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Emplotting children's lives: developmental delay vs. disability

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Abstract

While it is increasingly possible to envision “perfect” babies, it is not always the case that reproduction actually proceeds according to individual will; for example, there has been no recent reduction in rates of childhood disability. Nevertheless, in most studies of new reproductive technologies, the birth of those children whom few would actively choose—“defective” or disabled infants—is presented only in hypothetical terms. This paper argues for expanding the domain of reproduction to include research on the *parenting* of children with disabilities. Based on a qualitative research project carried out at a hospital-based newborn follow-up program that serves as an evaluation site determining eligibility for early intervention services for infants and young children with disabilities, this paper focuses on a particular part of women's experience of acquiring new knowledge about personhood and disability, that is, on the period of time when a woman has recently had confirmed that reproduction has, in her case, gone awry. Disability in many cultures, including the United States, diminishes personhood. I suggest that American mothers' narratives, by utilizing the concept of developmental delay, can *assert* personhood, or rather, the potential for its future attainment; in doing so, they justify ongoing nurturance of a disabled child in spite of negative attitudes about disability. A particular case of one mother's emplotment of her child's life within a story of developmental delay, in competition with the physician's story of disability, is analyzed. The paper concludes with reflections on how stories of developmental delay told by mothers just encountering a diagnosis of disability may differ from the stories told by those who have experienced mothering a disabled child over time, and on the implications of these differences for the cultural construction of personhood in the United States.

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Introduction

A vibrant literature in anthropology, feminist studies, and medical ethics has explored the role of new reproductive technologies in altering women's experience of conception and pregnancy (see Rothman, 1986; Petchesky, 1987; Rapp, 1987, 1988, 1990, 1993, 1999; Layne, 1990, 1992; Strathern, 1992; Ragone, 1994; Franklin, 1997; Taylor, 1998; Press, Browner, Tran, Morton, & LeMaster, 1998; Parens & Asch, 2000; Kahn, 2000). It is now possible, as Strathern claims, to think

about procreation “as subject to personal preference and choice in a way that has never before been conceivable” (1992, p. 34). In particular, we know that would-be parents undergoing prenatal testing in various cultures may be asked to reflect upon which types of disabilities are acceptable to them and which unacceptable. Concerned scholars and activists have also pointed out that knowledge emerging from the Human Genome Project and other genetic research, as well as from newly developing techniques of assisted reproduction, may bring forward *new* dilemmas for prospective parents and for society as a whole, forcing us to consider and to act on some of the most difficult ethical and political questions of any time: What constitutes a life worth living? With which traits should human beings be born?

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Yet if it is increasingly possible to envision “perfect” babies, it is not always the case that reproduction actually proceeds according to individual will. Indeed, there has been no recent reduction in rates of childhood disability, in a large part due to the more aggressive treatment and higher survival rate of extremely low-birthweight infants, infants who are in turn at high risk for disability (Hack et al., 1994). Authors of a review of the literature since 1970 conclude that the increasing survival of extremely immature infants (those born at or before 26 weeks’ gestation) and with a birthweight of 800 g or less has in fact resulted in a “steadily increasing prevalence of children with disabilities” (Lorenz, Wolliever, Jetton, & Paneth, 1998, p. 425). Nevertheless, in most anthropological and sociological studies of new reproductive technologies, the birth of those children whom few would actively choose—“defective” or disabled infants—is presented only in hypothetical terms, in the context of pregnancy or genetic counseling; we know little of the interpretation of disabled children as they are born and raised. I argue therefore for expanding the domain of reproduction to include research on the *parenting* of children with disabilities. By so doing we may provide useful data for prospective parents facing decisions about selective abortion for disability, extraordinary treatment for imperiled newborns, and/or adoption; we also move toward analysis of women and men who are engaged in the most anthropological of endeavors, those who, carrying out participant observation by choice or by circumstance, come to locate, interpret, and often to advocate for the personhood of one they would previously have known only as “the other”.

Background

Research on women who have given birth to children with disabilities derives largely from psychology and the helping professions. Concepts such as “denial”, “guilt”, “adaptation”, and “resilience” predominate in this literature, and the focus has been both on parental coping strategies and on how to assist families (Briskin & Liptak, 1995; Darling, 1979; Drotar, Baskiewicz, Irvin, Kennel, & Klaus, 1975; Irvin, Kennel, & Klaus, 1976; Fost, 1981; Frey, Greenberg, & Fewell, 1989; Knussen & Sloper, 1992; Patterson, Garwick, Bennet, & Blum, 1997; Singer & Powers, 1993; Tunali & Power, 1993; Summers, Behr, & Turnbull, 1989).¹ This paper,

¹ This research has largely been patronizing towards parents, and until fairly recently has assumed that a disabled child has a damaging effect on families. “The challenge for research was to catalogue and sequence the evidence of parental damage and to argue for the efficacy of this or that therapeutic intervention.... Apathetic or involved, angry or accepting: there was a

however, is part of a larger study in which I ask a different question. Instead of asking how women cope with children with disabilities, I ask: What have they learned? Rather than asking how we can help, I ask what women who nurture children with disabilities have come to know about what it means to be a person. This paper focuses on a particular part of this experience of acquiring new knowledge about personhood and disability, that is, on the period of time when a woman has recently come to find, or to have confirmed, that reproduction has, in her case, gone awry.

