
Reverberations: Disability and the New Kinship Imaginary

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Abstract

The concept of Learning Disabilities (LD) didn't exist until 1963. Now, LDs are the most commonly diagnosed category for American children in special education. Based on long-term fieldwork and focused interviews in NYC with parents of "atypical" children, the authors analyze how experiences of family life with a disability reverberate through the life cycle as well as the domestic cycle. Our findings show that families are reimagining kinship narratives as they refashion their expectations and daily lives around non-normative children, often taking their insights beyond the home, and contributing more broadly to new cultural understandings of human cognitive diversity. [Keywords: Disability, kinship, special education, narrative, United States]

Parenting with a Difference

After 20 years of life as a professional photojournalist, Dan Habib turned his camera in a new direction, on his son Samuel. Born with cerebral palsy, Samuel—in his parents’ words—“brought the disability rights movement into our home,” as so many children do. As “accidental activists,” both of Samuel’s parents soon found themselves acting on behalf of their son, in particular around his education in their New Hampshire town, as they sought inclusive settings for him that combined children with and without disabilities in the same classroom. Dan began photographing their journey, and soon a documentary film was in production. Two decades earlier, he had done a photo essay for the University of New Hampshire’s (UNH) Institute on Disability, telling the story of one of the first inclusive classrooms in the state. Remembering that experience in his film, *Including Samuel*, he extended the questions he had for his son’s unpredictable future to four other students with a range of disabilities at different life stages to ask questions about the possibilities and limits of inclusive education from kindergarten through college. Since its completion in 2008, *Including Samuel* has screened across the country and been widely publicized, not just for its compelling story but also for its visionary as well as practical advocacy. The documentary, which from the beginning was an extension of the Habibs’ commitment to social change, is now used by thousands of schools, parent organizations, non-profit groups, universities, and state agencies around the US and internationally to provide inclusive education. The Including Samuel Project website extends the activism to the creation of collective counter-narratives: the site invites fellow travelers to upload their stories of disability and inclusion, thus creating a kind of alternative virtual community. Habib, now Filmmaker in Residence at the Institute on Disability at UNH, calls all of this activity the “Including Samuel Effect.”¹

This story is exemplary of a recurring phenomenon that we see in our research and explore in this article: increasingly, as disabled kids move through the life cycle, their atypical experiences reverberate into the lives of their families in ways that reframe taken for granted assumptions about kinship. Parents in particular find themselves recognizing and reorganizing tacit expectations about familial relations and the temporality of the domestic cycle; in that process, the culturally ordered unfolding of a normative life course can no longer be assumed. Our analysis focuses on parents of cognitively “atypical children,” adults who are not only rethinking

the intimate world of kinship from the point of view of their experiences with children with a disability; we argue that they are also taking their insights beyond the home. The story of Samuel Habib and his family is only the latest in a growing movement of activist parents, for whom the process of reframing kinship in relation to having an atypical child catalyzes new forms of activism that are reshaping the ways that their communities respond to the difference that disability makes.

Cultural Innovation in Special Education

In the interests of full disclosure, our research with people such as Dan Habib began as a result of our many years of experience as mothers of children with learning disabilities. Ginsburg's daughter has a rare genetic disorder, Familial Dysautonomia (FD), which affects her autonomic nervous system and has consequences for learning that are not well understood along with her more global medical problems.² Rapp's son has classic dyslexia requiring accommodations for reading and writing. We became interested in this topic because of our own difficulties navigating the educational system on behalf of our children.

As a result, we have been carrying out multi-sited ethnographic participant observation research on "Cultural Innovation and Learning Disabilities" since 2007. Our current fieldwork, based in New York, carries us in many directions as we track sites where the landscape of learning disability is transforming most rapidly. We initially began our investigation of "LD" (Learning Disabilities) as an emergent, largely invisible category of disabling difference, but quickly discovered that neither the children so labeled nor the label itself are easily stabilized nor reified. We therefore have accepted into our study any child, family, school, or other institution for which an Individual Education Plan (IEP, the US school district-issued educational passport to special education services) is relevant. Despite our best efforts to contain it, we have found the categories that we are studying to be promiscuous violators of the walls erected by medical manuals and school bureaucracies. For example, the "visual activism" (Garland-Thomson 2009) of the films and filmmakers discussed in our opening paragraphs are part of a disability media world (Ginsburg et al. 2002) ranging from books to documentary work to disability film festivals and screening series to YouTube uploads. These new kinds of visual and narrative mediations of the experience of disability are rapidly transforming contempo-

rary American public culture; impairments that were once hidden are now increasingly rendered visible and sometimes celebrated.

Our research also includes fieldwork in neuroscience and epidemiological psychiatric research labs, where scientists use technologies such as genome analysis and fMRI (functional magnetic resonance imaging) to understand brain differences among children. Their goal is not only to map cognitive diversity but also to better understand how to design potential interventions. Additionally, we have been carrying out interviews with educators involved with schools and programs—both public and private—that are particularly accommodating to children who struggle with conventional educational skills and demands.

Much of our work is directed toward understanding the experiences of New York City families whose children are labeled and receive services through their IEPs. Our data set is drawn from a sample of over 50 interviews and fieldwork encounters conducted since 2007. Respondents are primarily mothers who we contacted or who contacted us via several internet support groups for families in the New York area involved in special education where an announcement of our research project appeared. While all those we interviewed consider themselves to be strong advocates for their children, many are not oriented toward more formal activism. While all had to have computer access in order to respond to our call for interviews, most were of modest economic background. Additionally, the sample “snow-balled” beyond internet group members as interviewees spontaneously passed on our names to friends they had made in the process of getting services for their children. We were particularly impressed and moved by the desire many parents (especially, mothers) expressed to be interviewed and have their struggles formally acknowledged via our work. Many spoke compellingly about the need for the stories of families such as their own to be heard by a broader public. Although we did not sample initially for diversity, the people who volunteered as research subjects were drawn from all five boroughs and represent multiple racial, ethnic, class, and educational backgrounds. Approximately 30 percent of our sample is African American; about 15 percent is Hispanic.

As engaged researchers, we are also participating in two post-secondary school projects that grew out of our research. The first is the creation of a small pilot “transition program” for students in Manhattan who have grown up with the institutionalized benefits and burdens of Federally-mandated Special Education labels, only to find themselves without con-

tinued support or a clear pathway towards a fulfilling adult life as they leave high school. The second is supportive work with the New York University branch of Project Eye to Eye, the first national organization created by and for college students with learning disabilities, as they develop mentoring relationships with LD students at local middle schools. As one of their t-shirt slogans makes clear, their goal is to “make a revolution in special education one classroom at a time.”

The New Kinship Imaginary

From an anthropological point of view, personhood is constituted fundamentally through kinship systems, public forms of governance, as well as a broad range of popular cultural forms and practices. As more anomalous cases enter such systems and reshape family life—such as the so-called epidemic in autism spectrum disorders—kin relations are inevitably transformed around issues of caretaking, specialized curriculum, and developmental expectations (Grinker 2007, Monastersky 2007).

