

**RECONSTRUCTING  
MOTHERHOOD AND  
DISABILITY IN THE  
AGE OF "PERFECT"  
BABIES**

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develop a critique of consumer culture as it has entered the domain of reproduction. Portraying their child as giver of a gift, not for which they were specially chosen but which they learned, through any normal mother's love, to receive, mothers reinstate their child's full personhood, situating it in opposition to the consumerism and social hierarchy that would devalue their children, their own motherhood, and indeed the lives of countless others.

## 6

ON MOTHERING, MODELS,  
AND DISABILITY RIGHTS

We're doing everything you'd do for a regular child, but maybe a little bit later. I say regular as opposed to normal. Somehow normal just doesn't—there is no normal.

(Darlene Mulligan)

My third child is now 15 years old. She is a bright-eyed, hard-working, usually cheerful, endearingly mischievous, and occasionally overly sensitive ninth grader with a keen appreciation for silliness and for a good (or even not-so-good) joke. Her name is "DJ" (for Dorothy Jean), and she has cerebral palsy. Nurturing her raised the questions that brought this book into being. So in the concluding chapter of this work, I very briefly return to the personal experience that served as its inspiration. In doing so, my intent is not to indulge in personal confession but to give life to the ambiguities and paradoxes inherent in the American experience of mothers encountering and living with a child's disability.

There was a time when I used to wonder, what if someone—a magician, a god, a doctor—were to say to me, "I have the power to remove your daughter's disabilities"? In spite of my great respect for—and theoretical agreement with—the disability rights position that discourages the quest for cures in favor of efforts to ensure a public policy of universal design and civil rights, I know that without a moment's hesitation I would respond, "Yes, please, give my daughter clear speech so that others could understand her thoughts and desires." 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: eat with a spoon, call a friend on a cell

phone, dress herself, make her own peanut butter sandwich, hold a pen or type on a computer with ease. And if there were gifts still to be given, yes, I suppose I might even ask that she get out of her wheelchair and walk. And yet, paradoxically, I suspect that such a joyous day would also be one of profound loss for me. For all my ability to fantasize in other areas of life (world peace, a cure for cancer, having enough free time to read all the novels I want), I can no longer even imagine who my daughter would be without her disabilities. Is there a separate self, the “real” DJ who would emerge from being “trapped” inside a disabled body? Is she, in the language of one version of the North American disability rights movement, a “person first,” someone with her own distinct personality who just happens to have a disability as one of her many characteristics but who would change little if her disability were to disappear? Or is who she is so intimately integrated with her body and its impairments and/or with her social experience of disability so as to be inseparable from them? Without the very impairments and disability I seek to eliminate, would she be someone else? Mothering a child who “departs from what is understood to be species typical” (Asch, 1998: 77) brings us to the very heart and soul of anthropological questioning: What is it that makes us human? What constitutes self and identity? What is unique and what the same about each of us? What sense can and should we make of profound differences within our shared humanity?

The perspective of mothers of disabled children on these issues is particularly appropriate for responding to the recent call for anthropologists to convey not only insights *about* but the insights *of* those we study into public policy debates (Anglin, 2002: 565). Often depicted as obstacles to disability rights—for perpetuating children’s dependency, for relentlessly seeking cures, and/or for colluding in their public portrayal as self-sacrificing “saints” tending to pitiable disabled bodies—mothers may nevertheless be well positioned to contribute to public policy discussion and to the development of more complex conceptualizations of disability. “When someone depends on someone else to do physical things for them,” disabled feminist researcher Jenny Morris has noted, “the more personal the task the greater the potential for abuse of human rights—and the greater the potential for the ‘caregiver’ to protect and promote human rights” (Morris, 2001: 14).

A goal of this chapter is to examine how mothers’ experiences and interpretations position them in relation to models of disability in disability studies<sup>1</sup> and in relation to the discourses and politics of disability rights activism. The intent is to enable what women have learned from nurturing disabled children and debates now taking place within the field of disability studies to mutually inform each other. The ultimate challenge of this work is not to determine how what we know about mothers of disabled children can be used to help parents “adjust” to or “cope” with children’s disability but rather to imagine how what mothers of disabled children have come to know can be used to further our understanding of humanity and to promote the expression and experience of full lives for all people.

### The Medical Model

Contemporary American mothers nurturing disabled children have available contending models with which to interpret and make sense of disability and identity. Models themselves are not theories or explanations, nor can they be proven wrong through disconfirming evidence; rather they are representations in which one established and well-understood system is applied to a less well understood system (Llewellyn and Hogan, 2000: 157). Any model is therefore a social construction. In various settings from doctors’ offices and shopping malls to family living rooms and Internet Web sites, mothers in the study interact with competing models, blending and reworking them in complex ways that provide insights into yet other possibilities for conceptualizing disability.