To illustrate the complexity of the larger, overall question, I speak, for a moment, as one such woman. I have a daughter with cerebral palsy. Like many mothers of children with disabilities, I play a mind game. What if someone—a magician, a god, a doctor—were to say to me, “I will remove your daughter’s disabilities”? In spite of my enormous respect for the disability rights perspective which values life regardless of (dis)ability and which eschews the search for cures, I know that without a moment’s hesitation I would say, “Yes, please, oh please, give my daughter clear speech so that others can understand her.” If that wish were to be granted, I would unabashedly beg that she be given the ability to make her hands do whatever she bid them to do—to pick up a crayon and draw, to feed herself, to write with a pencil or type on a computer with ease. And if there were gifts still to be given, yes, I would ask that she get out of her wheelchair and walk. And yet, paradoxically, I now suspect that such a joyous day would also be one of profound loss for me. For I can no longer imagine who my daughter would be without her disabilities. Is there a separate self, a “real” DJ who I love, “trapped” inside her disabled body? Is she, in the language of one version of the American disability rights movement, a “person first”, someone with her own distinct personality who has a disability as one of her many characteristics but whose self would change little if her disability were to disappear? Or is who she is inherently integrated with her body and its impairments and with her social experience of disability so as to be inseparable from them? Have my answers to these questions changed over the course of mothering my daughter?

How do mothers of children with disabilities define their children in relation to their disabilities? Living in a society in which disability diminishes personhood, American mothers of children with disabilities find themselves at the crossroads of four, sometimes mutually supportive, sometimes competing, discourses: (1) the discourse of popular culture, in which childhood disability is a tragedy which either a mother caused

(*footnote continued*)

professional explanation of the pathology behind any conceivable parental response” (Ferguson, Gartner, & Lipsky, 2000, pp. 76–77).

through her improper behavior during pregnancy, such as drug or alcohol use, or for which she was specially chosen by God as being strong enough to bear (see Landsman, 1999); (2) the discourse of pediatric medical practice that presents disability, especially mental retardation and central nervous system damage, as permanent, pathological, and located within the individual, i.e., in which children with brain damage or other disabilities are often “written off” as hopeless burdens; (3) the heroic discourse of progress and rehabilitation, in which disability can (and should) be cured or its effects overcome—a discourse supported by the concept of developmental delay, in which a combination of therapy, parents’ hard work, and a disabled child’s determination and force of will minimize or eliminate disability; and (4) the discourse of disability rights activism, the independent living movement, and the associated “social model”² of disability, according to which it is primarily society’s response to impairment, rather than impairment itself, that presents obstacles to a high quality of life, a position that presents disability, a high quality of life, and personhood as indeed fully compatible.

These discourses carry different weight in society, and are encountered by parents in the various contexts within which they find themselves: medical offices, physical or speech therapy sessions, parent support groups located on the internet, etc. The dominant, popular culture discourse on disability is most com-

monly found in the ordinary face-to-face-interactions with strangers, which “tend overwhelmingly to stigmatize the individual with a disability” (Frank, 2000, p. 48). Mothers move between these different discourses, sometimes defending the child’s potential to be non-disabled against a doctor’s grim prognosis of permanent disability, sometimes defending her child’s right to be permanently disabled *and* valued in a non-disabled world. Thus a mother stands at the center of a great paradox, saying to her child both: “I love you as you are” and “I would do anything to change you.”

How do American mothers of newly diagnosed children, negotiating among these discourses, emplot the events in the lives of their children? These are lives that sociobiologist Sarah Hrdy (1999) points out in her recent book *Mother Nature: A History of Mothers, Infants, and Natural Selection*, would be disposed of in many cultures. Committing oneself to such a child, Hrdy argues, is counter to self-interest and represents “true heroism”, the kind of behavior that “makes it awkward for even the most hard-core materialists to completely discount the existence of free will” (p. 460).

Ethnographic research suggests that, although by no means universal,³ the denial of full personhood, and even of life itself, to infants born with disabilities is not uncommon. Morgan cites Montagu’s research on the Arunta of Central Australia, among whom a premature infant is interpreted as being the young of some other animal, such as a kangaroo, that mistakenly entered the body of the woman (Morgan, 1996). In societies where “belief in reincarnation is strong, such as among Southeast Asian groups or in Indian society, a disability is frequently seen as direct evidence of a transgression in

²In contrast to both the medical and rehabilitation models of disability, in which the “problem” is interpreted to reside within the individual, disability studies scholars who propose a social model of disability argue that disability is “not a medical nor a health question. It is a policy or political issue. A disability comes not from the existence of an impairment, but from the reality of building codes, educational practices, stereotypes, prejudicial public officials... ignorance, and oppression which results in some people facing discrimination while others benefit from those acts of discrimination” (Pfeiffer, 1999, p. 106). Although there are different versions of the model, all make a distinction between impairment and disability. In the United States, the model is generally referred to as a “minority group” model, which draws the comparison of the discrimination and segregation experienced by disabled people with that which has been imposed upon members of other oppressed groups based on race, ethnicity or gender. Some disability rights activists also make the claim for a disability culture, arguing that a common sense of identity and experiences unite people with disabilities and distinguish them from the non-disabled population. Although this claim is a source of debate, most disability rights activists do make claims to a positive disability identity, and see disability as helping to generate new forms of creativity and insight. For other examples of recent discussion of models in disability studies scholarship, see Hughes and Paterson (1997), Johnston (1997), Kasnitz and Shuttleworth (2001), Llewellyn and Hogan (2000), Overboe (1999), Shakespeare (1994), Shakespeare and Watson (1997), and Williams (2001).