While our research initially targeted what we are calling “cultural innovators” who are reshaping schools, diagnostic categories, and media representations to accommodate children with disabilities, we noticed that all of these projects were deeply informed by a “paradigm shift” as families realized their experiences didn’t map easily onto pre-existing models of American domestic life. With nearly every interview, we have heard stories about how family members were reimagining everything—from household budgets to school careers to sibling relations to models of humanity—in ways that take into account life with a difference. It is this reframed accounting that emerged in so many of the narratives that we highlight in this article. We are persuaded that the stories they tell collectively constitute a “new kinship imaginary” with temporal and social implications. Not only does this new imaginary map an emergent terrain that encompasses a broader range of humanity; it also reframes the implicit norms and expectations of the life course as the “difference of disability” reverberates through the domestic cycle, changing its rhythms in unanticipated ways.

These reverberations and their impact on kinship imaginaries are thus fundamental to our analysis, bringing us back to one of the most basic “inventions” of our discipline. It is an axiom of cultural anthropology that kinship is a cultural system that accommodates nurturance and social reproduction. It is a resilient, demanding, intimate, adaptable, and,

above all, self-reproducing social form that can accommodate the study of fragmented, flexible families and geographically dispersed networks in the societies of late modernity.

The “new kinship imaginary” is not unique to the circumstances of disability. Over the last two decades, anthropologists have studied the reworkings of kinship around innovative transformations of the current era: sexual and reproductive choice (Lewin 1999, 2009; Weston 1991); the use of Assisted Reproductive Technologies (ARTs) (Franklin and Ragone 1997; Franklin and MacKinnon 2001; Inhorn 1994, 1996; Thompson 2005), adoption (Gailey 1998, Modell 1994, Yngvesson 2005), divorce and remarriage (Stacey 1990), migration (Freedman 2000, Rodriguez 2008) and organ transplantation (Joralemon 2001, Sharp 2006), to name some prominent examples. In these diverse studies, we note that transformative, even once-controversial technologies of family formation and continuity are often deployed in the service of reproducing enduring and normative kinship structures: radical transformations in intimate relations are normalized in the language and practices of “familism” (Banfield 1958, Carsten 2004).³ Some of these differences—such as the use of ARTs during a limited period of the domestic cycle for couples with problematic fertility, for example—are more easily absorbed into typical family narratives once a healthy pregnancy is achieved. Other kinds of difference, such as “queer kinship” or the incorporation of disabilities into family life that is our topic, usually endure in publicly visible ways over the domestic cycle, thus requiring new kinship imaginaries at every level, from family rituals to household economies to challenges to state bureaucracies. We have been struck in our work that changing kinship imaginaries are “everywhere,” providing the building blocks on which a transforming social narrative around disability is built.

The insights gained from our research build on a long history of scholarship on the impact on families of raising disabled children, much of it in the fields of psychology, sociology, and nursing and other helping professions as well as an emerging body of work in anthropology (e.g., Ferguson 2001, Landsman and Van Riper 2006, Skinner and Weisner 2007). Along with other colleagues in our discipline who study disability, we argue that kinship is a key hermeneutic in understanding the cultural dynamics surrounding embodied and cognitive difference. As we show in this article, this is foundational to a transformation that extends from the arena of familial experience to the broader social imaginary (Rapp and Ginsburg 2001, 2011).

When children's education is "stretched out" to accommodate differences in developmental time, so too is the time of parenting and the shape of the domestic cycle. When a child's developmental narrative is rewritten retrospectively by a relatively late diagnosis, so, too, is the family's sense of its history refashioned. When families experience a "dead end" in the search for innovative services or therapies that might enhance the life of their disabled members, some may become inventors, researchers, or therapists. When a child grows through adolescence into a trajectory that does not entail the expected reproduction of class and culture, she or he—along with intimate others—travels into an unanticipated future. In such circumstances that do not conform to the temporalities and expectations of conventional kinship narratives, we suggest families create new kinship imaginaries to accommodate the shifts in the rhythms of daily life to alterations in the life course and domestic cycle to parental expectations of a child's future. While families initially experience the demands of this time shift as a problem unique to their own household, eventually, encounters with others like them—for example in school settings—contribute to a much larger transformation.

Rewriting Family Stories

Parents often begin this process of recognition in the unanticipated but necessary restructuring of family life which often sets parents and their marriages and families apart from their peers. Managing household tasks and childcare are far more labor-intensive and not likely to fall within common norms of childrearing. For many, this creates a sense of "narrative urgency" as they search for an alternative understanding of domestic life, and a realistic and positive future-oriented framework for the lives of their children (Rapp and Ginsburg 2001). Gail Landsman makes a similar argument in *Reconstructing Motherhood and Disability in the Age of Perfect Babies* (2009), finding that over time mothers gain a hard-won distance from medical narratives as they tell increasingly self-confident stories that showcase their children's accomplishments rather than deficits.

While some diagnoses become apparent within the first year or two of life, as toddlers fail to "make their milestones" and parents search for explanations, others remain invisible until the demands of standardized schooling bring them out, typically by fourth grade, and some only become apparent in teen years. Schools that specialize in LD where self-

acceptance and advocacy are a key part of the curriculum, now recognize an added responsibility. Beyond the pedagogical challenges of their classrooms, they have identified the need to educate parents as well as children so that families can anticipate and narrate a changed life course explaining their circumstances to themselves, their extended families, and friends. One school has developed an “initiation ritual” for new parents. They screen a performance by the school teachers of their adaptation of *The Wizard of Oz* in which Dorothy is in the land of LD, rescued by the “magic” of strategies and alternative learning. Many parents who are new to the issue of cognitive difference are moved to tears as—sometimes for the first time—they recognize the alternative world they have entered along with their child and the distinctive responsibilities that come with the territory.