The medical model of disability portrays disability as a pathology located within the body or mind of an individual; the power to define and treat disabled people resides within the medical profession, and it is incumbent upon disabled people or their caregivers to seek expertise. This model structured the World Health Organization’s controversial 1980 International Classification of Impairments, Disabilities and Handicaps (ICIDH), in which impairments were defined as abnormalities of body or organ structures and functions and disabilities defined as the reduction of a person’s abilities to perform basic tasks as a consequence of such abnormalities (Simeonsson, et al., 2000). In their interactions

with physicians, mothers often encounter the medical model in the form of doctors attributing labels that, in the absence of a cure, locate a child permanently outside the norm. Engaging with early intervention service providers such as physical or occupational therapists, mothers may experience the model in its rehabilitation variant; here disability may appear as temporary developmental delay with the goal being to approximate the norm or compensate for functional liabilities. Whether as permanent damage or temporary delay, in the medical model there is a “problem” which is understood to derive from the impairment itself.

The medical model has perhaps made its most controversial entry into public discourse with the recent disclosure of the “Ashley treatment,” a specific combination of medical procedures performed at Seattle Children’s Hospital on a profoundly disabled girl at her parents’ request. Ashley’s parents describe their daughter as a “Pillow Angel,” a “beautiful girl whose body is developing normally with no external deformities” (<http://ashleytreatment.spaces.live.com/blog/>). She is, they write on their blog, a well-loved “sweet” child who stays right where they place her. Ashley is tube-fed and cannot keep her head up, roll or change her sleeping position, nor hold a toy or talk. Ashley’s parents describe their concern that as their daughter got physically larger she would be more difficult to care for at home; in particular, she would be harder to transport, reducing her participation in family life. Ashley’s mother sought and received for her daughter surgical and medical intervention to arrest Ashley’s adult height and weight. The hospital’s ethics committee formally approved the procedures.

In an article published in the fall of 2006 in *Archives of Pediatric and Adolescent Medicine*, the doctors involved described the growth attenuation treatment intended to improve Ashley’s future quality of life. They argued that after proper screening and informed consent, the therapy should be a therapeutic option available to non-ambulatory children with severe, combined neurologic and cognitive impairment (Gunther and Diekema, 2006). The medical procedure entailed high doses of estrogen, which closed Ashley’s growth plates and reduced her projected height by about 13 inches. Even more controversial, however, was the surgical removal of Ashley’s uterus for the purpose of eliminating menstruation and its discomfort. (The hospital later acknowledged that in carrying out a hysterectomy on a developmentally disabled

six-year-old without court authorization, it had violated Washington State law.) An additional and equally controversial part of the “treatment” was the surgical removal of the girl’s breast buds; her parents claimed that Ashley was not in need of developed breasts as she would never breastfeed a baby and that they “would only be a source of discomfort to her,” particularly in light of her maternal and paternal female lineage of large-breasted women.<sup>2</sup> In citing additional benefits of breast bud removal, Ashley’s parents explain that “large breasts could ‘sexualize’ Ashley towards her caregiver, especially as they are touched while she is being moved or handled.” Regardless of stated intentions, as a result of the procedures, Ashley could now appear to be a child, her parents’ “Pillow Angel,” forever.

Much of the ensuing debate revealed contestation over what constitutes being a good parent for a disabled child. For disability rights activist John Hockenberry (2007), the Ashley treatment both violates the personhood of the child and voids the parental relationship:

I am not going to argue that Ashley’s parents are immoral or unjustified in what they did. I will argue that they are no longer Ashley’s parents. Regardless of their love and affection for their daughter their decision to remove her breasts and uterus and maintain her in a state of pre-puberty is not a parental decision. It is more the kind of control one might enforce on a pet to manage the relationship. It is something a farmer managing the productivity of his or her operation would naturally enforce on livestock. This would be done humanely, morally, and no-doubt with considerable tender affection and love for the subjects. There would be no outcry and no controversy, yet no one would confuse these acts of husbandry as parenthood.

In response to those who criticize the treatment as an affront to disabled people’s dignity, physician Gunther tellingly posed a question: “Is there more dignity in having to hoist a full-grown body in harness and chains from bed to bath to wheelchair?” “Ashley,” Gunther continued, “will always have the mind of an infant, and now she will be able to stay where she belongs—in the arms of the family that loves her” (quoted in Gibbs, 2007). While this appears as an affirmation of parental love, underlying Gunther’s question is an assumption that the combination of adulthood and cognitive impairment is both incongruous and degrading.

Princeton bioethicist Peter Singer makes a similar argument, albeit by rejecting the very premise of the debate over dignity. Three-month-old babies, he argues, “are adorable but not dignified. Nor do I believe that getting bigger and older, while remaining at the same mental level, would do anything to change that” (Singer, 2007). Also weighing in on the issue is George Dvorsky, a member of the Board of Directors for the Institute for Ethics and Emerging Technologies on his blog *Sentient Developments* (2006), who was quoted by Ashley’s parents: “The estrogen treatment is not what is grotesque here. Rather, it is the prospect of having a full-grown and fertile woman endowed with the mind of a baby.”