³As Scheer argues, “cross-cultural research has demonstrated that the marginal status of people with disabilities is a variable cultural pattern, not a natural occurrence present in all societies” (Scheer, 1994, p. 249). She points out, for example, that among the Cuna Indian population on the San Blas Islands of Panama in the early 20th century, albinism was not a disability, but rather identified as “simply one of the many characteristics of an individual” (p. 249). Nicolaisen reports that among the Punan Bah in Central Borneo, those with physical and mental impairments live as members of their extended families, participate in social events, contribute to daily household work, and are recognized both as humans and as persons (Nicolaisen, 1995). For the Songye of Zaire, deviations of the body can, in comparison with able-bodied people, result in higher, lower, or undetermined status. “Therefore, not all deviation is stigmatizing, and not all persons with disabilities are marginalized because of their disability” (Devlieger, 1995, p. 95). Nevertheless, examples of denial of personhood to people with disabilities is widespread. The issue has recently been framed by the author of a report prepared for the UN General Assembly this way: “Discrimination against disabled children has existed in every community throughout history. But it is not inevitable” (Landsdown, 2001).

a previous life, either of the parents or the child”, with the result that “those who are disabled are frequently avoided or discounted” (Groce & Zola, 1993). Among the Mehinaku Indians of the Brazilian Amazon, a deformed infant is referred to as a *kanupa*, a “forbidden” or “tabooed” thing, and it is buried (Gregor, cited in Scheper-Hughes, 1990). Similarly, it has been reported that among the Tarahumara Indians of the Sierra Madre mountains in Mexico, parents commonly abandon infants with birth defects in the hospital or let them die shortly after they are discharged (Mull & Mull, 1987), and that among the West African Bariba studied by Carolyn Sargent, infants with physical anomalies and congenital deformities were assumed to be witches and were traditionally exposed, poisoned or starved (Scheper-Hughes, 1992, p. 376). A report prepared for the UN General Assembly Special Session on Children in 2001, utilizing the database of the group Disability Awareness in Action, documents ongoing violations of the human rights, including the right to life, of disabled children in *all* areas of the world. The report states that disabled children “are commonly allowed to die, denied resuscitation or have treatment withheld. Parents of disabled children are put under unbearable pressure by cultural and religious beliefs that their child is the embodiment of sin and disgrace... NGOs working in the field consistently document not just examples of children whose lives have not been protected but evidence that such judgements are informed by policies which consider severely disabled children as of insufficient value to justify pro-active intervention to protect life” (Landsdown, 2001).

Scheper-Hughes claims that the “physically different infant challenges the tentative and always fragile symbolic boundaries in many traditional societies between human and nonhuman” (1990); she suggests that particularly in those societies in which there is a high rate of infant mortality, sickly or physically different neonates “may be sacrificed in order to protect scarce resources (including maternal love and attentive nurturing) for older, healthier siblings or the lives of those yet to be born” (1990). Yet the denial of personhood and nurturance to children with disabilities is not characteristic of such societies alone. At the time of Meira Weiss’ initial study in Israel, “50.8 percent of all children born in Israeli hospitals who manifested a major physical or medical defect were abandoned in hospital” (Weiss, 1998b). Weiss’s study included religious Jewish and Muslim as well as secular families living in three different areas of the country, and included parents whose countries of origin were in Europe, North America, and the Middle East (see Weiss, 1994). Parents of *all* ethnic groups and across *all* socioeconomic levels in Israel, Weiss claims, use metaphors of monsters, animals and other stigmatic terms such as “devil” or “Satan” to describe their

appearance-impaired children, and reveal what she suggests may be a universal and “natural aversion to physical and, especially, facial deformity” (1998b). In using such terminology, parents label the child as outside the range of human acceptability, as a non-person. The term “person” as used by anthropologists refers to a being that is publicly considered an agent in the world (Harris, 1989). Personhood is not based on intrinsic or universal criteria, but rather contingent on social recognition (Morgan, 1996, p. 25); it speaks to issues of social value. Therefore there can be gradations of personhood. Israeli mothers’ narratives analyzed by Weiss deny the personhood of a disabled child, and in doing so, facilitate abandonment, violence, and territorial isolation within the home (Weiss, 1998a).

The denial of full personhood to individuals with disabilities in the United States is also well documented.⁴ Yet in striking contrast to the Israeli narratives analyzed by Weiss, I suggest that American mothers’ narratives, by utilizing the concept of developmental delay, can *assert* full personhood, or rather, the potential for its future attainment; in doing so, they justify ongoing nurturance of a disabled child in spite of the fact that in American culture disability also diminishes personhood. This will be demonstrated primarily through a case study of one mother’s emplotment of her child’s life within a story of developmental delay, in competition with the physician’s story of disability. The paper concludes with some reflections on how stories of developmental delay told by mothers just encountering a diagnosis of disability may differ from the stories told by those who have experienced mothering a disabled child over time, and on the implications of these differences for the cultural construction of personhood in the United States.

The Study

The data for this article derive from a study begun in 1995 with the cooperation of the Newborn Followup Program of the Children’s Hospital at Albany Medical Center, in upstate New York. The Newborn Followup Program has a 25-county catchment area which includes urban, rural and suburban communities; it treats infants who were hospitalized in the medical center’s neonatal

⁴See Edgerton (1967), Frank (2000), Goffman (1963), Landsman (1988, 1999), Murphy (1990), and Phillips (1990); for discussion of the divide between the non-person status attributed to disabled people in the US by the non-disabled and the self-identities of disabled individuals themselves; see Gill (2001) as well as Frank (2000). Perhaps the most striking and explicit statements advocating for the denial of personhood to infants with disabilities can be found in the works of the Princeton bioethicist Peter Singer (1993, 1995).

intensive care unit, as well as those referred by pediatricians, child care workers, parents, or others. It also serves as an evaluation site for determining eligibility for the state's early intervention program for children from newborn to age three with, or at risk for, disabling conditions. The New York State Early Intervention Program is the outgrowth of Part H (now Part C) of the Individuals with Disabilities Education Act, which created a voluntary program to assist states with funds to implement a statewide system for all eligible children with disabilities, from birth to age three. Both a child's evaluation and the services a child might receive if found eligible for the program (such as physical and occupational therapies, speech-language therapy, nursing care, teachers for the visually impaired, special education, nutritional services, and adaptive devices) are provided by law at no cost to families. The site therefore offered the opportunity to observe mothers across a broad range of economic levels.

I observed developmental evaluation sessions of 130 infants and young children, and recorded them on audiotape. Recorded were both the physicians' examination itself and the conversation between the mother (as well as anyone else present) and the physician as a diagnosis and/or prognosis was presented. Although I was an outside observer, the impact of my presence was "diluted" by the presence at each exam of at least one nurse and one or (usually) more hospital residents doing their rotation in developmental pediatrics, in addition to the one or more physicians conducting the developmental evaluation.