These different temporalities thus shape households at different points. In the case of a learning disability, for example, a child may require homework help for several hours a day through high school. The need for ongoing parental support through teen years may seem immature to the parents’ friends and relations. This, in turn, changes the tenor of work time, family time, and social time, as parents who help intensively—usually, but not always, mothers—are themselves slower to progress through their own life-cycle as their child “stays young” in relation to demands usually surpassed at a conventionally much younger age by typically-developing kids. One single mother of a dyslexic high schooler reported, for example, that several of her friends expressed a nagging impatience and astonishment when she “still” wasn’t available for weekday evening events as her son progressed through high school. She had a commitment to supervise high school homework, more typical of the way mothers work with third or fourth graders, and this prevented her from socializing in a way deemed appropriate by her peers whose kids had long ago “cut the apron strings,” freeing their mothers as well as themselves. Her life cycle no longer matched that of her peers who, along with their children, had aged out of this role many years ago. Another, whose child has a health-related disability and cannot stay out beyond her daughter’s usually-early bed time because of complex medical regimes, reported, “I can’t tell you how few friends invite us over now that we have had to say no so many times. They’ll often come for dinner here. But almost no one reciprocates the invitations any more. They’ve just given up on us.” The family’s social life had become more home-centered as the child grew up,

since her care made independent parental socializing difficult. A third recently took early retirement from her professorship with reluctance. As her child with a disability moves through high school, organizing her support services and shepherding her through grueling standardized exams that will open doors for tertiary education has become a full-time job. In such cases, parents do not necessarily look forward to the “empty nest syndrome”: expectations for the young adult’s job, community, and relational connections are fundamentally unknown, and will play out differently than those of his or her peers, affecting the shape of the life course for parents, and perhaps siblings, aunts, uncles, cousins, and grandparents as well. Further on, imagining a future, parents may shift their hopes for grandchildren, and make provisions for caretaking in old age that do not require their children’s support.

While parents were the most likely to speak directly to the changed work and home-life situations entailed in raising a differently-abled child, siblings, too, have to adjust their lives and narratives as members of “a handicapped family” (Oe 1995). Siblingship is a marked category in some of the societies anthropologists study, yet it is relatively invisible and harder to spot when working “at home” in the US. But we have been struck by the impact of having a sibling with a diagnosed disability on the work and family choices described by adults we encountered in our research: their siblings with LD, cognitive impairment, mobility limitations, brain trauma, and other disabilities figure large in the professional stories of researchers, media makers, religious leaders, and educators committed to “changing the story” of public intimacy with disabled persons, as some recent movies and books make clear.⁴ While public discussion of these kinds of sibling relationships is rare, they feature regularly in more specialized arenas such as the longstanding monthly magazine, *Exceptional Parent*, or in the special needs sections of bookstores.

Occasionally, a diagnosis reverberates across a genealogy, revising understandings of the family tree; a diagnosis of one family member often has retrospective ripple effects on the lives of others. John Ratey’s book *Shadow Syndromes: The Mild Forms of Major Mental Disorders that Sabotage Us* (1998) is enduringly popular, describing many histories of families in which parents, aunts, uncles, and grandparents started to rethink their own personhood in relation to familial difference. Diagnosis of a child or other close relative with a significant cognitive or affective disorder sometimes creates a new self-awareness for other family members liv-

ing with milder forms, recasting kinship narratives as “shadow syndromes.” Thus the LD, ADHD, bi-polar, or depressive diagnosis of a child can lead to medicalizing what was formerly perceived to be their own or other family members’ idiosyncrasies, refashioning a personal character trait into the language of genetic and medicalized explanation. The acceptance of intimate DNA-links to a relative with a diagnosis and its subsequent reverberations on undiagnosed relatives pervades the clarion journalism of Amy Harmon’s series of articles on genetic conditions in *The New York Times* entitled “The DNA Age” (Harmon 2006-2008). Maryanne Wolf’s book *Proust and the Squid* (2007) made the best-seller lists when it first appeared. In her synthesis of neuroscience, genetic, and remedial educational literatures on children’s reading problems, she includes a final chapter rethinking her own genealogy on the basis of what she has learned. This process of retrospective identification is commonly cited by parents we’ve encountered in this research. For example, at a Manhattan high school where one-third of the students had diagnosed LDs, one mother said “David is just like me. He’s brilliant, and disorganized. I feel his pain. I don’t know how he does this, but he’s doing very well in school...I just wish they wouldn’t call it a disability. He doesn’t have a disability. And neither do I. We’re both just very, very dyslexic. It runs in our genes.” In these examples, the reworking of kinship imaginaries in hindsight runs through the increasingly ubiquitous DNA narratives as the latest idiom to describe the unexpected consequences of familial connection, geneticizing affective bonds as well as now-diagnosed disorders.

Inevitably, genetic knowledge hovers over family futures. For example, one mother of four who had two offspring with the genetic disease, cystic fibrosis (CF) became very active in the local CF organization, bringing all her children—affected and unaffected—into its social networks. As the unaffected children grow into young adults, she worries about potential romances that may spring up between them and other siblings of children with CF: such future partners, like her two unaffected children, have a 50 percent risk of being carriers, thus considerably increasing the chances of reproductive transmission of the disease, should they choose to have children together. The mother recognizes the irony of her situation: it was her profound acceptance and normalization of the lives of her affected children that brought them all into an organization of like-minded families. Now, her non-affected children are potentially launched on an affective journey whose trajectory she never imagined.

Working it Out

Family members who experienced barriers and opacity in the search for diagnoses, interventions, or social integration of children frequently turned their own activities—and often these were professionally based—in new directions. As Dan Habib’s story makes clear, many shifted their focus of work as expertise, empathy, and perhaps indignation blossomed: our interviews include a remarkable range of ways that parents—mainly mothers—reoriented their working lives in order to have greater capacity to help their children. Some became remedial reading specialists, others speech pathologists and occupational therapists, and still others turned their scientific research toward their child’s condition. Their choices reveal how parents redesigned their work descriptions or forged new employment opportunities to focus on specific disabilities in the wake of their own child’s impairment. Sometimes, innovations (often made out of desperation) change the demographics of a specific field, as an article in the *New York Times Education Life* reported: mothers of children diagnosed with autism are currently an expanding demographic at selected colleges in New Jersey which offer programs in Applied Behavioral Analysis (ABA), the most popular (and very one-on-one intensive) therapy used with children who have this diagnosis (Gross 2008). For mothers who face the daunting task of helping to educate their autistic children, such training provides the professional skills for intensive therapy at home. At the same time, they upgrade and professionalize their skills while adding to the expansion of much-needed ABA services for others through their own certification. Their goals include building a salaried career with the skills they achieve, while also helping their own children. Our interviews suggest that earlier expansions of professional services in educational psychology, remedial reading, speech therapy, and occupational therapy also relied heavily on the mothers of struggling children who entered these fields from the 1960s onwards.