In these latter arguments, a low level of cognitive function, particularly (but in Singer’s case not exclusively) with an adult body, precludes dignity. Few would contest that in the United States as in much of the world, adults with profound mental retardation are not accorded great respect. However, when framed within a medical model, the solution for this problem is neither to challenge popular belief in the inherent indignity of mental retardation, nor to improve services to assist families caring for their mentally retarded children as they age but rather to surgically and chemically intervene in the individual child’s body itself. Through the Ashley treatment, body and mind are made to appear consistent with each other, as that consistency is culturally constructed. Ashley’s mind cannot be brought to an adult level, but in the next best approximation of normalcy, her body is medically altered to ensure its perpetual childlike appearance. The issue of why adult status is incompatible with dependency is an issue I will address later. The point for the moment is the medical model’s positing of the individual as both the source of disability and as the site for intervention in the pursuit of normalcy.

Some have categorized medical and rehabilitation models together with the special education model as three variations of a deficit model.

Each model specifies a deficit (health condition, employment condition, learning condition) which must be corrected to make the person with a disability “normal.” Of course many of these conditions cannot be corrected (whatever that means) so that the person with a disability will never be allowed to be normal (whatever that means).

(Pfeiffer, 2002: 3)

The medical model, historian Paul Longmore points out, “has dominated modern policy making, professional practice, and societal arrangements regarding people with disabilities” (Longmore and Umansky, 2001: 7). Critics have argued that it has advanced the agenda of professional interest groups, resulting in disabled people serving as a source of profit, power, and status for them (Longmore, 1995).

The medical model is the perspective on disability that most mothers in the study brought with them to their experience of having a child and the one into which they were shepherded by the early intervention system. Yet, as will be seen later, when brought to bear on a woman’s own child, the model appears to be situationally anchored; women utilize the medical model but also actively negotiate with it.

Assuming a binary opposition between the categories of normal and disabled, the medical model has broad social implications. The historian Douglas Baynton suggests that this notion of disability may to a large extent underlie social hierarchy itself, in that disability has been used in the West to constitute a range of *other* cultural categories as well. Categories such as race and gender, for instance, have been shown to be constructed as binary oppositions with one side posited as the norm and the other as deviation, as in the “universal” male in opposition to the “deviant” female, the “normal” European American in opposition to the “abnormal” African, and the like. He points to how historically opponents of equality for women cited women’s supposed physical, intellectual, or psychological deficits or deviations from the male norm, just as immigration laws at the turn of the century used disability to limit the entry of national or racial groups said to be prone to physical or mental degeneracy. “It may be that to some extent all social hierarchies rely upon culturally constructed and socially sanctioned notions of disability” (Baynton, 1997: 85). Elaborating on the degrading exhibition in nineteenth-century Europe of the African woman Saartje Bartmann as the “Hottentot Venus,” Rosemarie Garland Thomson points specifically to ways in which the concept of disability has been used to cast what is normative embodiment in one cultural context as abnormal and inherently inferior; a culture’s gender, race, and ability systems, she demonstrates, are intertwined (Thomson, 2004: 78).

In seeking their rights, members of denigrated social categories have themselves relied upon the binary opposition of normal and abnormal.

Woman suffragist Henrietta Briggs-Wall's poster "American Women and Her Political Peers," for example, depicts the Women's Christian Temperance Movement leader Frances Willard in the same legal category as Indians, criminals, "lunatics," and the mentally retarded, (Landsman, 1992: 270–272); it plays upon the viewers' sense of moral outrage at this political juxtaposition of normal, morally upright women and abnormal, deviant men. The assumption is neither that universal rights should be recognized nor that the dichotomy of normal and abnormal should be dismissed as inaccurate or artificial but rather that women of a particular social class are unjustly categorized with those (deviants) who may "justifiably" be denied full citizenship. The binary itself, as well as its grounding in disability, is maintained in this political stance; the debate is only over who should be placed in which category. "Oppressed groups do not challenge the basic construction of the hierarchy but instead work to remove themselves from the negatively marked categories, to disassociate themselves from those who 'really are' disabled" (Baynton, 1997: 86). On an individual level, many mothers first encountering a diagnosis of disability utilize the same strategy in regard to their child; in doing so, they justify the attribution of full personhood to their own disabled child in a culture in which personhood is diminished by disability (Landsman, 1997, 1998, 1999).