In addition to observing the evaluation sessions, I interviewed 60 of the women whose children were diagnosed with a disability or developmental delay at the Newborn Followup Program. Ages of those interviewed ranged from teenage mothers to those in their late thirties. Educational levels of women in the study ranged from not finishing high school (approximately 7% of interviewees) to having a graduate degree (also 7%); half of all interviewees were high school graduates, and about 35% were college graduates. Both single mothers (17% of interviewees) and married women were included in the study. A few adoptive mothers were included in the study, but no mothers interviewed had released their disabled child for adoption or sent them to institutions; all mothers interviewed were caring for their child at home and planned to continue to do so. However, many women expressed their awareness that at other moments in time, indeed within their own lifetimes, children such as theirs were routinely institutionalized or otherwise segregated from society. And while many women recognized that alternatives to raising a disabled child at home are chosen by other mothers, no woman in the study took, or even sought information about, such options.

Interviews took place in the mothers' own homes within a month of the child's evaluation at the Newborn Followup Program, and lasted from one to four hours. All interviews were recorded on audiotape and transcribed verbatim. All participants, including mothers, children, other family members, and all medical personnel, have been assigned pseudonyms. During the interviews, demographic data were collected from mothers, including age, educational level achieved, occupation, past and current religious affiliation, number of pregnancies, number of children, etc. The preponderance of each interview however was open-ended, and devoted to collecting women's narratives of their experience of finding out about and living with their child's disability. Slightly over one-third of the women were interviewed again one year later, for the purpose of examining the impact of the experience of mothering on the interpretation of disability.

Emplotment

For any story to make sense, to have meaning for its teller or hearer, it must have a plot. Plot is an organizing feature of narrative, constructing "meaningful totalities out of scattered events" (Ricoeur, 1981, p. 278). The various parts that comprise a narrative—its protagonists and events—"are selected and shaped in terms of a putative story or plot that then 'contains' them" (Bruner, 1991, p. 8); in hermeneutic circular fashion, parts of a narrative are themselves constituted in interaction with the whole. Each event has significance only by virtue of how it is made to contribute to the story. Through plot, then, events in a story are made to unfold in a temporal sequence, but the meaning of a story can only be ultimately determined by its ending (Good, Good, Munakato, Koyabayashi, & Mattingly, 1994).

How will the story turn out? How will the present be viewed from the perspective of the conclusion? These are the questions that structure the process of emplotment when people are still in the midst of their stories. Quoting Brooks, Good et al. (1994) aptly point out that our "chief tool in making sense of narrative, the master trope of its strange logic", is this very "anticipation of retrospection". I suggest that during and after developmental examinations, most (but not all) mothers of infants and toddlers diagnosed with risk of disability, like the paralyzed actor Christopher Reeve⁵ in his public

⁵Christopher Reeve is an actor who received a spinal cord injury in a horseback riding incident. He started a foundation (The Christopher Reeve Paralysis Foundation), the primary mission of which is to encourage and support research to develop treatments and a cure for paralysis. In televised fundraising speeches and statements on the foundation's

speeches, emplot the scattered events of their children's lives in anticipation of a particular and culturally acceptable ending—that of overcoming (or at the very least minimizing) disability. Each incident—whether a doctor's gloomy prediction, a neighbor's suggestion that one is wasting one's life, or a child's session with a physical therapist or special educator—becomes an obstacle to overcome or an opportunity to seize along an epic journey toward this hopeful conclusion.

Mothers find institutional support for their linear narratives of hope in the early intervention system itself that provides various types of therapies for children deemed eligible. The key term for eligibility for services, as stated in the federal legislation, is “developmental delay”. According to New York State's definition, developmental delay means that a child has not attained developmental milestones expected for the child's age adjusted for prematurity, as measured by qualified personnel using informed clinical opinion, appropriate diagnostic procedures, and/or instruments (NYS Department of Health). The functional areas measured are cognitive, physical, communication, social-emotional, or adaptive development. A child is eligible for services if he or she has a diagnosed disabling condition (such as spina-bifida or Down syndrome) with a high probability of resulting in developmental delay, or is found upon evaluation to have a 12-month delay in one functional area or a 33% delay in one functional area, or a 25% delay in each of two areas. It was in the context of evaluation for eligibility for early intervention services that most mothers were first introduced to the term “developmental delay”.

The developmental assessment of very young children derives from a *maturation* model, in which arbitrary cut-off points are used to define motor development or language development as delayed (McConachie, 1995). Research shows that children do proceed through “motor stages in an orderly fashion; attainment of these functions is clear-cut and dramatic” (First & Palfrey, 1994). Rolling front to back precedes rolling back to front, for instance, and is followed by independent sitting. However, some have argued that there may be less consistency in how children proceed through *other* domains of development. The maturation model assumes that intelligence is quantifiable and fixed, and that development should be linear and predictable through

childhood. “However, the reality is very different; research with young children who have impairments indicates that the course of early development is discontinuous” (McConachie, 1995). Nevertheless, children evaluated at the Newborn Followup Program in the various domains are rated along a linear scale. The percentage of delay in each domain is determined by the relationship between the child's developmental age in that domain and the standard scale. The measures thus present disabled children as “different” only in terms of their higher or lower placement on a linear model of development; the linear model itself remains intact, with disabled children defined as behind or delayed.

Given the definitions of personhood and motherhood with which American women in this study entered their personal experience with disability, narratives of developmental delay and of related potential developmental progression enable hope. Developmental examinations, at which time diagnoses are often determined and prognoses discussed, therefore can and often do become sites at which competing plot lines for the child are put forward, and sometimes negotiated. This negotiation process will be analyzed through a particular case described below.

