

## **Enlarging Reproduction, Screening Disability**

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### **I. Introduction**

Disrupted reproduction<sup>1</sup> now means far more than the use of assisted reproductive technologies (ARTs). In the present era in the U.S. and other developed nations, the dramatic growth in use of ARTs should be viewed in light of a much larger and more steadily increasing use of technologies of “neonatal salvage” (as well as less heroic medical interventions) that have enabled a much wider range of medically challenged infants to survive. Thus, the “disruption of reproduction” – as other chapters in this collection also make clear -- has much broader temporal and socio-cultural consequences than the language of reproduction might suggest. Our goal in this chapter is to look at the social processes by which this expansion occurs. We do so through a general discussion of the increasing visibility and acceptance of disability in both public media and the more intimate domain of kinship. We see this work as an expansion of our prior development of the concept of “stratified reproduction”, a term we use to describe “the power relations by which some categories of people are empowered to nurture and reproduce while others are disempowered” (Ginsburg and Rapp 1995 cf. {Colen, 1995 #115)

With more and more premature and medically compromised infants surviving, the consequences of “disrupted reproduction” are thus felt most intimately and significantly in the lives of their families, often far beyond the temporal limits of neonatal intensive care units (NICUs), at least in Western countries where these technologies have become routinized. In an era when American families are no longer encouraged to institutionalize their non-normative babies (or other family members at later life stages), it is no longer

simply reproduction, birth and early infancy that are disrupted. As babies with disabilities grow, many assumptions about kinship relations, domestic cycles, and community membership are challenged as well. The arrival of disabled infants (and others) into families, in most cases, rearranges presumed narratives of “normal” family life, as parents, siblings, extended family, and a broader community learn to reframe expectations of everything from developmental milestones, to the introduction of sign language and ramps in places of worship, to the discovery of what constitutes a “least restrictive” educational environment. “Learning the ropes” of living with disability is often fraught with resistance and prejudice. Battles inside and between families, communities, and institutions frequently entail costly interventions in situations of scarce resources (Landsman 2000).

To restate the case, understanding “disrupted reproduction” requires a wider gaze, one that goes beyond the immediate event of reproduction to take account of the vagaries of domestic cycles and the broader structures that shape the lives of “handicapped families” (Oe 1995) which range across many domains. These include:

1. Changes in the law that recognize (or challenge) civil rights for the disabled;
2. Mandated inclusion of disabled children in public schools and the ways in which this is (or is not) carried out;
3. The increasing presence of disability and its treatment or cure in science and medicine, undergirded by the support of politicians and celebrity activists around issues such as stem cell research. These are often driven by a discourse of salvation;

4. The expansion of medical and para-medical services – from NICUs to occupational and physical therapy to home health aides -- that support the care and integration of people with a wide range of disabilities; and
5. The increasing, although still limited, presence of non-normative bodies and minds in public media of all kinds, including popular books, magazines; commercials, sit-coms, independent and even Hollywood films, and sports coverage of events such as the Special Olympics.

Without question, there have been groundbreaking achievements. Over the last twenty-five years, disability rights activists have helped to catalyze policy initiatives that offer a potentially radical 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 postwar federal legislation that have established the framework for the civil rights for Americans with disabilities, although they are currently endangered in both the Congress and the courts under the present Bush regime's initiative to privatize a broad range of public services. Still, these accomplishments have dramatically transformed both the institutional and intimate frameworks within which American families operate. Subsequent (if often contested) legal decisions have elaborated on these gains in the fields of education, medicine, and the built environment.

Along with many disability scholars and activists ((Albrecht, Seelman et al. 2001) (Davis 1997; Barnes 1999; Corker and Shakespeare 2002) (Linton 1998)), (Priestley 2003)), we contend that these legal victories are necessary but not sufficient to alter the

cultural landscape that extends into the realms of “public intimacy” ((Berlant 2000)). Beyond the securing of formal rights, there lie the hearts and minds of a broad range of people – from family members to neighbors to teachers and others --- who not only vote but also shape the environment in which children with disabilities come of age. Formal accommodations in schools, for example, are not automatic. First, children must be given an appropriate diagnostic category that allows services to be legally mandated. Making sure they are actually made available can require enormous labor for advocates. This is work that most often falls on families and other daily intimates of youngsters with disabilities.

In this chapter, we argue that transformations in these different domains of public life are crucial but cannot be understood apart from the intimate arena of kinship and community. These are the locations where changing understandings and practices of reproduction and disability are often first played out. While each constellation of kin and community follows its own idiosyncratic learning curve, inevitably, they discover that they are part of “an unexpected minority” (Gliedman and Roth 1980), one of the many social networks of people with disabilities that take shape both formally and informally. In other words, while the term kinship is conventionally associated with the private or domestic sphere, we highlight the considerable cultural work that is performed in public (Franklin and MacKinnon 2001). This includes not only demands for political equity but also the circulation of kinship narratives that are inclusive of disabled family members through a variety of media, as we discuss below. Such stories that reframe normalcy are an essential element in the refiguring of the body politic as envisioned by advocates of both disability and reproductive rights. Indeed, many become involved in creating more

visible and enduring structures, from support groups to websites to legislation. ((Oe 1995) (Rapp and Ginsburg 2001)).