Upon first hearing their child diagnosed with a developmental delay or disability then, many mothers rejected the designation of their child as disabled (i.e., as "abnormal"). As we have seen in Chapter 4, mothers in the study told numerous "the-doctor-was-wrong" stories, in which they describe being given misdiagnoses and dismal predictions that were later proven wrong by a child. Overcoming past obstacles and/or predictions made during hospitalization (such as that a child would not survive or would be permanently blind, for instance), became incorporated into plot lines in which the child would continue to progress and ultimately disprove a doctor's label of permanent disability. Though in these stories these women rejected the authority of the physician to define their child, their resistance was not a rejection of the medical model itself but only of the accuracy of a particular medical professional's judgment in placing an individual in a specific category. This was particularly the case for mothers of children who were diagnosed through observation and clinical judgment rather than through laboratory tests such as

chromosomal studies or brain scans, which were more often taken as authoritative. For example, Tara Vernon questioned whether her daughter fit the classification of autism.

Sometimes she doesn't have all the characteristics; you're like, is she misdiagnosed, and because we're treating her in this fashion that she will show more symptoms?... It's not something I focus on all the time, but you know, you watch these stories of a person who didn't have any psychological problems is put in a psychiatric ward, and all of a sudden they're—so it's not a cut and dry diagnosis. It's because of their characteristics that it's diagnosed. It's not like they did blood work and said, guess what, she's got Downs because of her chromosomes, you know?

In resisting an evaluator's placement of her child in a marked or stigmatized category, many mothers cite contradictory prognoses given by different physicians and therapists. Lisa Hart, the mother of a child diagnosed by a neurologist with cerebral palsy and mental retardation, describes being given the latter diagnosis:

On the last report he sent us, on the end he had "mental retardation." Just threw down there. So, I called him. I said, "On what basis are you saying she's mentally retarded?" "Well, she has microcephaly and a lot of kids who have that end up having mental retardation and she's really far behind.".... Meanwhile all her reports from her therapists are saying that she's doing really well, and you know, it was just like he just added this on like it was like no big deal. I said, "And what test did you give her to come up with this assessment?" I was in the office. He said, "Well, none." I said, "Well, I think usually they give you a test before they just put that on there." He's like, "Well, it's the same as developmental delay but she's more than 10 percent behind so instead of it being developmental delay, it's mental retardation." I said, "I don't think so." So, it was funny. I went and I spoke with her pediatricians about it and they were like, "Oh, she's way too young to be labeled—you know, we certainly don't think she is from what we see, and he didn't even give her a test".... It was always developmental delay and, you know—and her therapists were all like, "You know, we don't see that. We see her making good strides and she's very bright" and her new OT [occupational therapist] just thinks she's

Mothers may accept medical categories, but they exercise agency in determining which medical experts to believe. Their narratives commonly involve the criticism that the doctors did not have enough time with a child to make an accurate assessment, that a child exhibits certain behaviors and capabilities at home but chose not to during the evaluation, or that the child was particularly shy or tired that day. Michelle White claims to have “pretty much dismissed the PDD,” a diagnosis on the autistic spectrum. “You know I just don’t think that for the short amount of time that Dr. Svenson was in the room watching Brittany, I was just very shocked that she came up with the diagnosis that quickly....” During an interview, Sara Anderson reminded me that at the evaluation, her daughter, diagnosed with microcephaly due to strep B infection, did not follow a red toy and that when she dropped her head she didn’t show the reflexes to come back up; however, Sara counters that her daughter in fact does follow toys and have the reflex to come up when she is with her at home. Furthermore, she complained, “These doctors are seeing her when she’s just taken that phenobarbital, and that phenobarbital has got her so worked up, she gets very aggravated after she takes it. He (doctor) doesn’t see how she really is.” Physicians and mothers here mutually rely on the medical model, agreeing that diagnoses label intrinsic abnormalities, which in turn predict a child’s reduced life opportunities. Conflict between physicians and mothers center on what counts as evidence of disability, not in general but in the case of a specific child. At the risk of being labeled “in denial” or “not ready to face reality,” a mother may in such instances declare *herself* as expert.

The medical model measures the child against a standardized norm, with disability appearing as a deficit to which a mother may respond by denying the applicability of a diagnosis to her child or resigning herself to the child’s label and its culturally constructed implications. In either case, she is evoking a discourse of pity. Alternatively, she may seek to return the child to the track of linear progress that marks full personhood in American culture. In other words, she may engage in the socially approved project of “overcoming” disability. Yet this is tricky business; to obtain the tools necessary to move the child from disability to normalcy, a mother needs the doctor’s documentation of disability as determined by her official evaluation opens or closes the gate to early

intervention services. To be eligible for services, a child must receive a specific medical diagnosis of a disabling condition such as spina bifida, cerebral palsy, or Down syndrome, or be labeled with a measurable delay: 33% delay in one domain of development or 25% delay in two domains. The disabling condition or degree of delay provides the basis for the Individualized Family Service Plan (IFSP) that commits the services of early intervention providers: speech pathologists, physical therapists, special educators, and the like. Agreeing to these services by signing an IFSP, a mother literally “signs onto” the child’s labeled deficit.

