were they born into extremely supportive families that contested the medical wisdom of their day, but they were born into families well-positioned for activism.” Another mother, Gail Williamson, whose son Blair has DS and has also appeared on television, was moved to establish Hollywood’s first talent agency for disabled actors in the entertainment industry (Gray 1999).

Many Americans met their first person with Down syndrome in the late 1980s through the virtual presence in their living rooms of Chris Burke, who became a teen star in ABC’s *Life Goes On*. Introduced by cast members singing the Beatles’ popular song, “Ob-La-Di, Ob-La-Da, Life Goes On,” the show provided a realistic depiction of disability as part of everyday family life, while indexing, as the theme song’s lyrics do, an optimistic message of possibility. But Chris’s story is not only about his heroic triumph over adversity as an individual (Burke and McDaniel 1991). It is imbricated in the complex nexus of changing contexts sketched above that have radically altered the biomedical, familial, practical, and legal narratives structuring disability in America over the last three decades.

Inevitably, the advertising industry was quick to follow the lead of *Life Goes On*, recognizing the potential for growth, not only in direct sales to market niches ranging from psychotropic pharmaceuticals to adaptive technologies, but also in a more indirect appeal to the loyalty of families with disabled members, through the inclusion of DS kids and teens in commercials for McDonald’s, Benetton, and even in popular advertising circulars. Such efforts have been subject to criticism from some activists for reducing issues of citizenship to consumption. Yet the presence of people with visible disabilities in the landscape of popular and commercial culture has been embraced enthusiastically by many families as a sign of the growing public incorporation of this historically stigmatized difference. It



speaks as well to the erasure of disabled characters that continues to prevail in the popular media since the appearance of such figures, even in advertising, is still regarded as exceptional.

### “What Are You Staring At?”

Whatever progress has been made, there are still relatively few televisual spaces for children that regularly feature kids with disabilities talking about their own lives (as opposed to what some disabled children refer to as “models in wheelchairs”). The shows discussed above are salient exceptions, as is the Nickelodeon children’s cable network’s magazine program, *Nick News*. “What Are You Staring At?” was an innovative special produced by *Nick News* that aired repeatedly during 1999. The half-hour program featured a group of kids and teens with a range of disabilities—DS, hearing and visual impairments, cerebral palsy, polio, burn injuries—talking about their lives with celebrity crips, journalist John Hockenberry and actor Christopher Reeve. The anecdote that follows, an account of one youngster’s experience of this show, may be read as an illustration of the way that such public interventions can help to create an alternative horizon of kinship extending beyond the nuclear family.

In the summer of 1999 in New York City, ten-year-old Samantha Myers surfed onto “What Are You Staring At?” and was riveted. When the final credits ended, she announced to her mother that she wanted to talk about her disability on television. Samantha’s disorder, Familial Dysautonomia (FD),<sup>6</sup> is an extremely rare condition of the involuntary nervous system that affects all forms of body regulation, including temperature, blood pressure, swallowing, and respiration. With some adult assistance, she found the Web site for the Make-A-Wish Foundation, a group that grants “wishes” to children with life-threatening diseases. She e-mailed them, explaining that her wish was to go on *Nick News* and talk about her life with FD. Within two weeks, she was working with a friend and a Make-A-Wish volunteer, making a pitch book with color photos and handwritten text about her life and disability. Sam’s inventory of her life included police-style pictures she took of all her medical equipment, as well as photos of her dog, friends, and relatives.

By her eleventh birthday, she was working with a producer from *Nick News* to make a five-minute segment that she narrated, replete with footage of her school,

6. Information on FD is readily accessible at two Web sites: [www.FamilialDysautonomia.org](http://www.FamilialDysautonomia.org) and [www.FDVillage.org](http://www.FDVillage.org).

**Public Culture**

doctor, friends, and some whimsical computer animation to make it kid-friendly. In late April 2000, the show was broadcast; as a result, over the next few months, Sam was invited to show her tape and talk to a number of groups. Of greatest significance to Sam was that so many FD kids were able to see another child like them on television. She was deluged with e-mail from families with FD children around the country who were thrilled to see an image and story that for once included their experience. Many, like Sam, went on to use copies of the tape to help teachers and classmates understand the particular issues that kids with FD face on a daily basis.

**Mediated Kinship**

The media world into which Sam surfed at the end of the twentieth century is evidence of a transforming public culture in which disability is becoming a more visible presence in daily life. This anecdotal evidence—Sam's immediate sense of kinship with the disabled kids she saw and heard on television and her desire to join that process—suggests how significant such imagery can be to those who do not see themselves regularly in dominant forms of representation. Indeed, much of the early writing in disability studies focused not only on the need for changes in civil rights legislation, but also on the absence of disabled people from literature and popular media—or, where present, the negativity of their portrayal, citing the legacy of freak shows, circuses, and asylums (Bogdan 1988; Thomson 1997). Others were working actively to alter the media landscape itself. Along with parent-activists who worked in the mainstream media, such as Emily Kingsley, there were people like Mary Johnson and Cass Irvin, who in 1980 founded the alternative journal *The Disability Rag* (Shaw 1994). Nowadays, the work of activists in visual media is increasingly evident in the plethora of photography shows and film and video festivals devoted in part or entirely to the topic of disability. And, of course, the Web sites, e-lists, and chat groups of the Internet have dramatically expanded the range of sites at which images of disability are being negotiated.