Here, we focus on the impact of disability across the life cycle and in families, with particular attention to the shifting boundary between visibility and invisibility in public consciousness. Thus, we are especially interested in the increasing presence of disability as “a part of life” in a broad range of popular media – books, films, television shows, websites, magazine writing, theater, as well as public space. We have grown accustomed, for example, to the ubiquitous signs of wheelchair accommodation and the increasing number of elevators equipped with auditory floor signals. However, disabilities which are not readily visible have not made a claim on public awareness as these have. It is still difficult, for example, to imagine signage accommodating dyslexic readers, as is clear to any parent of a learning disabled child who has had to maneuver on a New York City subway. Clearly, there is a moving edge of recognition, as well as a hierarchy of which disabilities “matter in public”, an issue that is made more complex by the stratification of corporeal distinctions, from the routinized visibility of people who use wheelchairs and ramps to the imperceptible but growing presence of the learning disabled. While the increasing range of publicly accessible representations of disability gives us reason for cautious optimism, as we discuss below, other trajectories in contemporary life that valorize normalcy and its variants often work at cross-purposes, as we have argued elsewhere regarding the imperatives of genetic testing ((Ginsburg and Rapp 1999; Rapp and Ginsburg 2001)). These are so deeply embedded in our daily “mediascapes” (Appadurai 1996) that their epistemological collisions easily go unnoticed

even to the tutored mind. Yet the two go hand in hand as the perfectibility of ARTs meets the democratic assertions of disability rights.

## **II. The changing state of contemporary reproduction**

Our consciousness of “reproductive disruption” has changed radically and recently for reasons well-known to researchers in the field, who are well aware of the political and historical specificity of the present moment. The medicalization of reproduction –from pre-conception to neo-natal care and rehabilitation of highly vulnerable newborns, infants, and children—continues apace in those countries and class strata with entrée to the latest technologies. And it reveals problems and possibilities which are themselves often disruptive: women with medical access find their prenatal landscape littered with: pre-conceptual nutritional and lifestyle counseling, level 2 sonograms, prenatal diagnosis (PND), prenatal genetic diagnosis (PGD) and more. Percutaneous umbilical blood sampling (PUBs), chorionic villus sampling (CVS), and quadruple screen blood tests may produce or confirm prenatal diagnoses, along with amniocentesis. Should the prenatal news be bad, some may choose to experiment with fetal surgery (Casper 1998); although abortion remains the “choice” of many receiving disturbing news of life-threatening or life-altering fetal disabilities (Rapp 1999). At the same time, over 20,000 pregnant women each year give birth in New York City’s emergency rooms, having received no prenatal medical care whatsoever. Proportionally speaking (and despite how unnerving we find the New York statistics), the news is much worse from other parts of our country, where the “medical insurance crisis”, always high on the list of voter concerns, is routinely manipulated and politicized. This is a

quintessentially American situation in which reproductive “decision-making” is usually experienced as an individual “choice” of vast and anxiety-laden possibilities. Yet as these techno-demographics indicate, it is also always highly stratified in our national and rapidly-changing social context. These choices frame the dilemmas facing the current generation of American women (and their supporters) of childbearing age, choices that were unimaginable not even two decades ago.

Some aspects of these new technological interventions are widely shared: approximately 10% of fetal deaths, for example, are now diagnosed on early sonogram, increasingly available to most women who receive prenatal care, rich and poor alike (Rapp, 1999). Others are class-specific: multiple high-order births routinely result from the expanded use of in vitro fertilization (IVF), which remains uncovered by most insurance policies and is, in any case, the prerogative of the well-to-do (Bakalar 2005; Lee 2005) (Chavkin 2007). On the whole, they affect older parents. And successful IVF produces a disproportionate number of low birth weight newborns. Yet the babies of the poor—especially, the African American poor—are also at elevated risk of low birth weight and extended stays in neonatal intensive care units (NICUs) here in the United States, a problem upon which we elaborate below. A generation ago, we would have, indeed, assumed that the scourge of low birth weight (LBW) was mainly associated with poverty; now it is also associated with advanced maternal age and fertility-assisted reproductive techniques.

Such obvious commonalities and differences place both the multiple births of costly assisted fertility techniques and the babies of the poor “at risk” to become diminutive patients in NICUs. Continuing the story, the successful treatment and salvage

of low-birth weight premature babies contributes to the increased incidence of children with learning disabilities who are exquisitely stratified in their access to educational and other social resources ((**Bakalar 2005**) (**Grady 2005**) (**Lewin 2000**)). They, in turn, commonly live with diagnoses of “co-morbidity” that fuel and are fueled by the revolution in pharmaceuticals, where drugs for ADHD and other neurological disorders are among the most-dispensed and best-studied prescriptions of the last two decades (Conrad and Potter, 2000). And, further along, formerly LBW babies frequently grow into children requiring and receiving: occupational therapy (OT); physical therapy (PT); speech-audiology therapy; reading services; and special education accommodations. It is no exaggeration to say that both highly privileged and underprivileged consumers of new reproductive technologies — including sonograms, NICUs, and the routine long-term use of medications -- live on a rapidly expanding biomedical, biotechnical and pharmaceutical horizon, whose full impact is yet to be assessed. Without question, whatever its outcome, the uptake of these technologies is highly stratified.