New York State’s Early Intervention Program makes no promise of a cure and is rather broad in its family-oriented goals: the program’s literature states that early intervention can help a parent learn the best ways to care for a child, support and promote a child’s development, and include the child in family and community life (New York State Department of Health, 1998: 1). Nevertheless, the commitment mothers expressed to the Early Intervention program, as rendered in Lisa Hart’s comments earlier, is largely predicated on their belief that mitigation or elimination of a child’s disability is possible through a combination of early intervention services, the commitment of mothers, and the hard work, determination, and strong will of the child. Women across a wide range of educational backgrounds and ages express this belief. Recall that married, college-educated, part-time accountant Patricia Marks refers to herself as a “synapse-builder” who will work with her twin premature daughters to repair brain damage. Similarly, Jean Barbarino, a young, working single mother whose unemployed boyfriend rejected their son diagnosed with cerebral palsy, seeks more physical therapy for her child in the belief that “if it’s something that he works with” every day, his body will change.

They tell people who are paralyzed they’re never going to walk. Why do they walk? Because it’s just something they worked on every day, right? I mean, your mind is with it, you know, you have the motivation. This child has the motivation. He’s got the determination. He wants to do it. Now he needs the help.

In taking this stance, mothers fit squarely within the medical model and its current imagery of the body as project. An extension of the late eighteenth-century notion that life is the raw material with which we

are expected to do something, the “contemporary twist on the modern project of the self is that many of us moderns.... include doing things with our bodies among the ways to seek the unique point of our lives” (Frank, 2006: 72). With neoliberal medicine, sociologist Arthur Frank argues, the “flesh as God-given reality—for better or worse, this is how I am— gives way to the flesh as stuff to be worked with by various sorts of body workers....” (2006: 71). Among these body workers are not only the cosmetic surgeons and other physicians who form the focus of Frank’s analysis but physical therapists, occupational therapists, special educators, and above all, “good” mothers.

### Mothers and the Cure Debate

What are we to make of mothers’ desires to help their children change? The passion with which parents seek a “cure” for disability and/or their linkage of a child’s value to his or her valiant efforts to overcome disability have seemed to place parents and disability rights at cross purposes. Disability rights activists have long argued for and acted upon what has been called in the British context the “social model” and in the United States, the “minority group” or “civil rights” model of disability. The British social model offers a materialist perspective, focusing on the impact of the capitalist mode of production in the creation of disability, while the minority group model utilized more commonly by American disability scholars points to similarities between those with impairments and other oppressed groups. The different trajectories and divergent theoretical developments of U.K. and U.S. disability studies may be due to history, politics, space, place and the search for identity (Meekosha, 2004). Both disability models, however, locate impediments to a high quality of life *not* primarily within the body of the disabled person (such that the person should be cured, put out of his or her misery, or prevented from being born in the first place) but rather within the society that discriminates against disabled persons.

Central to the social model is the distinction between impairment and disability, perhaps first formally articulated by the Union of the Physically Impaired Against Segregation (UPIAS) in 1976. Impairment in this model refers to bodily dysfunction. Disability for both the social

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: 106)

Impairment is not by definition disabling (Read, 1998: 287). Nor in this model are the suffering of the family raising the disabled child or the burden to society of having disabled people inherent consequences of an individual’s impairment or different functional abilities; instead they are predominantly the result of “a society that fails to provide adequate resources, and sees disabled people as a financial burden and a drain on scarce resources” (Triano, 1999). As Dowling and Dolan (2001) argue, the negative impact on families of caring for a disabled child—stress, lower income, and the like—do not derive from the burdens of actual caring but from the constant stream of appointments and therapies, and the inflexibility of available jobs such that families must live on a single income, and the like. The response to the Ashley treatment by the Disability Rights & Education Defense Fund (DREDF), with its explicit call to provide more services to families of children like Ashley (see footnote 2), is an example of a political position emerging from a social or minority group model of disability.

The development of the social and minority group models had a profound relationship to disability rights movements in Britain and the United States. They helped set the agenda of these political movements, the goal becoming not cure but removal of barriers to full inclusion and citizenship; the models also encouraged disabled people to think of themselves in new ways, empowering them to take action to change society rather than to change themselves (Shakespeare, 2001: 10–11). Consistent with British social models of disability, Harlan Hahn’s (1994) minority group model specifically identified the role played by public policy in shaping the physical and social environment; in the U.S. minority group model, public policy is related to both the causes of and the solutions to disability (Putnam, 2005: 189). The Americans with Disabilities Act (ADA), passed in 1990 with wording crafted in



part by disability rights activists, represents the establishment in law of a narrative of civil rights and minority group politics (Haller, Dorries, and Rahn, 2006: 67).