Of course, men have also been drawn into “disability worlds” through their experiences of parenting atypical children, as the opening vignette about the filmmaker and advocate Dan Habib makes clear. A father of a young man with a rare genetic disorder stepped into the Executive Directorship of the foundation that supports clinical care and research on this condition after years in a technology industry, in part because he felt no “outsider” would give the same energy and passion to fundraising, scientific research, and the support for this orphan disease. Other men have

turned their academic talents to educating the public through their stories of raising a child with a disability. Notably, in 1996, the literary scholar Michael Berube published a book—initially excerpted as a widely read article in *The Atlantic Monthly*—*Life As We Know It: A Father, a Family, and an Exceptional Child* (1996). In it he not only chronicled the first four years of daily life with his son Jamie, born with Down syndrome, but also explored the larger philosophical and political issues as well as the reframed kinship imaginary raised by the presence of this particular disability in his family. Ten years later, Roy Richard Grinker combined his expertise as an anthropologist and as the father of a daughter with autism to write a work of popular scholarship that told the intersecting stories of autism cross-culturally and in his own home. His book, *Unstrange Minds: Remapping the World of Autism* (Grinker 2007), addresses what others have called an “epidemic in autism,” while also conveying a distinctly American sense of hope—not only for his own daughter—but also for the global reverberations of local activism enabled in part by technologies such as the web. As he put it in an interview:

“I’d really like parents to know,” he says, “that when they go out on a walk or a jog to raise money, or they go to a fund raiser, or they talk or write about autism awareness, that the payoff isn’t just in this country, or in their local community. For all they know, the payoff is for a woman in the hills of northern India, who doesn’t know how to understand her son and what’s happening with him.” (Monastersky 2007)

In our research, we have been struck by gender differences among the parents we have interviewed. Far more mothers than fathers have profoundly adapted their working trajectories on the basis of what they learned in supporting their child’s differences, whether this involves highly visible public activism or becoming a special education para-professional, often in already conventionally feminized fields. Many fewer fathers agreed to be interviewed—a potential bias in our sample—deferring to their wives and partners who often “specialized” in managing the care of their child from feeding and dressing to working the bureaucratic structures in pursuit of appropriate services. Nonetheless, in addition to the more high profile examples cited above, some fathers have adapted their work lives significantly, for example, by founding small, independent businesses. They do so to have more time flexibility in order to be more

readily available given the intensity and relentlessness of the care required by their child.

Attitude Adjustment

Of course, not all families identify with a child's struggles or even accept their offspring's label. As the head of an independent school for children with LDs told us, "It's a big piece of what we do (in our) work with new parents. When you get diagnosed, it makes a big difference. Sometimes the parents don't want the label and it's the kids who tell them once they are in the school, 'Look, I have an LD, this is what I've got.'"

Coming to grips with the implications of a child's diagnosis takes time. For some, temporality is not necessarily experienced as linear but rather as episodic. We encountered several mothers of older children recently diagnosed with LDs who demurred from being interviewed: "Everything is fine in Jamie's school right now," said one. "I don't want to rock the boat or even think about this too much." Another said, "I really don't want to talk about it right now." While some might use the psychological language of "denial" to describe their behavior, we find ourselves instead regularly deploying the "journey metaphor": we think of such parents as on a journey of unknown length and duration, with periods that are more and less turbulent.

Gray areas of interpretation may be both diagnostic and a matter of chronos: some only reluctantly discover family voyages that they never knew they were on, compelling them to later recast their stories. For example, the mother of a bright high school senior with a spotty academic record only took her daughter's anxious ADHD jokes seriously when the teenager asked to be moved to a private girls' school after spending her entire educational career in local public schools. There, she was diagnosed with LD/ ADHD at the age of 16. "It's the first time I ever thought of myself as a bad mother," she told us. "She's going to leave my house without the tools to deal with this, and that's not true of the rest of her life," the narrator said of her changed family story: "When I think of the years of struggling over homework, riding herd on Louisa, I'm heartsick. Anger is just built into how I've handled her lack of discipline, and it didn't have to be this way. Now I know her brain works differently." This is a family tale in transition: mother and daughter must both rework their understanding of generational conflict as Louisa's learning differences come to take central place.

We note that in our research, in a register that reflects American optimism that all obstacles can be overcome with sufficient effort, some parents continue to imagine that their children will be “cured” despite the efforts of educators to help families come to a realistic acceptance of the enduring nature of the issues their child faces. One principal of an LD high school reported that every year, a handful of parents of juniors and seniors are shocked that their young adults are not necessarily college bound. At a different school, we were told that despite many years of working with parents about adjusting their expectations and finding appropriate tertiary education for their children, some were still surprised that elite colleges were out of the question. Other parents told us that they hoped their children would outgrow their problems. “A lot of kids are better once they get through puberty,” one said. Not all parents are able to incorporate their child’s difference into a comprehensible narrative as they move through the educational system into young adulthood. This is hardly surprising given the fact that the dominant American cultural life-story for young adults is that “everyone” should be able to attend college; we want to distinguish this well-recognized aspiration from the 2009 US census data showing that just under 39 percent of American young adults actually graduate with a Bachelor’s or Associate’s degree (US Census Bureau 2009). Despite these statistics, it is difficult for families to interpret pathways other than college as anything but failure.

Public Intimacy

We have thus far been elucidating the reverberations which rock the intimate world of kinship relations when a child with a diagnosed disability is nurtured as an integral part of daily household life. To reiterate our argument regarding the restructuring of the kinship imaginary, all intimate others—parents, grandparents, siblings, godparents, close family friends—are affected in ways that are increasingly being displayed and discussed in public. Since the 1990 passage of the Americans with Disabilities Act, the presence of disability has become more socially acceptable in the USA, as it has in many other nations not only through legislation but through the daily practices that build a sense of what literary scholar Lauren Berlant calls an “intimate public” (Berlant 2000, 2008). Her discussion of this concept in relation to her interest in gender politics applies equally well to our interest in disability as it reverberates through the intimate arenas of kinship

and community. In the following quote from Berlant, simply substitute “disabled person” for her “x”:

...an intimate public is an achievement...it flourishes as a porous, affective scene of identification among strangers that promises a certain experience of belonging, and provides a complex of consolation, confirmation, discipline, and discussion about how to live as an x. One may have chosen freely to identify as an x; one may be marked by traditional taxonomies—those details matter, but not to the general operation of the public sense that some qualities or experiences are held in common. The intimate public provides anchors for realistic, critical assessment of the way things are and provides material that foments enduring, resisting, overcoming, and enjoying being an x. (Berlant 2008: viii)

Consider the example of one of our research subjects, Dana Buchman, the glamorous New York fashion designer. In 1986, she found herself parenting a first baby who failed to make many developmental milestones. Distraught and determined “to get to the bottom of this,” Dana struggled to come to terms with this “impediment” to her fast rising career and her assumptions that she could “have it all,” including a “perfect family” (Buchman and Farber 2006). She turned her attention to trying to understand what her daughter Charlotte’s neurological condition might be and how to provide supports for her to “learn outside the lines” (Mooney and Cole 2000). Buchman might have simply stopped there, just as the Habibs might have considered the successful inclusion of Samuel into their local public school an endpoint. Instead, in both cases, they saw their family struggle as linked to a broader world and thus established the sense of public intimacy that Berlant discusses. As a figure in the NY fashion scene, and in a classically American way, Buchman used her cultural capital to become a high profile public advocate, spokesperson, and fundraiser, as well as president of the National Center for Learning Disabilities (NCLD). She followed in the path of Anne Ford, scion of the elite automobile fortune; Ford’s experience with her daughter Allegra’s learning disabilities mobilized her to join with others to make the NCLD an influential policy presence in Washington. Ford also wrote two books reaching out to families struggling to identify what might help their child with a learning disability to be educated and eventually to become independent in an earli-

er era when few people—whether wealthy or poor—made such stories public (Ford 2004, 2007). In Buchman’s case, she wrote *A Special Education*, an account of her journey through personal and social enlightenment, as well as the maze of approaches to learning differences (Buchman and Farber 2006). The book was widely reviewed—Buchman went on the book circuit throughout the country, including a coveted appearance on the Oprah Winfrey show. For Ford and Buchman, the heart of the narrative is not only acceptance of a child’s difference and the consequences that has had for their family. It is also the struggle for a diagnosis that allows them to find a pathway for their child to follow that may open up a world beyond kinship. Increasingly, many parents recognize that they need to become involved with—and even act to shape—the medical/scientific worlds that both endow diagnoses, and open up possibilities for intervention not only for their own child but for others classed as disabled.