In the following extensive excerpt, Brenda Wilson discusses with the developmental pediatrician the diagnosis for her younger daughter, Lisa. Brenda is a white college-graduate and a Catholic. At the time of the evaluation from which the excerpt is drawn, Brenda was a full-time homemaker in her 20s, living in a duplex in a modest suburban housing complex with her two children and husband, who worked as a salesman. At the time of her second interview a year later, Brenda had gotten a part-time job as a cashier in a liquor store, and her husband was working for a neighbor.

At 5 months of age, Brenda's daughter Lisa had become seriously ill with a respiratory infection and had to be transferred to a hospital across the state where she had been placed on a machine to undergo extracorporeal membrane oxygenation (ECMO). While on ECMO, Lisa suffered a common complication of the procedure, a stroke. The meaning of the consequences of that stroke—the potential endings to Lisa's story—are here being negotiated between doctor and mother (BW). The conversation is taking place during a developmental exam approximately 11 months after the stroke.

Doctor: Okay. Do you have some particular things that you'd like to talk about or questions you want -

BW: Well, first of all, you know, I think it's important to stress that we've accepted Lisa for how she is and we're determined to make her the best little girl that she can be. Of course, my concern as a parent is what the future holds for her, but I mean that's even with my four-year old too. What I've seen

(footnote continued)

website, Reeve has predicted a cure for paralysis in the near future, and has expressed his desire to celebrate his 50th birthday by standing up and toasting those who have helped him. Reeve is controversial among disability rights activists, for he is perceived as using his celebrity status to divert funding and public concern from political issues such as access and employment discrimination through an appeal to the more culturally accepted “triumph-over-tragedy” cure narrative.

in the past eight months has been incredible, so I'd like to say Lisa is going to develop at a slower rate than other children. If she'll ever catch up, I don't know. But with the services we are getting, I've seen an improvement, of course, and I'd like to continue, of course with that. But I like to see different doctors and get their ideas, you know. That's why we went to Boston to, you know, we went in there and they said 'we've seen this, we've seen this.' This is common to their, you know, out there.

Doctor: To their practice.

BW: Yeah...

Doctor: So, from the physical standpoint, I feel really positive about how she's doing. Really, very positive. The other thing that I would comment on today, is that well first having seen her from hospitalization, onward, I have a perspective that's been very helpful to me. And I would fully agree with you, when I consider where she was, even after the hospitalization the first time you came here, where there was really very little awareness of her outside environment, vision that was questionable, she's obviously made some very important strides forward, extremely important strides forward.... So, let me put it in a bigger picture. The first thing that happens is, or what had not been happening, is you get visual information, and for her it was almost like on a blank screen, it wasn't registering. Now the visual information is coming in and it's registering, not 100%, but it is registering. The next stage has to be to take the register of that information and apply it to your previous experience, to your memory. But it means something about something that happened before or that could happen is going to give me a tool that I hadn't had before. That's the next jump that has to happen for her. Okay, now she made the jump to vision, now she has to put the vision together with learning thought processes. Okay, that's another big jump. That's a huge jump. So if you look at her current status she has made, you can't give a number to the progression because it went from almost zero to something more concrete in terms of where she was with her learning. So it's been maybe a thousand times better, but that thousand times better has to come up by another thousand to really make the impact in terms of learning that has to occur. So she's at another critical stage, and by critical stage I mean the next year or two. Okay. And the critical stage has to do with what I call integration of information. So now she has some open channels, now she has to put those channels together and make sense out of them. If that happens, if she gets into that issue and begins to understand how things relate to one another, visually, touch, hearing, she's going to continue

strong progress in learning. If they stay separate channels—and that is a distinct risk—mental retardation is clearly going to be present.

BW: I don't agree with that, though.

Doctor: I said "if".

BW: Okay, but I think to bring mental retardation into it at this point, is kind of premature, don't you? I mean, from just speaking to neurologists in Boston and everything....

Doctor: I'm a different way of thinking because I'm giving the best case and worst case here, all right?

BW: Okay.

Doctor: That's how I look at my job, kind of put this in that perspective. Okay. You say what is mental retardation? Mental retardation is that difficulty with taking information, making sense of it and applying it your life. Okay. And what I was just saying about taking that vision information, making sense out of it, and applying it to learning, if she doesn't make that jump, you're going to be in a situation where learning is not going to occur the way you want it to.

BW: A delay.

Doctor: Not delayed. I'm talking about if that jump doesn't occur, it will be delayed but there will be a permanent effect and that's mental retardation.

BW: All right, so effectively she would plateau and go no farther?

Doctor: She would plateau in areas that are critical to what we're going to call functional capabilities, okay?

BW: Okay -

Doctor: How do you take care of yourself, how do you communicate, how do you manage in your environment? Now that's the core issue of mental retardation. You don't have the understanding to make it through life, even with the physical disabilities. If you ask the question is she retarded today, the answer is that she's in the process of development and some clinicians would say she has strong signs of mental retardation.... Okay. She hasn't had experience with vision for a couple years almost. Now she's got to take that and somehow use it. If it occurs, she's going to be in really good shape. But if it doesn't occur, you're going to recognize learning is progressing but nowhere near the rate it needs to. What happens generally at two to three years of age are tremendous accomplishments, at two and three years of age. So while she might make progress, the other two and three year olds made a huge jump forward. So you're going to see a gap.

BW: We already see a gap.

Doctor: But what I'm saying is that a gap could actually increase even though she's making progress, the other kids could be way ahead. I'm pointing out worry markers along the way here. That's what I have to do, that's my job.

BW: I know that, I know that, I know that. But from what I understand, I mean, I have a question—if someone, an adult, has a stroke, are they labelled mentally retarded?