The expanding terrain of techno-reproduction where decision-making and experiences of childbearing intersect our social fund of knowledge concerning childhood disabilities requires a broadened framework.<sup>2</sup> Beyond the womb, families face the nursery, the kindergarten, and primary, middle and high schools, where the tensions between the experience of living with difference and the normativity of educational institutions play out in daily life. Yet we know little about the stratification that influences how families, networks of care, professional child-service providers, and communities of acceptance and rejection integrate decisions and differences surrounding childhood disability. Nor do we know very much about what constitutes a visible,

invisible, or partially-visible disability in different communities and families. Down syndrome, for example, is widely, if not universally, recognized, stigmatized, and differentially accepted: at the risk of building on old stereotypes, poor women use abortion services after a prenatal diagnosis of this condition, just as richer women do. But they appear to end pregnancies at lower rates (Rapp, 1999). The phenotypic familiarity of Down Syndrome is clearly part of the recognition, stigma, and high abortion rate (Rapp 1999). By contrast, learning disabilities are relatively invisible and they are not prenatally diagnosable directly, although they often accompany the diagnosis of LBW. We know correspondingly little about how parents, siblings, and children and young adults with learning disabilities relate to this increasingly common label ((Rodis, Garrod et al. 2001) cf.(Varenne and McDermott 1998), or what its class differentiated (or age or gender or religious, etc. differentiated) meaning might be.

Stratified disability has become visible along multiple dimensions. Quantitative research makes clear the impact of broad social fault lines, as we elaborate in the next section. Most of what we know about childhood disability has come through an avalanche of demographic and health statistics; indeed, they provide the primary and powerful frame through which we understand these social phenomena. This is clear in the rising proportion of children in special education relative to NYC birthrates ((Lewin 2000)). The professional expertise of statisticians is culturally dominant, as many social scientists have noted ( (Asad 1994), (Daston 1987), (Greenhalgh 2003) (Krause 2001), cf. (Hacking 1990) etc.). And we welcome it as a first-cut in making clear the enormity of this complex landscape.

Qualitative perspectives are less developed in the research literature. Yet we believe that they have the capacity to reveal the many small-scale and daily practices that we take for-granted, as shown by some groundbreaking exceptions in anthropology and related fields ( Frank 2000), (Landsman 1999; Landsman 2000; Landsman 2003) cf. (Murphy 1987)). Additionally, a cottage industry of first person accounts and familial memoirs give enormous insight into life course issues ((Beck 1999), (Berube 1996), (Moore 2005), (Park 2002)). These provide, we suggest, indices of the historicity, stratification, and struggles over the meaning of normality. Their analysis helps to illuminate the everyday impact of a changing technological horizon, the landscape on which babies – and the children and adults they become -- are currently conceived, cared for and stratified.

As noted earlier, our concern lies with the representations and practices of kinship, community, and life cycle that are key to emergent understandings of disability as part of daily life. Neither the social construction of an embodied difference, nor its consequences remain stable as individuals, families, and kin groups grow, grow-up, and change. The cute kindergartener with a newly diagnosed learning disability holds a different valence as s/he grows into (or does not become) a high-schooler, a job-holder, a technical school or college student, a potential spouse or parent. Thus, until we breathe life into reproductive stratification across the known fault lines of gender, socioeconomic class, racial-ethnic, religious, and national backgrounds, we cannot address the daily benefits and burdens entailed in adjusting non-standardized newborns and children to an increasingly standardized world. Moreover, hierarchies are not shaped only along lines of class or race. Disability itself is stratified across its many medicalized and socialized

categories, despite the strong and democratic demands of the disability rights movement that all forms of impairment be equitably understood and accommodated.

One key division is the social visibility or invisibility of the differences to which kinship and community speak. Learning disabilities, ADHD, and mild mental retardation manifest themselves differentially in social space when compared, for example, to the uses of wheel-chairs, the stereotypes accompanying Down Syndrome, or the marked profiles of people born with other visible impairments. Furthermore, a life-course perspective clarifies how we make *meaning* out of different kinds of disabilities as they change through individual, familial and social life times. Arranging for an early intervention infant stimulation program is not, for example, the same family task as rethinking assumptions about parental retirement when a young adult offspring is unlikely to ever live independently, or be adequately employed in order to cover the considerable expenses required to live with necessary forms of medical and social support. And in a post-Freudian world, a person with a disability can be presumed to have a different perspective on independence and life goals than parents, siblings, friends, caregivers, and bureaucrats. These varied relationships to visibility, invisibility and life-cycle consequences of diverse impairments are hard to pry loose from the vast data sets which currently populate the terrain of disability over time. It is therefore to the life-cycle that we now turn.