Buchman went on to found Promise, along with physician Michelle Shackelford, in order to provide low-income families with the kinds of comprehensive evaluations that had been available to her own daughter and which are crucial to appropriate treatment. This hospital-based diagnostic program extends pediatric evaluations to those who face a maze of bewildering services and stigmas when their child has severe school problems, and for whom the cost of a careful evaluation in the private sector is prohibitive. Such efforts are a crucial but often unrecognized form of activism; without such evaluations, children cannot receive appropriate intervention.

Similarly, Lois Kramer⁵ redirected her working life, developing a new form of expertise when her son Paul was born. As his trajectory veered into autistic territory, she became more and more interested in early intervention services. She abandoned her career as an aspiring New York actress, and began volunteering at a “special needs” nursery attended by Paul, then going back to college to get her teaching credentials in early education. Having been a head teacher in a public special education nursery school, and then at an independent special education school, she went on to run a class for young children with autism in a school in the newly developing for-profit educational sector serving special niche markets of which autism is one. She now is head of the lower division of that school and works as a consultant to others. As her son develops, so does her career in special education, as well as her proficiency in understanding the complexities of autism. Once again, a child’s difference changed a parental pathway.

While these stories are drawn from our work with a particular group of “cultural innovators” in New York City, they are just the tip of the iceberg as parental activism on behalf of kids with disabilities is widespread across social class, race/ethnicity, religion, and geographical location, expanding a sense of public intimacy with disability (Ginsburg and Rapp 2010). For example, the NYC-based Parents for Integrative Education (PIE) uses parental life stories from families across all the boroughs as a strategy to bring popular pressure for reform of the delivery of special education services by the Department of Education. Similarly, the ARISE Coalition, which unites 32 local organizations concerned with access to special education in the public schools, frequently requests that people submit testimonies for public hearings. As they noted in a recent listserv email intended to mobilize parents and educators to speak out against current cutbacks, “stories carry a lot of weight.”⁶ In our research, we have been struck by the frequency of such stories: often, a child’s atypical development leads a parent toward new understandings—both existential and/or medico/scientific—and from there, toward new choices in work and in community life, and sometimes toward activism to mobilize others.

These examples are hardly idiosyncratic; rather they are exemplary of the expanding arena of public intimacy around the experience of disability. Consider three books published since 2006 by activist parents determined to change the cultural scripts that isolated not only their children but also themselves. *Shut Up About Your Perfect Kid*, for example, is a collection of “stories from a wide range of parents of “imperfect” children, narrated by two “imperfect” sisters and mothers of children with Asperger’s syndrome and bipolar disorder, on the absurdity of raising imperfect children in a perfection-preoccupied world” (Gallagher and Konjoian 2006). Their heartfelt effort to change an oppressive zeitgeist, along with their wacky humor, turned this self-published book into an underground hit. As a result, it was picked up by Random House for republication with a slightly revised title in 2010. Another book, adroitly entitled *The Elephant in the Playroom: Ordinary Parents Write Intimately and Honestly About the Extraordinary Highs and Heartbreaking Lows of Raising Kids with Special Needs* (Brodey 2007), was written by professional magazine editor Denise Brodey, whose life was turned upside down when her son was diagnosed with sensory integration dysfunction and depression. She collected the family stories of many others to write about “life with children who are ‘not quite normal.’” The sense of narrative urgency

(Rapp and Ginsburg 2001) to establish a robust counter-narrative is palpable in their work.

On a related topic, a guide for parents announces its mission in its title: *Married with Special Needs Children* by Laura Marshak and Fran Prezant (Marshak 2007). The book offers solace and therapeutic advice to those whose marriages are under the particular pressures that come with raising special needs children. *More than a Mom: Living a Full and Balanced Life When Your Child has Special Needs* (Baskin 2006) delivers the collective wisdom garnered from over 500 interviews with mothers of atypical kids to provide both a sense of community and practical advice for women who find their own needs disappearing into those of their children (Baskin 2006). A 2009 publication, *My Baby Rides the Short Bus: The Unabashedly Human Experience of Raising Kids with Disabilities*, Bertelli reflects a shift to a more activist alternative consciousness (Bertelli et al. 2009). The editors showcase a broad range of contributors as part of the “radical mothers” and “hipmama” movement.⁷

Two decades ago, *Ordinary Families, Special Children* by Milton Seligman and Rosalyn Benjamin Darling (1989) was an early precursor of such guides. This 1989 book—in its third edition in 2007—became an underground classic among families caring for children with disabilities, combining the language of practical professional guidance with the recognition of the resilience of families in the face of inadequate social services. Such books provide parents, and especially mothers, with a bulwark against the isolation and frustration that comes from being marked as different in a highly standardized world. While some deploy comforting and supportive advice, gathered from a broad range of experience, the most recent books—and YouTube videos, and websites with products—turn to very 21st century modes of irreverent and unapologetic humor that resist the constraints and stigma imposed by the categories that render their children—and by extension mothers—imperfect. For example, on their website, Gina (Terrasi) Gallagher and Patricia (Terrasi) Konjoian, authors of the aforementioned *Shut Up About Your Perfect Kid* and self-described founders of The Movement of “Imperfection,” feature a sterling silver Mother’s Day gift suggestion with the following sales pitch: Show the Beauty of Imperfection—Introducing Shut Up Bling—the Ball and Chain Bracelet!⁸

Such rhetorical and representational strategies provide a particularly compelling meta-commentary on the dilemma of categorization; indeed, the ball and chain might be seen as a visual symbol for that problematic.

As Foucauldian scholars have long argued, to bring a social category into existence—that is, to recognize it—renders it available not only for social supports but also for governmental and medical control and possible abuse. While it is impossible to escape the “categorical imperative” of governmentality, by drawing attention to its constructedness (even as a bracelet), these authors also offer new forms of self-conscious recognition and sometimes resistance to normative cultural models that pathologize parenting with a difference.

