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Emplotting children's lives: developmental delay vs. disability

Gail Landsman*

Anthropology Department, University at Albany, State University of New York, 1400 Washington Avenue, Albany, NY 12222, USA

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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?

*Tel.: +1-518-442-4705; fax: +1-518-442-5710.

E-mail address: landsman@csc.albany.edu (G. Landsman).

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).

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