Advocates of the social and minority group models of disability have actively criticized parental commitment to rehabilitative therapies designed to help eliminate or overcome impairment. Michael Oliver, for instance, interprets the popularity of "conductive education," an intervention for people with motor disorders, as

a product of the ideology of the able-bodied individual, for its aim is to teach children with cerebral palsy to walk, talk and engage in all other activities in as near normal way as possible. No consideration is given to the issue of the ideology of "normality" nor to the idea that the environment could be changed rather than the individual.

(Oliver, 1990: 55)

For advocates of the social model, parents are often seen as misplacing their efforts on correcting the impairment rather than on addressing the disabling conditions of society; in this view, rehabilitation therapies encouraged by mothers represent tyranny.

However, the parental goal of seeking a cure and/or of normalizing a disabled child is precisely the stance that is sanctioned by the larger society. It is the role that I, as a mother of a girl with cerebral palsy, am expected to take, and of all the efforts I make on behalf of my child, it is the one for which I am most likely to get credit. Support has been less forthcoming for my activism to get accessible buildings, transportation, and inclusive summer camp programs or for my efforts to negotiate a different work schedule to enable me to accommodate my daughter's daily needs.

Explaining why she, a former "poster child" later came to protest the Jerry Lewis Muscular Dystrophy Telethon, disability rights activist Laura Hershey reflects on the place of "the cure" in American society.

But for all our progress in the areas of legal protection and accessibility, there's still this lingering attitude that what people with disabilities *really* need is to be cured. Society wants the problem to go away, so it won't have to accommodate people with long-term disabling conditions. It wants *us* to go away or at least to "get better." One of my major

objections to the telethon is the way it reinforces that attitude.... The *cure* is a simple, magical, non-political solution to all the problems in a disabled person's life. That's why it's so appealing, and so disempowering. The other solutions we have to work for, even fight for; we only have to dream about the cure. The idea of a cure is at least in part an effort to homogenize, to make everyone the same.

Mothers' pursuit of cures is tempered by a deep desire to live a typical life in which women play with their children rather than schedule their lives around therapy appointments, and in which babies are not measured against a fixed scale of developmental milestones but treasured for the joy they bring to their families. Reflecting on mealtimes with her mentally retarded son Jacob, Jennifer Borden explains, "I know they want us to push, they want us to put different... types of foods in his mouth, you know, different consistencies, and... I hate doing it. He's doing this everyday.... You know, can't I just enjoy him?"

"It takes up a lot more energy to think about this," comments Suzanne Dalton. She compares her approach to toys and play with that of mothers of typically developing children. "You know, when baby sitters come and you tell them 'these are the play skills that we want them to follow,' no one else does that with their kid, you know.... When I'm searching in the stores for toys, I'm.... thinking, what kind of skills does he need now? How can I get these things so that it can help him pull and, you know, get good grasping skills? You know... there are periods of time when you think, wow, this is really all consuming!" But in an environment of competitive mothering, individual choice and mother-blame, the yearning to abandon attempts to repair a child's deficits are weighed against the belief that women cannot be good mothers unless their children show "progress." For this reason, some mothers feel the need to protect themselves from information that would divert them from this project.

Women who refused diagnostic tests explained that they did so because they fear that they will treat their child differently by virtue of knowing specific medically sanctioned information, and will thereby do damage to their child. Ironically, most often this is framed in terms of faith in intervention—a concern that if diagnostic tests prove definitive, a mother risks seeing the situation as futile and thus might give up on

her efforts to “cure” or mitigate the impairment. The result might be to forego potential progress. A mother of a premature baby at risk for cerebral palsy thus reflects on the value of an undefined future. “I still have this belief that if I don’t know, if no one can tell me, maybe I’ll treat him differently and maybe he’ll be better.... And I just always thank God that there’s so many services available to him and we spend so much time with him and we just love him to death.... All these things put together will be as good as he can possibly be. So maybe he’ll be just like a normal kid.” And ever so tentatively, a mother of a ten-month-old child with severe brain damage challenges the doctor’s prognosis during an office visit: “Okay, what if, I’m not saying it’s going to happen, I’m trying to be in reality, but what if he do walk?.... He might walk, but I’m still in reality, but what if he do wake up one morning and decide he can walk?”

Mothers’ resistance to medical authority and labeling of their child in these cases supports the medical model of disability in which disability is defined as a pathology located within the body and/or mind of an individual and in which disabled individuals are positioned as “less able than those who can recover from illness or who are non-disabled” (Gilson and DePoy, 2000: 207-8). As discussed in Chapter 4, not knowing the pathology leaves room for hope that a child may “overcome” his or her disabilities in spite of doctors’ predictions.