Unlike more overtly stratified relations of difference like race or gender, children with disabilities are largely unanticipated, often unrecognized, and distributed across all kinship formations. Two generations ago, some children of these parental activists might well have been institutionalized, while many others would have been barred from mainstream education because of racial or disability prejudice. They now belong unambiguously to their families, communities, and schools. Recognition of their disabilities through medicalized and legal categories has been essential to their inclusion as citizens and the provision of often-essential services. At the same time, such recognition harbors a paradox; the labeling of difference always carries with it the risk of stigma and reification despite democratizing ideologies.

While we are aware of the potential dangers of this paradox, we are also deeply appreciative that categories—and those who are assigned to them—are unruly, promiscuous, and constantly mutating as they move across social fields from education, science, and medicine to the kinds of projects we describe above. Sometimes the arena of public intimacy around disability produces unlikely bedfellows. For example, Sarah Palin provided extraordinary “material” in her effort to anchor disability as part of the Republican Party platform conspicuously on display in the 2008 US Presidential campaign. As the Party’s Vice Presidential candidate, she appeared regularly with her baby Trig, diagnosed with Down syndrome (DS) before birth. During the campaign, she and her running-mate John McCain referred frequently to autism—a condition her son does not have—perhaps because parents of children with this diagnosis are widely known to be highly mobilized, numerous, and often desperate for hope; recent statistics place this condition as high as 1 in 150 births. Palin spoke about families with disabled children needing “choice” in sending their kids to private and religious schools, as if having an infant with DS automatically made her knowledgeable about this complex issue faced by

families with a disabled child later in the life course. Paradoxically, she used the circumstances of having a disabled newborn to further conservative arguments for defunding the public sector.

The fact of the long historical struggles for federal legislation and enduring litigation that have made some very hard-won resources available through the public schools to children with disabilities seemed unknown to Palin, as many commentators on disability blogs and news programs pointed out. Yet some parents of disabled children claimed her as a rallying point, dubbing her as a potential “friend for disabilities in the White House,” underlining the work that still needs to be done to make disability issues more visible on the national stage. The presence of Trig in 2008 as a political asset shows that the American body politic has come some distance since the days when FDR hid his wheel chair in public appearances. Regardless of where one stands on the political spectrum, Palin’s clear public and proud acceptance of her child with a visible disability and the attention it mobilized is a reminder of how rare such “publicly intimate” displays of an inclusive family remain.

Such a shift in “first family displays” over more than half a century indexes a remarkable transformation not only in legislation but also in the achievement of an increasingly acceptable “intimate public” created by the familial embrace of disability. Over the decades, the experiences of a wide spectrum of American families in reshaping their narratives to encompass disability have reverberated in the public domain with remarkable effect. Close to 50 years of cultural and political activism of these families and fellow travelers have been foundational to legal and jural transformations in the US, enabling the integration of children and adults with disabilities. We stress that these are all ongoing projects, fought out by ordinary and extraordinary people, whose consciousness grew from their daily experiences of difference to an insistence that these experiences be accommodated in the public domain. As scholars interested in the use of personal narratives in the social sciences and history have made clear:

...beyond the time frame of the individual life course, narrators usually refer to a range of other temporal and historical frames—familial, institutional and national—when they tell their “own” stories. (Maynes et al. 2008:44)

We are indebted to the work of these and other scholars who have also highlighted the significance of life-stories of people with disabilities in the transformation of personal and public identities. These range from anthropologist Gelya Frank's (2000) deeply dialogical "cultural biography" of the life of Diane de Vries, "a woman born with all the physical and mental equipment she would need to live in our society—except arms and legs"; to literary/disabilities scholar Thomas Couser's multiple studies of disability and life writing. In Couser's 2009 book *Signifying Bodies*, he examines the "memoir boom," arguing that disability is central to the genre. The authors he studies explore what it means to live in an anomalous body, feeding a public fascination with the experience of difference, while also revealing the complex relationship between disability narrative and disability law. That relationship is also central to an award-winning 2003 book, *Rights of Inclusion: Law and Identity in the Lives of Americans with Disabilities* by legal scholars David M. Engel and Frank W. Munger (2003). Drawing on that work in a 2007 article, they point out that "narrative has many meanings and potential uses in the study of disability rights" (Engel and Munger 2007:x). In a special section they edited of the journal *Narrative*, they write about "a recursive theory of identity and rights," as a way to understand how experiences that heighten awareness of disability rights are "absorbed into the life-story narratives and become part of the continual process of revision and transformation" (Engel and Munger 2007:x).⁹ Our interviews confirm their findings: it is impossible to unravel the individual, cultural, and social strands that are woven together in the lives of those whose encounters with disability catalyzed the writing of alternative cultural scripts. Kinship narratives are constantly resonant with the historically transforming experiences of family life lived around the fact of disability.

Transitioning to Nowhere?

We have told this as an American kinship story, and indeed, it is. In the US when children are diagnosed with disabilities, parents seek whatever claims to personhood and community membership are possible on a constantly shifting terrain. The enduring effects of the specific, creative, and sometimes desperate work of parents and their allies at particular historical moments and its impact should not be underestimated. For typically developing children, those claims—and their trajectory towards a cultur-

al future—can be at least partially taken for granted. The temporal assumptions of the familial middle-class imaginary—college, job, marriage, children—may or may not come to pass, but the cultural script has been firmly in place since the postwar period.

From the 1970s forward, legislation and litigation have slowly expanded this script to include children with disabilities who have likewise become entitled to a “free and appropriate” public education (even if such placements are unevenly available). In other words, the schooling portion of the cultural script is bureaucratically routinized, even though the bureaucracy is often leveraged strategically to deny services in large measure because of the cost. Families must be constantly vigilant to maintain the provision of school supports, especially in a time of draconian cutbacks. For example, at the Committee on Special Education’s annual review of her child’s case, one mother was handed her IEP for the following year and asked to leave. She noticed that the Committee had removed her daughter’s categorization as someone who needed a 12-month annual program in order to stave off the effects of her congenital condition, replacing it with a standard nine-month recommendation. In answer to a query, she was told that they wanted to assign the student to a local public school that did not have a summer program—nor did it have any of the services her child required. When she asked what might have changed the classification of child with an incurable degenerative disorder, no one would look her in the eye, but a social worker handed her a slip of paper with her private cell phone number. A later conversation quickly revealed that the team was under pressure to deny a certain number of cases. “Deep throat” urged her to lodge a complaint and demand another hearing. As the social worker predicted, the second meeting went smoothly and appropriate services—including a 12-month program—were restored. While this particular story has a “happy ending,” there is no doubt that this “rescue” was exceptional and that many families have lost services to which they were entitled. We recognize that these classifications serve a disciplinary and gatekeeping function, but they are carried out in a context where all diagnosed children are entitled to services that can have a profound impact on their life course.