### **III. Stratifying the life-cycle**

As feminist anthropologists and their fellow-traveling scholars have long noted, the universal “fact” of pregnancy is lived quite differently and specifically, according to

the social position and the access (or lack of access) it brings to other valued resources (e.g., (Bledsoe 2002) (Glenn, Chang et al. 1994) (Martin 1987) (Rapp 1999) (Sargent 1989)). Age of first and subsequent pregnancies, total completed family size, presence or absence of marital and kin-based support systems, religious institutions and practices all intersect structural issues like medical access to prenatal care, venue and quality of birth services, and many nutritional issues –subtle and not-so-subtle— affecting maternal/ child health. Some structural and institutional conditions may appear quite “experience far” ((Geertz 1967). But if, for example, public struggles over the quality of schools, revised requirements for disability support entailed by federal and state welfare reform, or the condition of the job market seem distant, they nonetheless are highly influential in the reproductive choices and outcomes with which mothers and others are faced. Here, we argue that this stratification is lived differentially across the life cycle and generations as well.

This is, for example, particularly apparent in a 2003 book by a team of quantitative sociologists who have taken on the vexing issue of low birth weight babies. Dalton Conley, Kate Strully, and Neil Bennett have parsed the dense data on low birth weight in the United States to offer a biosocial interpretation. Approximately 9% of U.S. babies are now annually born at low birth weight (at or below 2500 grams); about 20% of them exhibit very low birth weight (at or below 1500 grams). These very vulnerable babies are one of medicine’s great success stories: before WW II, most would have died from prematurity and its infectious sequelae. Since the advent of antibiotics and incubators in the 1950s, and NICUs with their sophisticated external respiratory systems in the 1960s and 70s, there has been a dramatic shift upward in neonatal survival rates.

About 90% of the improvement between 1960 and 1980 is attributable to the salvage of LBW babies who formerly would have died (Conley, 2003, p.11). Roughly speaking, the very smallest of these very-LBW babies grow up to have substantial health impairments; the much larger group of just-LBW babies is likely to face more subtle educational challenges. While some escape unscathed, this overall pattern in disability is striking. We as a society now integrate a substantial number of babies whose medical success implies educational and health challenges throughout their early years, and often throughout their life course. This, in turn, has consequences for new and experienced mothers — or, as one magazine for families with disabled children calls them by its title, *Exceptional Parent*. It also has an impact on siblings and extended family members, communities of support and derision, and the schools and other institutions in which these children will someday dwell. So it is not only the disruption of “the starting gate” of pregnancy and birth that needs examination: the world of families through the generations also requires our attention. And as “(a)verage birth weights among groups are very sensitive to social inequality, such that African Americans and the poor are at a disproportionate risk of being born low birth weight” (Conley, 2003, p. 7-8), there are profound and often class and racialized consequences for the rest of their lives. A generation or two ago, we would not have discovered this problem.

To complicate the example, African American LBW could easily (too easily) be chalked up to a biological or genetic susceptibility: it runs in families and newborn girls are at higher risk than newborn boys. Moreover (and frighteningly), there is substantial evidence that physiological stressors experienced by grandmothers are imprinted in ways currently unknown on the tiny bodies of their grandchildren (Conley, Strully et al. 2003).

In other words, once LBW enters one's genealogy, its exit is hard to achieve. Yet even in such a seemingly intractable demographic, this team of sociologists argues convincingly that:

(While) biological and social advantage or disadvantage, inherited from previous generations, frequently interact with one another to determine a person's social position...if low birth weight parents enjoy a high income, the effect of parental low birth weight diminished. Similarly, having been born low birth weight oneself significantly hinders education attainment, and hence long-term economic prospects. But if a low-birth-weight child grows up in a household with a high enough income, the biological effects of low birth weight may begin to recede ((Conley, Strully et al. 2003), p. 121)

Low birth weight thus presents a perfect object of nature/culture implosion that involves disrupted reproduction as it moves through time. At stake are the intimate cultural narratives of family concern and attentiveness and sibling competition and cooperation. At the same time, public and institutional forces are key: the economics of school-enhancing employment leads, for example, to more successful jobs across the generations. And the politics of preventative programs and practices, including the black box that stress represents nutritionally, medically, and financially, all enter into the meaning of being born LBW. Thus the educational component of learning disabilities so highly associated with LBW can only, we argue, be understood in its fuller social context. And this includes a domestic cycle and life cycle perspective on how advantage and disadvantage pass down through the generations.

This point is well-made for the more generalized category of disabilities by Gail Landsman (Landsman 2003) in an important contribution to the emerging qualitative research. When she undertook research with families of children enrolled in an early diagnostic program for babies at risk at SUNY-Albany medical center, Landsman was struck by the transformative narrative that mothers of tiny babies struggled to produce. Over five years' time, their despair and anger mutated into a struggle with clinicians and other helping professionals who often failed to see the slow and quite subtle progress they individually diagnosed in their kids. Often disparaged as “denial” or “subjectivity”, the insights of mothers and others adjusted to both the lack of milestones when compared to the well-trod path of normal and normative child development, and the polarizing discourse of medical personnel, often despite their best intentions. This change took time; it was not evident in the niche of reproduction, but made itself visible like a negative floating in a chemical bath as it developed under specific conditions. Accompanying this experience of “mothering on mars”<sup>3</sup>, was also a transformed social landscape: dominant discourses often flattered the “special mom” with inappropriate and sugary praise that isolated her as a hero rather than supporting her as an ordinary woman in struggle with extraordinary labor-intensive conditions of childcare. At the same time, Landsman found that many people subtly or overtly bestowed blame on mothers for causing the child's disability: clinicians, neighbors, church co-congregants, and mothers-in-law all queried, for example, what she had eaten and drunk during an otherwise uneventful pregnancy that produced a diagnosable child. So the life of the mother (and by extension: the father, the sibs, the grandparents and others) was also transformed over time by the birth of a baby who was diagnosably different.