Yet some mothers’ narratives revealed another, perhaps darker, fear of believing the medical profession’s prognosis of permanent disability: that the mother will herself look at her child as less valuable or less worthy of nurturance. Laurel Messerschmidt’s comments, presented earlier, take on new meaning in this light. “One of the things that kind of surprised me is that there was like sort of a point where I wanted to push Ellen away,” she explained.

You know, it was sort of like, I felt like, I just sort of thought of the stuff we learned in school about when an animal perceives one of the pups is not going to make it, sort of push him away, and it was sort of like an unconscious thought that rose to the surface to a certain extent. And after a short time, it’s sort of the—she’s not perfect, so I’m not sure I want her, type of thing, and that was kind of a difficult couple of days.

“When was that?” I asked her. “It was after we’d been to the doctor, and we actually had a horror story,” was the reply.

This interview excerpt represents an intriguing reflexivity, for it reveals a mother’s awareness both of her child’s inherent value and human rights, and of her own socialization in a culture in which personhood is diminished by the label of disability. In this context, “not knowing” becomes an act of preserving her child’s status as normal not only for a woman’s own psychological needs, as the concept of denial would suggest, but for purposes of shielding her child from discrimination, in this case discrimination by the mother herself. Mothers accept the medical model’s authority to define disability as a deficit or defect of the individual, yet at the same time, reveal a belief in a *disablement process*, a fledgling recognition that disability may not only be about impaired bodies but about societal attitudes and politics as well.

#### Disability as Oppression

Indeed, when asked what their greatest concern for the future was, mothers consistently responded not in terms of their child’s physical or cognitive impairment itself, but rather in terms of how the child would be treated by others. This concern was raised by mothers of all social classes and educational levels, and appeared regardless of the type of impairment.

I laid awake and thought about it.... Is he going to get a prom date? Kids are going to make fun of it. This is going to be terrible.

(Donna Leiden)

I worry about kids maybe picking on him because he’ll be the smallest. I worry about if he still has the flat spot on his head kids are going to make fun of him for that. I know kids can be pretty mean at times. Those are things I’m thinking about where I hope he doesn’t have to deal with, but I don’t really know.

(Mary Jane Pickard)

I worry that she’s a girl, and that some boy’s going to take advantage of her as she gets older because she’s not going to be quite as with it as other

kids. And I worry about what other kids are going to say to her, and do to her, and all that kind of stuff.

(Mother of a girl with Down syndrome)

I don't know that this will answer your question but I'm going to say it anyway. My biggest fear for him is, I mean, I've heard people talk, you know, as I was growing up making fun of people, things like that, that's really my biggest. I don't want him to have to ever hear or deal with that. I know that to some extent he will and he's a very smart child no matter what the doctors are able to test for. And he knows. He knows what you're saying and that's my—really, I just hope he doesn't ever have to hear or listen to that.... He's, you know, still my little boy and not matter what he can or can't do...

(Lucy Baker)

I don't care what is wrong with her, but I don't want her to go to school and stuff, or go out on the street and people will pick on her. That's what angers me.... Because I see how people are, and how I sometimes see it, you know, people driving up the street in a wheelchair and you're like, "get out of the road or I'll hit you." I don't want people to pick on her.

(Sara Anderson)

I mean, what does the future hold for her? Do they get to have a family life or do they live singly by themselves? .... That part bothers me, I think, more than anything else. What happens when I die and she's left here by herself? Is she going to be by herself the rest of her life? Is she ever going to have a partner? I mean, that part, because that's normal, and that part is hard.

(Alice Brooks)

I worry about the first time he's in preschool or daycare. And the kids have to hold hands and how the kids are going to react to it. And then, everybody tells me, and I see it anyway because I'm a teacher, well kids make fun of each other anyway. Like this one's fat or that one's ugly or this one's stupid and that one's got a lisp. And I understand that. But that's something that everybody has to contend with. But then he's got this on top of that. He could turn out to be a *fat* kid with no hand, you know.

(Connie Brown)

I worry a lot about what people are going to think about her.... What her perception of other people's perception of her is, and that again, gets into the issue of school, and sometimes I do have images of her being ridiculed, and that's the hardest thing.

(Terry Johnson)

Although not conversant with the terms so central to the language of disability rights and the social/minority group models of disability, in conceiving their child's future, mothers over and over again distinguished between impairment and disability. Asked her concerns for the future, "Well, I don't know—how the world will treat him" was the reply of a mother of a child with cerebral palsy. Echoing the concerns raised by mother after mother in the study, she continued, "Not really how he'll be. He'll be fine, but how other people treat him...."

The rhetoric of the disability rights movement often appears accusatory of parents, charging them with attempting to "fix" or "normalize" their disabled children. This study suggests that this accusation is in itself valid, particularly for mothers whose children have been recently identified as disabled; however the study also reveals that the efforts at normalization may not necessarily preclude understandings consistent with the British social model or American minority model of disability. Like disability rights activists and proponents of the social and minority group models, mothers of newly diagnosed disabled children do, as the excerpts above reveal, believe that the greatest obstacles to a child's happiness and development are not a child's biologically based impairment, but rather the prejudice of the larger society. The most detrimental issue, they recognize and openly express, is not truly located within the child. Yet the narratives of mothers just encountering a prognosis of disability also reveal more faith that their *child* can be changed than that *society* can.