The American stress on “independence” poses deep challenges to people who have grown up under the shadow of an IEP diagnosis. As this expanding population comes of legal age, their families confront the question of imagining and designing a future whose shape is not yet discernible. Some

respond with activist innovation; families work with their young adults to create new pathways, and in the process, invent a new version of their life course script, that may go in any of a number of directions presenting possibilities, dangers, and disappointments. It is our argument that in the process, new forms of personhood and family life are invented as well.

While progress has been made in the educational sector through high school despite the many obstacles that parents and their children may confront, the transition beyond high school is far more problematic. For many young people with IEPs, even colleges with good support systems may not be an option. Thus, the task of organizing an atypical adult future falls jointly on individuals and their families and requires considerable work to understand what viable support systems might be available for young adults and beyond. As advocates for “interdependent living” have long understood, planning requires a framework that includes and often extends beyond a kin network, what has become known among professionals sensitive to these issues as “person-centered planning” developed with a person’s “circle of care.”¹⁰

It is in the transition to life after high school that families may experience a cultural free fall in attempting to establish a future path for their young adults with disabilities. As difficult as negotiating school may be, having a child in an educational setting is nonetheless a normative part of the life cycle. It is also the only American institution where entitlements are legally in place for the education of every child. Beyond graduation from high school, the typical steps for supporting young adulthood are far less clear. The dominant cultural narrative suggests that all can go on to higher education, so that other kinds of transitions are seen as failures. At the same time, vocationally oriented high schools, a time-honored location for young people who struggled in more traditional academic settings, have been in decline for almost 20 years. As a result, many find alternative pathways out of high school even more difficult than navigating the school system. This problem of transition planning has been written into the IDEA since 1997. It requires that a comprehensive post high school plan be developed for all students with IEP’s over the age of 14—a fact that is rarely taken into account in New York City, as was made clear in a 2007 report aptly entitled *Transitioning To Nowhere* (Advocates for Children 2007). While some governmental social services are available for supported work, health care, and recreation, depending on one’s diagnosis, the structuring of life after school is often haphazard.

For those who go on to post-secondary education, all colleges receiving federal money are mandated to provide a “learning center” to support students with documented disabilities who choose to disclose their diagnoses. An increasing number of colleges—more than 750 according to the most recent guides—are either dedicated to or have specialized programs for students who need learning supports (Peterson’s Guide 2008), Princeton (Review, 2007). Landmark College in Vermont is the oldest of a group of post-secondary institutions that increasingly specialize in higher education for those with diagnosed LDs. For those who can afford them, such “scaffolding programs” are at once a creative parental and professional acknowledgement of the slower growth and need for a protected, protracted educational environment for young adults with LDs, as well as a market niche.

Transition programs for young adults with LDs for whom college is not an appropriate option are now springing up on an experimental basis across the US. Parental insistence that a slower but meaningful program be designed to accommodate their offspring with disabilities is key to many of these, e.g., like the SKILLS program, a joint project of two local independent LD high schools and faculty from the NYU Council for the Study of Disability. Inaugurated in Fall 2009, SKILLS integrates academics with curriculum in life skills, self-advocacy, internships, and person-centered planning.

Young adults who grew up with the labels LD/ADHD are also innovating for themselves: on almost 30 college campuses coast to coast, chapters of Project Eye to Eye (PE2E) have been founded by labeled students who succeeded in getting into college, and now mentor youngsters in middle schools near their universities. In the “Beyond Normal Art Club” that they offer to younger students, PE2E participants use an arts curriculum to preserve and enhance the children’s self-esteem by demonstrating the skills, creativity, and humor that the young adult PE2E mentors have learned to deploy along their own slower route to success. Thinking ahead, Jon Mooney, founder of PE2E, now works as a liaison in Los Angeles between public utility companies and technical colleges, designing certificate programs that are committed to bringing young adults with LDs into the skilled work force.

Our data remind us that college itself is not necessarily a panacea. However valuable tertiary education might be, it often defers broader questions of transition to adulthood and the normative expectations that

accompany it. In the course of our research, we've encountered the sobering descriptions of parents (usually mothers) who have intensively supported a child diagnosed with ADHD or Asperger's Syndrome successfully through college, only to find themselves with a depressed young adult boarder who stays at home without a job or a community life. As one aunt of a high-achieving college student with Asperger's Syndrome who received a degree from New York University told us after we congratulated her on her nephew's accomplishment, "No, it was a terrible choice for him. He never had friends in school and now people think he is overeducated for the jobs he is really qualified for." Another parent bleakly put it, "When my son was in school, things were tough but we knew our path. Now, he lives on his own with a job and some disability resources but there's no one in charge. It's an unlatched window out there." Her reference was to the dangers of this point in his life course when the safety net of school had disappeared, and his trajectory was anything but clear. The reverberations of LD within what we call the kinship imaginary and what the bureaucracy calls "circles of care" are profound, and insufficiently acknowledged.

The Future of Life with a Difference

Every family imagines a future for each child, drawing on a standard cultural repertoire—in this case American with particular ethnic/racial/religious declensions—and implicit assumptions of class and culture, as well as the specificities of their relationship with their offspring. Parents never know where wishes and dreams will intersect reality, but rarely question that a child's growth will lead to a trajectory of independence with maturation. When this story goes awry, parents and young adults face the task of reinventing their lives together as well as the cultural narrative. For some, facing this unknown pathway creates a sense of "epistemological vertigo" (Crapanzano 1980). As one dean of an LD high school put it in a poignant moment describing what we would call the loss of the old, taken-for-granted kinship imaginary, "We have to acknowledge the mourning that needs to take place as kids and their families face the loss of dreams for the future, before they can come up with alternatives."

Although responsibilities of state and family formally end between the ages of 18 and 21 unless guardianship is sought, many families remain involved with "transitional services"¹¹ for their children with disabilities for many years beyond. The concerns of managing daily life with a disabil-

ity may require substantial energy, imagination, and change; in many cases, as our research shows, that transformation is wrought by the world-changing activities that families themselves inaugurate.

Their narratives—and their actions—offer cultural critiques on available conventions of development and often imagine other possibilities. For example, Dr. Dolores Malaspina, Steckler Professor of Psychiatry at NYU-Langone Medical Center and a world-renowned researcher in psychiatric problems of childhood, took an evolutionary perspective on the mass production of the temporalities of maturation and the burden this places on families whose children are atypical learners. Excerpts from her interview with us in 2007 reveal this anti-standardizing perspective toward human growth:

The availability of public education needs to go to 25 and not 21. A lot of things that are (now defined as) learning deficits are actually learning styles. And the rates of maturation of the brain may simply be different. So people can continue to achieve milestones much longer at a much slower pace. So the absolute amount of learning a person can accomplish is one index, and the rate of learning is another...And we need to have an appreciation that adolescence and young adulthood go through their mid mid-20s and that some people will take that long to amass the information that they need to be successful in society...Now, people feel that unless they have kept up at a certain rate, they have dropped out completely. Or parents who think that their children won't keep up at that rate have to...get them a diagnosis. Whereas if we had an appreciation that learning occurs at different rates for different people then we wouldn't need to push them into a diagnosis and into a special ed track. We would have tracks that went forward at different rates...We are meant to learn a lot of what we do in a very social, interpersonal way...[parents] are always upset by young people on the computer. But they have 10-20 friends and they are recreating the initial small groupings that people used to live in. Everybody's on their cell phone. What's the total network? Twenty people. In a very large universe, what they are doing is recreating a little kinship group...But the reality is that contemporary families have to adjust to the world of school bureaucracies and the transition to the unstructured life beyond schooling.