The circulatory reach of electronic media is the key factor in the creation of what we call *mediated kinship*. Emerging as a neighboring—and sometimes overlapping—field to the formal, institutionalized discourse of disability rights, mediated kinship offers a critique of normative American family life that is embedded within everyday cultural practice. Across many genres, a common theme is an implicit rejection of the pressure to produce “perfect families”

through the incorporation of difference under the sign of love and intimacy in the domain of kinship relations. We suggest that these mediated spaces of public intimacy—talk shows, on-line disability support groups, Web sites, and so on—are crucial for building a social fund of knowledge more inclusive of the fact of disability. These media practices provide a counterdiscourse to the naturalized stratification of family membership that for so long has marginalized, in particular, those disabled from birth. It is not only the acceptance of difference within families, but also the embrace of relatedness that such models of inclusion present to the body politic that makes these spaces potentially radical in their implications. As sites of information and free play of imagination, these cultural forms help to create a new social landscape.

The struggle to form inclusive familial units takes place within an increasingly complex discursive world, a terrain in which the so-called genetic revolution—and the part played within it by prenatal testing—cannot be ignored. One suggestive source of images by which that revolution is imagined is via a classic trope of science fiction: the neoeugenic dystopia, as portrayed in books such as *The Handmaid's Tale* (Atwood 1986) and in films such as *Gattaca* (Andrew Niccol, 1997); these are stories of monstrous kinship. But a more common discursive field is the science or business page of the newspaper, where advances in scientific knowledge, especially genetic technologies, are regularly reported, yet the social dilemmas they index go largely undiscussed.

These dilemmas beg questions about who is entitled to make interventions into reproduction, the capacity of kinship to encompass difference, and the social location of care. Although these are experienced as private, family matters, they cannot be contained within domestic domains. Caretaking is perhaps the most naturalized of these, conventionally attached to the unpaid labor of women in the home. Yet, in the United States, it is rapidly becoming a politicized arena in a privatizing economy in which families are expected to be “always on call,” as Carol Levine argues in her book of that title, to care for disabled kin (Levine 2000; see also Nussbaum 2001). If paid, the labor of family caregivers would cost about \$200 billion a year (Langone 2000). Nevertheless, while health insurance increasingly covers the routinization of new reproductive technologies (NRTs) and the costs of neonatal intensive care units (NICUs), most home-based personal assistance—a need estimated at 21 billion hours yearly—goes unpaid by public funds, despite the demonstrable bodily, emotional, and economic benefits of deinstitutionalizing support (Johnson 2000: 14; Linton 1998; Russell 1998). This is a skeletal sketch of the political economy of health care and assisted liv-

**Public Culture**

ing “choices” that affects all Americans. Yet it is a barely visible landscape to most people unless and until their own or a family member’s disability reveals its limitations on a practical, daily level.<sup>7</sup>

These revelations of the limits of kinship-based caretaking and the need for broader social recognition and resources for people with disabilities fuel the narrative urgency we have described throughout, beginning with Oe’s compelling story of a “healing family,” offering stories of familial inclusion that can serve as models of social inclusion as well. Additionally, progress in legal arenas has problematized the presumption of American citizenship as the exclusive entitlement of a normative, able-bodied, nondependent, wage-earning individual. At best, this model of personhood describes only a portion of the normal human life cycle. At worst, it systematically erases the rights of the disabled and their caretakers to have their fundamental needs addressed in the public arena.

Although we have focused here on the nexus of disability rights and reproductive decision-making as highlighted in the parent-child relationship, kinship and disability—as instantiated by congenital difference, accident, illness, infancy, or old age—remain entwined throughout the life cycle. Thus, the disjunction between the aspiration for democratic inclusion and the fantasy of bodily perfectibility through technological intervention has energized much popular cultural expression, creating a growing sense of public intimacy with experiences of disability. In this gap, disability narratives offer what we have called *unnatural histories*, visions of lives lived against the grain of normalcy. It is here, we have argued, that the relations of kinship have the capacity to enable disability, giving narrative shape and cultural imagination to efforts to form a more perfect union.

7. In the United States and throughout much of the world, the tasks of caretaking continue to be naturalized in the domain of unpaid domestic labor. Increasingly, however, challenges to this situation are emerging as a result of the expanding needs of caretaking over the life cycle. The increased rate of survival among such formerly high-risk groups as low-birth-weight babies, the chronically ill, and the elderly make claims on public resources, usually mediated through their kin. Advocacy groups such as the growing movement for Independent Living seek public support for personal assistance, a policy that, they argue, “would relieve an enormous amount of stress on families and, over time . . . would begin to alter the public perception toward significantly disabled people and the people who relate to them” (Marca Bistro, head of the National Council on Disability, quoted in Johnson 2000: 14).

**Rayna Rapp** is a professor of anthropology at New York University. Her most recent book is *Testing Women, Testing the Fetus: The Social Impact of Amniocentesis in America* (1999). **Faye Ginsburg** directs the Center for Media, Culture, and History at New York University, where she is also David B. Kriser Professor of Anthropology. She is the author of *Contested Lives: The Abortion Debate in an American Community* (2d ed., 1998). Rapp and Ginsburg coedited *Conceiving the New World Order: The Global Politics of Reproduction* (1995) and are beginning a new research project on learning disabilities.

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