Doctor: No, mental retardation has to be in the developmental period. So it has to be during childhood... Now that's the worst case. Let's get away from that worst case issue. Okay. Again, if she was still at the point of saying vision hadn't improved, we'd all be saying, "gee, what's her future?" The question I think that is a legitimate one is, as she's getting closer to two, as her health is stable, is she at the physical standpoint of say, more intensive service in terms of being in a classroom situation for four hours a day? Would that be to her developmental benefit?... I mean you have the whole array of services so I don't offhand have another one to add to that, and I think the idea of stabilizing her ankles in such a way that she has more support down below is going to help with her stance. [Turning to physical therapist] Are there some issues from your standpoint that you wanted to talk about?

While physician/parent interaction is often conceptualized in terms of the physician "giving", and the parent "receiving" bad news, this exchange illustrates the way in which diagnoses and prognoses may instead be negotiated. Here the mother prefaces the discussion with a positioning of the physician as only one of the sources from whom she may obtain and accept information; she is prepared to discredit the doctor's story (although not biomedicine itself) if need be, for there are experts elsewhere with greater experience. Most importantly, however, she frames the interaction in terms of her daughter's "incredible" improvement. The doctor also begins his statement of evaluation by acknowledging the girl's progress, validating the mother's observations and thereby establishing common ground. However, the ensuing negotiation is in large part over the place of the girl's progress within a larger story. Within which plot should Lisa's "progress" be incorporated?

For neither participant is the girl's current medical status meaningful in itself; indeed it makes sense only from a position of "anticipation of retrospection". For Brenda Wilson, her daughter's progress (especially in regaining vision) is incorporated as an event in a temporal sequence leading towards the hoped-for end-

ing; while the child is delayed in her accomplishments relative to her peers, she is moving along the appropriate linear sequence toward recovery after a stroke. Lisa's current medical status is meaningful when viewed retrospectively precisely because in the plot of the story Brenda tells, the developmental distance the girl has crossed in the past is made to portend the future. For the physician however, the progress made is in itself insufficient to qualify for "delay"; its significance to the story is to be judged not by a comparison of the girl's current status with where she has come from, but rather with where she needs to go ("a huge jump"). In this interpretation, the girl's current condition is a "worry marker" that the doctor embeds within the plot of permanent disability. Both narrators are using the strategy of foreshadowing, casting events and characters in terms of a future trajectory they each claim to know (see Ochs & Capps, 2001, p. 5). Delay vs. disability: mother and physician have emplotted Lisa's life differently, and the "scattered events"—the return of her vision, in particular—are organized into different totalities accordingly.

Both doctor and mother identify Lisa's situation as out of the ordinary, as a break from the expected, normal path of development. As Becker (1997, 2000) found in her study of men and women facing infertility and Ginsburg (1989) described in her study of abortion activists, it is at precisely at such moments of disruption that narratives come into play as people try to make sense and give meaning to the disruption. Like so many other mothers just encountering a diagnosis of disability, Brenda utilizes a plot that incorporates her daughter within an already known and valued American story of struggle, hard work and progress. The story works to create consistency between her current personal experience and mainstream cultural expectations about the normal course of life.

At her developmental evaluation Lisa herself is, of course, still in the midst of the story being told about her; an ending cannot definitively be known at this time, for her future has yet to be reached. Having introduced their competing plot lines, the mother and physician can therefore negotiate the outcome of the evaluation. The physician introduces the possibility of mental retardation. The mother flatly rejects the label proposed by the doctor as premature, citing other authoritative sources ("neurologists from Boston") and utilizing the discourse of developmental delay. In response, the physician backs off slightly, reminding her that this is only one possible story ("I said 'if'") and represents only a worst-case scenario; other endings, he concedes, are still theoretically possible. Nevertheless, like Brenda Wilson herself, he also bolsters his interpretation with claims of authoritative support for his particular emplotment of events ("some clinicians would say she has strong signs of mental retardation"). Again the physician reiterates

the significance of the projected gap between Lisa and her normal peers. Again the mother interprets the future gap in terms of the existing gap; that is, in terms of developmental delay rather than permanent mental retardation. At the end of this excerpt, the physician attempts to resolve the discrepancy between the two stories with a move away from projected endings and towards more immediate actions upon which all can agree. He acknowledges that the progress Lisa has made so far makes an ending of mental retardation less certain; if she were still at the point where her vision had not improved, he suggests, we would all be even more concerned about her future. As it is, he suggests, since the ending of the story is unknown, we can move on to asking questions about immediate plans for her: Would more intensive services be appropriate? Should her ankles be braced? With the latter question, he abandons debate on mental retardation/delay altogether and turns to the physical therapist.

After the physician converses with the physical therapist, he asks Brenda if she has issues she would like to talk about, to which she responds somewhat curtly, “no”. Again, the physician retreats from his stance on mental retardation, accommodating his story to hers. “I want to emphasize the extremely strong progress she’s made, from where she started to where she is now. And more encouraging, the visual changes that have occurred recently...” The mother responds more expansively this time, explaining to him the value of hope.

BW: Right, right, yeah. That kept us going because when they labeled her legally blind, they had felt it was a cortical impairment and they gave us that hope that cortical impairment, you can regain your sight and that’s what kept us hoping. As to why that happened, we don’t know why, at this point we don’t know if it had something to do with the spasms. She’s been having spasms all along.

Doctor: It may have something to do with that.

Physical therapist: Are there any suggestions that you have?

Doctor: I think you covered it extremely well. Like I said, I know I have been impressed with Mrs. Wilson from the beginning in terms of her desire and capabilities in understanding her daughter’s needs to follow through. I would say you have a model program, from the administrative side of things it sounds fine. I’m sure you have a group of therapists that are excellent. And (turning to Brenda) your strong attitude about ‘we’re going to find the best for her’ is really what works.

In the exchange above, the physician acknowledges the mother’s expertise; she may, for instance, be

right about the cause of the blindness, and her efforts to get the best for her daughter do, after all, show results. With this accommodation from the physician, Brenda reflects on the difference between how she and the doctor have emplotted the events of her daughter’s stroke:

BW: I guess that’s why I’m so like, I didn’t mean to jump on you about the mental retardation, but how I get through this is, I have a child with a stroke and that’s you know, until someone can actually say to me, your daughter’s mentally retarded, I can’t even hear that word right yet. I know in the back of my mind it’s there, but I just take it one day at a time and I try not to focus on that, ‘cause I know if you do focus on that, then she’s not going to get where she is today.