Dr. Malaspina's thoughtful view of how differential brain development affects education and social life for atypical learners synthesizes scientific and cultural meanings. Its wisdom surely draws from her own familial experiences: as the sister of someone diagnosed as a teenager with schizophrenia, and the stepmother of a now-grown teenager with learning disabilities, she has considerable appreciation of the work of kinship in remaking the life cycle of those whose diagnoses reframe their educational, work, and community lives. As a scientist with a recognition of the cognitive diversity of the human species, she articulates a keen appreciation of the "unruliness" of developmental temporality that cannot always be squeezed into the lockstep grid of educational governmentality. Like many others who have been touched by the difference of disability as it reverberates from life experience to public work, Dr. Malaspina uses the idiom she knows best—biomedical research—as a basis for constructing a counter-narrative that will contribute to a more capacious social order.

Conclusion

There is a powerful movement sweeping across America. Imperfect parents...are coming out of their messy closets and boasting about the accomplishments of their imperfect children...

"The Coffee Clash" (2007)

This quote from the humorous YouTube video made by the authors of *Shut Up About Your Perfect Kid* (2010) follows a scene around a kitchen table where a group of suburban mothers brag about their brilliant children and their accomplishments while the two mothers of the children with disabilities fortify themselves with shots of vodka under the table to endure this ritual of middle-class female domination. Finally, they tear open their blouses to reveal t-shirts with the slogan that they also shout: "Shut Up About Your Perfect Kid." An announcer's voice reads the quote above; the audio is accompanied by an image of a huge wave crashing on the shore followed by the "imperfect" mothers falling out of overstuffed closets. Their "imperfect" video, making good use of humor and irreverence, underscores an entertaining but powerful point confirmed in our research: a new kinship imaginary that positively embraces family members with disabilities is emerging—if unevenly—across America and

through a variety of idioms. If social mores once dictated that family members with disabilities be hidden from view and stories about them silenced, our research strongly suggests that this cultural script is being revised on a daily basis, creating a seismic sea change felt across multiple locations, from the intimacy of kinship to the public world of educational policy, research, and social services.¹²

As our many cases in this article make clear, parenting with a difference first reverberates through family life, creating new understandings and orientation of what one author has aptly described as “life as we know it” (Berube 1996). Over time, many use the idioms available to them to reach out beyond the world of kinship to forge a new arena of public intimacy where atypicality is the norm. To return to Berlant’s insights into this process:

The intimate public provides anchors for realistic, critical assessment of the way things are and provides material that foments enduring, resisting, overcoming, and enjoying being [part of the world of disability]. (Berlant 2008:vii)

As we have seen, such “anchors” are placed in many locations, and use a variety of idioms. Every one of their stories we recount starts with a transformation of life cycle expectations built out of their experience of parenting an atypical child, blossoms into a recognition that the challenges they confront go beyond the domain of kinship, and takes root in projects that rework the place of disability from the family out. We have discovered that along the way, many involved in these projects, from Dr. Malaspina’s reflections to the irreverent humor of the “Shut Up Moms,” also become everyday philosophers of human diversity as they come to terms with the meaning of what they once thought of as “unnatural histories,” and now simply regard as life with a difference. In the process, the reinvention of American kinship imaginaries plays a foundational role.

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ENDNOTES

¹Accessed from <http://www.includingsamuel.com/home.aspx> on Aug 17, 2010.

²For more information, see <http://www.familialdysautonomia.org/>. Accessed on Jan 7, 2010.

³We have borrowed this term from a classic monograph describing how Italian townfolk safeguard and shepherd their resources by relying on the ideology of family solidarity as a bulwark against a hostile world (Banfield 1958).

⁴For media examples, see the 2005 CBS adaptation of Rachel Simon's 2002 memoir, *Riding the Bus with My Sister* about her year coming to terms as an adult with her developmentally disabled sister Beth, whose lifestyle centers around riding buses in her home city. See also HBO's *Warm Springs* (2005), an award-winning television movie about Franklin D. Roosevelt's struggle with polio, his discovery of the Warm Springs, Georgia spa resort and his work to turn it into a center for the aid of polio victims, and his resumption of his political career.

⁵We have assigned pseudonyms to all those we interviewed, excepting those who had already publicly told their own stories prior to our interview, or requested attribution during their interviews.

⁶Accessed from <http://www.arisecoalition.org/about.php> on Aug 17, 2010.

⁷Accessed from <http://www.hipmama.com/node/115> on Aug 17, 2010.

⁸Accessed from <http://www.shutupabout.com/> and <http://www.schmoopie.com/ball%20and%20chain.htm> on Aug 17, 2010

⁹While carrying out 60 interviews about employment conflicts among people with disabilities, Engel and Munger 2007 found that narratives could not be so easily contained. Their interviewees insisted on placing the question of employment problems in the context of fuller life-story narratives, which then became the centerpiece of their analysis.

¹⁰Person-centered planning was created in the UK, US, and Canada in response to problems caused by social service systems for people with disabilities, with early references going back to a 1988 book by John and Connie Lyle O'Brien. The term originates from the psychologist Carl Rogers in the 1950s, who pioneered the practice of person-centered counseling as an empowering alternative to a Freudian approach. Person centered planning can create a space during which someone who is not usually listened to has center stage, surrounded by those intimates who form a "circle of care," a term that has recently come into use in a range of service bureaucracies and educational/caretaking professions to identify those who are most immediately involved in supporting the daily lives of individuals with disabilities. These may or may not be kin. In New York State, the Office for People with Developmental Disabilities has mandated the use of person-centered planning in all new service development for people with mental disabilities. Accessed from http://en.wikipedia.org/wiki/Person_Centred_Planning on Aug 17, 2010.

¹¹Mandated by the IDEA since 1997, transition planning is supposed to be a "fact of life" for children from 14 years of age on. But compliance with the law is spotty, at best. In New York City, for example, the well-respected non-profit group, Advocates for Children, issued a report in 2007 entitled, "Transitioning to Nowhere." 82 percent of pupils surveyed received no transition planning on their IEP documents or in their Continuing Review meetings.

¹²Indeed, on their revamped website, there is a link labeled “Your Story,” inviting parents to share their stories with each other. Accessed from <http://www.shutupabout.com/index.php?link=2> on Aug 17, 2010.

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