Other forms of social stratification deeply mark this m/othering: For example, the essays in Linda Layne's edited collection, *Transformative Motherhood*, make the point that non-normative motherhood takes on specific ideologies associated with "damaged goods" in a market-oriented, consumer culture that devalues mothering disabled children, multiracial children, adopted children and much more (Layne, 1999). The mother/child relations described by Danielle Wozniak, for example, focus on the gifts and burdens of legal fosterage, a state-regulated and culturally inferior context in which both hidden and overt disabilities could use healing. Often damaged by multiple losses and sometimes multiple threats, foster children may also be relatively unadoptable because of more obvious and visible disabilities (Wozniak 1999). Likewise, Frances Winddance Twine and Helena Ragone, entitle their collection on non-normative or problem-drenched parenting, *Ideologies and Technologies of Motherhood* (Ragone 2000). Although the editors do not stress this aspect of the book's essays, a reader can glean a lot of information on the burdens and benefits of mothering under culturally disabling conditions across the life cycle. Prejudices of race, divorce, homelessness, and poverty affect the acceptance of mothers and their children.<sup>4</sup>

Of course, this common experience of holding women accountable for the quality of their offspring – the "blame the mother syndrome" -- is widespread, and not limited to the mothers of children with disability. But it is particularly present as an unfortunate "learning experience" in our national culture, as mothers have to learn to insist that they are not the cause of symptoms; children need to be properly diagnosed and remediated. More positively and often unexpectedly, mothers and other family members often discover that disabilities in the family open up awareness of something

rarely recognized in our highly rationalized market-driven culture. The experience of disability is fundamentally about the range and significance of our common humanity. In response to that experience many have become “moral pioneers” in their families, schools, communities, and beyond (cf. (Rapp 1999). Some --- who already had a foothold in the world of media – expanded beyond these domestic networks to make disabilities visible in the public domain.

#### **IV. Screening disability**

....what do movies have to do with disability rights? ..... "If an issue doesn't appear in print, on television, or in the movies to most people it doesn't exist."

Clearly, the ways in which the disability experience has been perceived by the media remains severely limited. I spoke to a group of graduate students about the depictions of people with disabilities in film, television and literature last week and one clear sentiment emerged, if a story -- this is true with both news items and narratives -- doesn't fit into an existing frame, that is to say if it isn't about heroic crips, tragic crips or evil crips then most people can't even process it because, for them a more accurate frame of reference does not yet exist. ...

Moreover, a case could be made that until those not yet in the disability club or in the know better understand the very real lives of people with disabilities; until they can better identify with our stories, disabled people, for all intensive purposes, will continue to be invisible. Until new narratives are seen, heard and read the general public will not be able to develop a new, more accurate frame of

reference by which they can better understand our lives -- and by extension, our issues (Carter-Long 2005).

Disability activist Lawrence Carter-Long's grim appraisal of the place of disability in public media is well-founded. Nonetheless, the media presence of disability as a fact of life – on screen and off – is clearly on the rise in popular television, independent film, and Hollywood cinema, and on the web. These forms of positive public mediation play an important role in refiguring the cultural landscape for new generations engaging with the social fact of disability<sup>5</sup>.

Things were radically different a half century ago, as the social historian Martin Pernick makes chillingly clear; media images of disabled children were anything but sympathetic. Disabled minds and bodies were represented as a danger to the body politic, setting a stage on which acts of passive infanticide were regarded as acceptable ((Pernick 1996). Thirty years ago, the “mediascape” (Appadurai 1996) began to change. It took the “moral pioneering” of one parent, Emily Kingsley, a scriptwriter for the children's television program Sesame Street, to show how things might be different. When her son Jason Kingsley was born and diagnosed with Down Syndrome in 1974, his parents were told that their son “would never have a single meaningful thought” and they were counseled to institutionalize him immediately and to “try again” ((Kingsley and Levitz 1994): 3). Instead, his mother 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,

leg 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 book, *Count Us In* (1994), 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" ((Brown 1987)). 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 and professional families. As Michael Bérubé and Janet Lyon 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.” ((Berube and Lyon 1998): 282) 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).

In the late 1980s, many Americans met their first person with Down Syndrome through the virtual presence in their living rooms of Chris Burke, who became a teen star in NBC’s “Life Goes On”. Introduced by the Beatles’ popular song, "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 newsprint advertising circulars. Such efforts have been subject to criticism from some activists for reducing issues of citizenship to consumption. Yet, seeing people with visible disabilities in the landscape of popular and commercial culture has been embraced enthusiastically by many families who identify with their presence 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 rare.