Doctor: And my purpose again was the same. The next couple of years are very critical for her and this issue may come up in terms of a yes or a no, or a probable or not probable. By four years of age, three and a half, four years of age.

The doctor’s original plot in which the likely ending of the story is mental retardation, Brenda implies, leads to resignation rather than to action. If she were to have believed the physician’s ending, she could not have worked to bring about the dramatic progress that has been achieved.

The very permanence of disability, the reaching of a plateau or “hitting the wall” removes a child from the course of linear development which marks the full personhood of “normal” children in American culture. Thus the story one tells is performative; it can establish or deny the potential for a child’s full personhood. Narratives at this site are performative in yet another way as well, for the story negotiated by mother and evaluator often sets in motion the early intervention treatment plan for a child and family. For the story to result in early intervention services, it must from the point of view of the “system” include sufficient “delay” in the sense of a gap between the child’s performance and that of its “normal” peers to warrant expenditure of public funds; but for the parent to commit to early intervention the story must involve sufficient hope that the gap can be reduced or eliminated through hard work and therapy. In the example above, the child’s well-being, doctor and mother agree, is the purpose to which both are committed. By the conclusion of the session, the mother and physician, unable to reconcile competing plot lines, have negotiated a story whose ending is tentative and open; something they give themselves time to see revealed in a more distant future.

Significantly, Brenda’s concluding statements to the doctor assert her daughter’s value. She offers her

daughter as a reference for others going through the difficult experience of ECMO. She herself had found no one with similar experiences with whom to make contact in the area. “So I hope it doesn’t happen to anybody,” she tells the physician, “but if it does, I’d like to use Lisa as a reference, because she’s incredible, an incredible kid.”

Narratives of uncertainty/narratives of hope

In the case above, Lisa is described as “incredible” in large part because she has persevered and overcome enormous obstacles. She survived her serious illness; she regained her sight after a stroke; eventually she did learn to walk (an occasion marked by her parents with many photographs and a much-planned-for party). These events, like the developmental milestones reached by other children about whom doctors had made dismal predictions, lend themselves to emplotment within a story of progress. Such stories, in which a child may not conform to an absolute scale of attaining developmental milestones in particular domains, but nevertheless shows progress, are common features of mothers’ narratives regardless of the mother’s age or education; by leaving a prognosis undetermined they allow hope for a future without disability. Thus when Amy Garrison, a young, white, high-school graduate, was told that her premature baby suffered periventricular leukomalacia, she chose not to ask what could happen as a consequence because she’d “rather just take things one step at a time; I don’t want to think he’s going to be different”. Maria Peters, a young Puerto Rican woman who dropped out of college her first semester when she became the mother of a baby who is blind and has cerebral palsy, recalls a doctor’s frightening prognosis at the time of birth. “He was like pessimistic about the whole situation, and I was like, ‘thanks a lot’. I felt, I was really mad.” Maria believes that if the doctor had to give a poor prognosis it should have been told to her husband rather than to her, for “Jeff wouldn’t have run back and said that to me. He’s like ‘you know, this stuff might not happen. He (the baby) might not be able to get through this, but we’re going to pray and hope,’ instead of what he (the doctor) said to me.” Referring to one of her premature twins who is considered by physicians to be at risk for disability, white, college-educated Suzanne Dalton states:

I’m not dumb. I know there’s probably going to be some effect, but I’m also not going to treat him like he’s disabled yet, because they’re doing better than they would have expected him to do so far.... I continue to believe that with the right attention and all the loving attention and all the

special services that we can take advantage of, he will be fine.

Hope, as Becker points out, “is inextricably linked to notions of progress, which are embedded in US values of activity, achievement, and a focus on the future” (2000, p. 179).⁶ Committing not to a diagnosis of disability but rather to a concept of developmental delay, American mothers of newly diagnosed children can envision for their children a future without disability. Thus, for a time, they can retain both their received negative stereotypes of people with disabilities *and* belief in the full personhood of their own disabled child, personhood to be achieved through “loving attention” and “special services”.

Mothers discuss their commitment to Early Intervention services in terms of belief in their efficacy in promoting progress, with progress largely being defined as movement toward normalcy rather than accommodating disability. A mother of a child with a limb deformity argued with her husband over receiving these services, which he considers “being on the dole”. Insurance alone, she pointed out, simply did not cover enough occupational therapy to help her son achieve the developmental milestones reached by other children his age. She explained to her husband, in what “was like one of the biggest rifts we’ve ever had in our marriage, I said ‘this is what my baby needs to come up to snuff with all the other babies that are his age.’” Kelly Strathmore, whose child has a language delay, argued with her physician over his unwillingness to write a prescription for speech therapy, telling him “You should post a sign—‘NONE OF US BELIEVE IN SPEECH THERAPY, SO THEREFORE, IF YOUR CHILD NEVER TALKS, WE DON’T REALLY GIVE A SHIT.’” And Peggy Hoffmeister, hoping to pull her son out of his pervasive developmental disorder (on the autistic spectrum) was relieved to know that she was “getting for him what research shows to be the best kind of therapy that I could get here”. At her first interview, and after having set up therapy services, she could say, “he really has so much going for him. He’s got us and we will never give up on him.”