Interestingly, recent television dramas not only make disability a prominent part of the narrative of important historical figures and their worlds; they are also reflexive in structure, commenting on the ways that disability was rendered invisible in the eras that they depict. For example, nostalgia-hungry Americans watching *Masterpiece Theater* on PBS over the Christmas season of 2005 expected a costume drama of a British world on the brink of the transformation wrought by World War I. They got that, and more. Director Stephen Poliakoff chose to tell this story from the point of view of a stigmatized member of the royal household: the young Prince John whose epilepsy and learning difficulties were hidden from public view until now; hence, the title, "The Lost Prince". This film was created in dialogue with a 21<sup>st</sup> century media world in which disabilities

are gradually “going public,” in contrast to the period a century earlier he was invoking. Poliakoff eloquently describes this process.

One morning in the spring of 1998 I saw a photograph of an ungainly looking boy staring out of the front page of a national newspaper. He was dressed in the customary sailor suit that most Edwardian upper-class children wore, but there was something about his gaze that was both unsettling and welcoming. This was the first time I had seen what Prince John had looked like and I was immediately fascinated. I quickly found out that there was practically nothing about Prince John published in the public domain, most royal biographies confining themselves to a few sentences about the poor epileptic and autistic prince who had to be sheltered away from the rest of his family and the world. But as I gradually pieced together a picture of Johnnie from the few snippets of information that were sprinkled over a wide range of royal histories, I realized that a different boy was emerging. It turned out Johnnie was very far from being the monster child that grew enormous for his age whilst having the mental age of a three year old which is the way, for instance, one article on the internet described him. Johnnie had learning difficulties and was prone to severe epileptic fits but he was also capable of interesting and humorous observations about people and situations and inspired devotion and love from his nurse Lalla, a devotion that lasted nearly half a century after his death. For me, the most surprising modern echo of the lost prince is how, nearly a hundred years after the events I describe took place, we are only fractionally more flexible and wise about how we treat children who are 'different' from the Edwardians.

**(Poliakoff 2005)**

Another 2005 televised film, the Emmy award-winning HBO drama, *Warm Springs*, tells the story of FDR's struggle with polio, beginning in the 1920s. The film starts as a 39-year-old Franklin Delano Roosevelt – whose political career was just taking off -- becomes a paraplegic in 1921 due to a bout with polio. The narrative of the film is shaped by the battle between the contemporary dominant view – that the disabled should be sequestered – and the emergent radical position that they should not. These positions are embodied in the characters of his mother, Sara Roosevelt, who regards her son's political life as over; and his wife Eleanor, who is his staunch advocate, despite marital infidelities, and are replayed in the broader political arena. FDR, discouraged and depressed at the lack of treatment, travels in 1924 to Warm Springs, a dilapidated spa in rural Georgia, where the water is rumored to provide “miracle cures” for those with polio, while Eleanor, his wife, shakes off her shyness to become a public figure. By 1932, he is elected president, the first of four terms. His cabin at Warm Springs is dubbed the Little White House.

Much like Poliakov's fascination with his discovery of the lost prince, *Warm Springs*' scriptwriter, Margaret Nagle, was compelled by the story of FDR's polio that had been “hidden in plain sight.” We quote her at length because her story reflects both a view of disability not available to prior generations, and the inclusive perspective that comes from a life lived in intimate connection with this form of difference.

I've always loved Franklin and Eleanor and been fascinated and intrigued by them. I read somewhere five or six years ago that Franklin was actually a paraplegic. And I kind of went, "hey, whoa." so I started going through the stacks at the Beverly Hills Public Library and I found two books that were way out of

print that had been written by people who had gone to Warm Springs (where FDR went for treatment) and who themselves had polio...So of course his disability wasn't discussed or made public, not just because he was a public leader, but because people connote a lot of other things with disability...you did not know how you got polio. There was no cure for polio. Most people with polio died. If you were left a paraplegic or paralyzed, you usually died within a couple of years. People thought that polio went to your brain. That was one of the misnomers. They thought you got it potentially because of some moral failing, that you were maybe being punished by god. If you were a handicapped child in the United States at that time, you were denied public education. You were not allowed to go to school.

...So there were all these very scary myths surrounding polio in general that would make it something that you would not discuss. Ever. Publicly. When someone becomes disabled that you love, your whole perspective on life changes. You revalue your values... Just like the person who becomes disabled revalues their values.

I started to look at all these books and realized no one's really covered this. And the reason was is that no one really wanted the extent of his disability to be known. And I understood this instinctually, because people are really afraid of disability. And they are afraid of people with disability. And it is still, even today, I know from whenever I go in-in public with my brother, just how fundamentally uncomfortable people are with all of that.

The brother she refers to is very much part of the motivation she brought to the film.

Well, it was actually quite personal for me, because my own brother, my older brother became disabled in a car accident when he was little. And he and I grew up sharing a room. He was in a coma for a long time. He had to re-learn absolutely everything. He did, finally, after years, get up and walk, and his speech was unintelligible but I always knew what he was saying and I would translate for him. So our house was sort of like a 24-hour rehabilitation center. And that was my orientation to life in general. And it was interesting because I was the baby, I didn't know my brother before the accident. Everybody else did and they all had a kind of grief in their eyes that I didn't. I just took him at face value for who he was. (Nagle 2005)

While these films offer a wonderful illusion of transparency, gazing back on a prior generation's struggle with less enlightened views in which disabled Americans were kept out of public view, it is important to reflect on these films as social texts in and of themselves. It is no accident that mainstream media makers – such as PBS and HBO – not to mention actors such as Kenneth Branagh, Andie MacDowell and Rosie O'Donnell -- invest their time and resources in these compelling stories about how families are able to transform the experience of disability.