The concept of developmental delay therefore sets a script not only for the child, but for the mother as well. Her actions—her refusal to give up on her child’s ability to progress, her determination to get various early intervention therapies, her efforts to teach and provide stimulation to a child—are integral to the plot and are experienced as moving forward the child’s story toward the (hoped-for) conclusion. Mothers here are actors in the story, but they also act having adopted “the point of

⁶For discussion of the pervasiveness of narratives of linear progress in American culture, see Layne (1996) and Newman (1988).

view of a narrator, reading actions backward from an ending” they somehow know (Mattingly, 1998) or hope for. Their children, then, are not “written off” and depersonalized, but rather “written into” a story of struggle and progress, and thus of personhood as Americans define it. Return of a child’s vision or an increase in range of motion are not selected as desperate attempts to deny reality or cope with disappointment, but rather are experienced by mothers as developmental progress toward normalcy, often in spite of physicians who tell a different story. And the everyday acts of nurturance by mothers of young children with disabilities—children who in other times and places might be abandoned or institutionalized—are carried out within the meaning-laden context of the “overcoming disability” story whose ending mothers hope to realize.

Reflections on disability and mothering

For some, the commitment to pursue a life without disability for one’s child remains throughout the course of mothering; for other women it fades or coexists with belief in a child’s full personhood without “progress”, that is, *with* permanent disability. A year following the initial evaluation at which Brenda vehemently told a story of developmental delay against the doctor’s plot of mental retardation, Brenda reflects on how she now describes her daughter Lisa.

It was harder last year to even think about, and then as time went on, it’s like I’ve just accepted her for who she is and I wouldn’t want her any—I mean, I wouldn’t change her for the world. I mean, I would change what happened to her, but it’s just like an acceptance with her now, you know. I don’t know. It’s not hard anymore to say it or to even think it because she’s alive. I guess I’d rather have—I said to my mom, I said, ‘I’d rather have that label of mental retardation than to say my daughter’s deceased’.... So, you know, there’s no getting around it. That’s what she is, but it’s not a bad word anymore to me. It’s not a scary—I mean, it’s kind of scary, anything is scary, but it’s not like, ‘I can’t believe I have a mentally retarded daughter.’ I don’t even think like that anymore, you know.

At her second interview, Jenna Mosher, a married, college-educated mother of a child with multiple disabilities described her feelings about the use of the term *developmentally delayed* versus *mentally retarded*.

I don’t know if this came up when we spoke the last time, but I thought a lot about the labels. People don’t like to use the phrase *mentally retarded*. Now, I personally feel that it’s a rather accurate description. It just means mentally slow, and developmentally

delayed, to me, is a euphemism because I sort of feel—when you say your plane is delayed, you know that it’s eventually going to come in. Well, Daniel’s plane isn’t eventually going to come in, in a lot of ways. I guess it’s important for me to tell people the truth. I don’t want to cover up what the reality is because it’s hard, and he is severely mentally retarded, and it’s not that I want people to feel sorry for me, but I don’t feel the need to pretend that it’s anything other than it is. I don’t really feel that the phrase *mentally retarded* is derogatory.

The term *developmental delay* implies a comparison of each child to a norm, a standard model of maturation against which each child is measured. In part mothers who come to abandon the term do so out of their belief in the impossibility of comparison, their understanding of the uniqueness of each child. “I think we’ve basically come to the feeling Daniel’s just sort of his own entity, his own person, and that’s the way we have to think. You can’t really compare him,” remarked Jenna Mosher. Lucy Baker is a high-school graduate who stays home with her children during the day and does part-time cleaning work at night; once ashamed, now when she looks at her mentally retarded son a year later, “It’s not a problem anymore, it’s you know, that’s just Scott.” What these mothers here are suggesting is that there is an inherent interrelationship of their child’s disability and the child’s identity. “You have this child that you love so much,” comments a mother of a child missing part of his brain, “and if they didn’t have that, who would he be?” To love this particular child is to love his disability as well; they are now understood by the mother as being inseparable.

I have focused on how, in a society in which popular discourse presents disability as tragic and stigmatized, the plot of developmental delay temporarily retains the personhood of a child at risk for disability, that is, at risk not only for permanent impairment, but for discrimination and prejudice. It is beyond the scope of this paper to analyze the process whereby some mothers move away from commitment to a story of developmental delay or hold it simultaneously with belief in disability as a permanent feature of their child’s valued identity. But the research does suggest that mothers’ employment of their children’s lives may vary over time. As mothers find that their children do not, and may never, match American conceptions of *normal*, many reassess the meaning and value of normalcy, and develop a critique of the dominant discourse that would diminish the social value of their child. Narratives emerging from disjunctions between cultural expectations and the individual’s life course reveal the ways in which change is ordered and given meaning (Ginsburg, 1989). For some American mothers of disabled children, progress, “a core aspect of American individualism”

(Becker, 2000, p. 290), may become less constitutive of a meaningful and valued life. Personhood, neither an intrinsic biological given nor a static social construction, is thus defined and redefined through practice.⁷

Much of the psychological and social work literature would have us interpret the change described by parents like Lucy Baker or Brenda Wilson, in which a label once “denied” is now accepted or embraced, as a sign that a parent has finally adjusted to the trauma of having a child with a disability. But to take this position is also to deny what mothers themselves claim is the hard-earned knowledge, acquired through love and mothering, that a child’s disability need be neither a tragedy to be overcome, nor incompatible with full personhood. What at first appeared to so “naturally” represent “reproduction gone awry”, instead may now appear as just another version of reproduction, a version the misfortune of which is not that it exists, but that it is devalued by the larger society.

So I return with love to my daughter, who laughs and makes hard to understand silly jokes and painstakingly does her fourth grade homework on the computer using an adapted keyboard while sitting in a wheelchair.... In my desire for my daughter to progress, to change, like Brenda Wilson at her child’s evaluation, I probably offend the disability rights movement and support mainstream American disability perspectives. But from the latter viewpoint, my co-existing and seemingly paradoxical passion for my daughter’s right to be who she is, *as she is*, my inability to even imagine her without her disabilities, lends itself to claims of resignation. I would argue instead that it represents not defeat, but my own growth and transformation.

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⁷For discussion of the effect of the experience of mothering a disabled child on a woman’s recognition of personhood with disability, see Landsman (1998, 1999, 2000).

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