As researchers interested in the changing cultural landscape, we are equally concerned to understand what happens “off screen”. For example, while none of the stars are themselves disabled in *Warm Springs*, many of the other actors are, an important breakthrough that speaks to the legacy of the disability rights movement in this country. The fact that this is a relatively new development is clear from the following comments

made in a blog kept by Laurel Lawson, one of the wheel-chair using actresses who appears in a very moving scene in the film, where she dances in her chair, at a party at Warm Springs.

All of the cast and crew have been very nice and the leads have all come up to comment about how much they enjoyed watching our rehearsals and to ask questions about authenticity on gimp stuff. Margo is the official disability advisor being one of the last polio cases in this country and all three of us have been helping out in that aspect. It's certainly been needed – the first instinct everybody has on crutches is to lift one leg up out of the way. We've carefully explained that being paralyzed means that you cannot pick up your leg, or indeed move it in any way..... the three of us have our own (excessively large) tent – since of course, we can't get into a trailer, as even with a ramp, we wouldn't have enough room to turn around. (Laurel Lawson, 2005<sup>6</sup>)

Representations of disability in the present tense are another more unruly matter. They are not tucked safely into historical eras; the task of reframing attitudes, especially among adolescents, remains arduous, particularly around issues of intellectual disabilities. In a recent national survey, for example, 6,000 middle school students consistently underestimated the abilities of peers who have intellectual disabilities; 67 percent would not spend time with a student with an intellectual disability if given the choice, and almost 50% would not sit next to one on a school bus. <sup>7</sup>

This bias is examined across the life course and domestic cycle in Rachel Simon's successful and compelling memoir, *Riding the Bus with My Sister* (Simon 2002), and its less successful adaptation as a Hallmark Hall of Fame TV movie in spring 2005 (Huston

2005). Both the book and the movie use the technique of flashbacks to show the love and frustration that accompany life with a developmentally delayed child from the point of view of a slightly older sister in a Jewish middle class family, whose life is ripped apart for reasons that are left ambiguous: is it Beth's intellectual difference? The father's overwhelmed response to caring for four children at one time? The mother's inability to survive as a single parent, influencing her increasingly terrible choices in later partners who become violent toward the kids? Yet beyond these ambiguities, one theme repeats itself: the siblings are being told again and again that their responsibility lies in keeping Beth as a family member. The parents, going against the mores of the time, resolutely refuse to institutionalize one of their children. Her siblings grow up knowing that their sister Beth's survival outside an institution is tied to theirs. In a key scene, Rachel (played by Andie MacDowell) and Beth (portrayed by Rosie O'Donnell), are at their father's funeral, where Beth acts out, unable to bear the Jewish mourning rituals. The experience provokes a flashback as Rachel remembers the impact of her mother's decision to keep Beth at home with the family on her own life from an early age.

As Rachel looks back on her own successes, bought in part at the price of moving away from "Cool Beth" (as Beth calls herself), her now-adult sister living independently with much state and municipal aid in a medium-sized Pennsylvania city, she becomes curious about Beth's stubborn insistence on doing things "her own way". This trait once divided the family as mother, father, sisters and brother all responded differently to Beth's intransigence. Beth has refused additional training, education, healthcare or a job: she dedicates her life to riding the city busses on an exacting 7-day-a-week, 52-week-a-year schedule. Rachel reluctantly agrees to spend a year commuting between her own life

and Beth's. Eventually, she comes around. Rachel describes the enlightenment she receives from witnessing the deep affection and even tough love that the bus drivers – our modern philosophers of public intimacy — bestow on Beth. Rachel's deep connection to an adult sib who is developmentally delayed only comes to “make sense” in this intimate yet public sphere, marked indelibly by her sister's visible presence (and difference), the consequence of her parents' refusal to sequester her. It is the shadow of institutionalization –and the victory of deinstitutionalization that grew from a public and international movement against it — that haunts Rachel's experience of family life. It is the year on the bus with her sister that transforms her. As the publicity for the book puts it, “it will make you prouder of your distinct individuality, while also making you proud to be part of the whole human family.”

This trope – of an enriched and diverse human family -- underlies a growing number of mainstream TV movies, independent films and Hollywood creations. We suggest that these representations are not an accident. They emerge not only from the efforts of the disability rights movement but also from the increasing survival of individuals, families, and communities touched by the presence of disability.

## **V. Conclusion**

We have argued that the concomitant rise of new technologies in two key fields — medical support for reproduction, vulnerable newborns, and genetic testing on the one hand, and the increasing visibility of disability across a range of popular media on the other — is not accidental. Beyond simple correlation, we suggest that these different fields of cultural production in medicine and media, linked to the care of the body and its representation, are synergistic, producing an emergent social field.

Without question, “disrupted reproduction” now extends far beyond pregnancy, birth, and individual choice; it is eminently social and cultural, breaching the walls of maternity wards and the temporalities of pregnancy and infancy. The survival of babies who might well have died in prior times has a ripple effect across many social domains. A focus on disability makes this stunningly clear, as the arrival of non-normative family members – whether at birth or later in the life cycle – is a “disruption” that now spans the life course, restructuring relations among kin, community, and caretaking institutions. In turn, these quotidian changes in family life are reflected in publicly mediated culture.

As we discuss in the early part of this chapter, developments in medicine and media have enabled the increased survival, as well as visibility, of those with disabilities. They shape and are shaped by an even broader field of emergent historical transformations in law, education and social action. As disability activists remind us, much more remains to be done in these areas of public life where bias is still the rule rather than the exception. Nonetheless, it is important to remember that much has been accomplished. Only thirty years ago, the notion of civil rights for the disabled was almost as invisible as the presence of non-normative bodies in public media. Indeed, the battle over how FDR might be represented at his long-delayed Memorial site in Washington D.C. crystallizes this historical shift. During his political career, the stigma attached to disability caused him to hide the physical evidence of his paralysis: his wheelchair. Some argued that this etiquette should be honored in contemporary representations. Others allied with disability activism argued for the profound significance of rendering visible to the public and future generations his role in leading the nation through war and Depression from a wheelchair. No doubt because of the

changed political and cultural climate, the disability activists won this battle over representation. For future generations, the fact of FDR's use of a wheelchair will be not only visible, but also non-controversial; this exemplifies the kind of synergy between medicine and media that is changing the social field. This broader perspective — which we think of as “enlarging reproduction” – encompasses the medical and screen technologies that now transform the possibility of life itself, and its recognition. Our use of the term “screening disability” implies far more than the neo-eugenic possibilities sometimes associated with genetic testing; here it invokes the increasing cultural presence (rather than absence) of disability in our public media. We see such work as a sign of our collective capacity to respond creatively to difference, underlining the promissory note of our enlarged humanity.

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**Notes:**

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<sup>1</sup> Reproductive disruptions take many forms. In their call for papers on “disrupted reproduction”, the conference organizers noted at least three themes: (1) Reproductive Disruptions are historically and politically specific; (2) Reproductive Disruptions exist in the “intersections of power”: that is, they are highly stratified; (3) Reproductive Disruptions participate in redefining not only the abnormal, but the normal, as well (cf. Canguilhem, 1978) here. It is our intention to show these themes at work in arenas which are not usually tied to the niche of reproduction and its disruption.

<sup>2</sup> As we have argued in a series of related articles, (Ginsburg & Rapp, 1999; Rapp & Ginsburg, 2001), these two socially segregated domains of knowledge –reproduction and disability—are increasingly brought into close conversation as the telos of technological perfectibility meets the democratic impulse of social movements militating for new forms of inclusion. Otherwise and more simply said: our technology beckons, tempts, and encourages us to value the dream of “perfect babies”, whatever their gendered-personal,

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social, and economic cost. At the same time, our political and cultural arenas are home to new constituencies demanding a voice in how their impairments will be categorized, compensated, and sometimes, contested

<sup>3</sup> Faye Ginsburg coined this phrase to describe the experience of mothering an anomalous child for whom there is no conventional knowledge, advice manuals, or collective common sense.

<sup>4</sup> In terms of this literature, we note, too, that the gender bias inherent in taking seriously the care of young children is magnified when our attention turns to fetuses, babies, children and young adults with disabilities (Landsman, 2003; Rapp, 2001 cf. Levine, 2000). Reproduction's association with women made it less prestigious as a research subject until recently, when a cottage industry of scholarship, fueled by the intellectual energy of feminist commitments and questions, has transformed the situation. And we would argue that this lack of knowledge is especially significant when a vulnerable infant turns into a person with a disability, with whom caretakers and intimate others often share a "courtesy stigma" (Goffman, 1963)

<sup>5</sup> Recent works in independent film include the quirky drama, *The Station Agent* (Tom McCarthy, dir., 2003) starring the "Little person" actor Peter Dinklage; and the feature-length documentary on disabled men who play wheelchair rugby, *Murderball* (Dana Adam Shapiro and Henry-Alex Rubin, dirs. 2005). In Hollywood cinema, *The Ringer* (Barry Blaustein, dir. 2005), supported by the Special Olympics, and *Radio* (Michael Tollin, dir. 2003), the story of an athletic coach who takes a developmentally disabled men under his wing, are recent examples. A Google search for websites yields an impressive 351,000,000 possible sites on disability. Two examples of compelling community-building sites are Disability Webzine, <http://www.disabilityworld.org/>, Learning Disabilities Association of America. <http://www.lidaamerica.org> (both accessed 19 Jan 06).

<sup>6</sup> Many thanks to actress Laurel Lawson for sharing her chronicle with us.

<sup>7</sup> This survey, carried out by the Center for Social Development and Education, University of Massachusetts, Boston was quoted Bauer, P. (2005). What's So Funny About Disability? *The New York Times*. New York: 22.