Amundson notes that when individuals try to hide their disability, their behavior has been interpreted patronizingly, "as evidence of the failure to accept one's limitations." He argues that such attempts at passing for non-disabled should instead be seen as a rational "recognition on the part of disabled people of a deep social prejudice against them" (Amundson, 2000). Many mothers denying a physician's diagnosis or engaged in efforts to "fix" their children may indeed be failing to accept

their child's limitations; but they, like disabled individuals trying to "pass," may also be strategically assessing and acting upon the discrimination they know confronts those with impairments.

Mothers' analysis of disability is in this way not inconsistent with the social and minority group models developed within disability studies and the disability rights movement—disability is, for most mothers, understood to be caused by prejudice, oppression, and the denial of agency and autonomy. But the (immediate) *response* of mothers remains rooted in the individualized, medical model of disability. In the first round of interviews, women tend to describe their role as mothers as involving protecting their child from the discrimination they fear for them in the future. This role is generally not conceptualized in terms of political action but in terms of making sure that their child appears as "normal" or as consistent with American values as possible. This effort may address skills or knowledge, as in the case of Alice Brooks, a mother whose daughter has Down syndrome.

It is very important to me that she speaks as normally as possible to the point that—see, that's going to be one of her stumbling blocks, I think. If she can't speak right, no one is going to want to listen to her, and they're going to shut off quicker. Her appearance is going to be part of it, but if she can't carry herself properly, then I am going to be in real trouble with her, and I don't want that. I want her to go to college. I want her to live as normal a life as possible that we can give her.

This same mother, a married, part-time waitress, also sought information about a special vitamin regimen for children with Down syndrome. Her goal was not to change her daughter's personality or intelligence level, but rather her physical appearance; it is on the basis of appearance, Alice and many other mothers believe, that society makes judgments that will determine employment and other opportunities in life. In this excerpt, Alice discusses not only her own daughter, but mine as well, predicting society's reaction to our children if intervention does not occur.

She is what she is. I asked about the vitamin hoping that it would change her outward appearance, not her inside. It's more important for outward appearance because people judge you on the outside first. nothing inside.

Your daughter's probably very intelligent but no one's ever going to know that because they're not going to give her a chance, unfortunately. And that is sad. And that really, really bothers me a lot. Maybe she'll (daughter Susan) change people, I don't know. Hopefully, she can make a difference, and maybe people will look at her and say, gee, she has Down's, but she's intelligent. You know, gee, she doesn't have to sweep floors, she doesn't have to bag groceries. And that's not good enough for me and I won't accept that for her. You know, I wait tables because I choose to, not because I'm not intelligent enough.

Women may refer to their experience as mothers as helping them to see through the petty values of a consumerist society; nevertheless in the name of protecting their disabled children from discrimination, mothers claim to make an additional effort to ensure that their disabled child has the material goods that society associates with valued persons.

I said to Barbara, I said, "I make a point when we go out that they look spectacular." And I said, "without it being, you know, over-kill"... because I always want the first thing that they hear somebody say is "how pretty you look." Or "how pretty you are." I said, before you get the, "how come you've got those on your legs? or "why do you wear glasses?" or whatever... and I have encouraged other people to do that, especially folks who have had some bad experiences with their kids out in public. Because people pay attention to how the kid's dressed and, you know, this and that. And, I mean, even as babies; I had one lady, you know, point out to me one day that she didn't think that those socks and clothes went. And I just went, well, I did, you know; okay well, we'll not put this together in this combination again!

(Patricia Marks, mother of twin premature girls with cerebral palsy)

You know your kid gets picked on if he wears cheap sneakers, you know. You know they're going to get picked on if they look different, if they act different. That's one thing that we always say, that no matter what we have to do he's always going to have, like he has to wear glasses, and we kind of got him the style like yours. But when we first got him glasses we had Medicaid and all Medicaid wanted to cover was those big plastic, cat eye, ugly... I'm like why do they do that? This kid has enough

problems without having to be picked on about his glasses. It only makes his problem worse. And we're always going to make sure that he has... well, he can only wear nice sneakers because his feet don't go in other ones, but we'll always make sure that he has at least the things that make him look the same as the other kids.

(Kim Boland, mother of son with autism and Down syndrome)

Mothers here clearly locate disability not within their child but within the external society; they appear to locate the "solution," however, in attempts to normalize their child either through image management (reducing the appearance of impairment) or through the search for a cure. Mothers' analyses of the limitations facing their children thus share with advocates of social and minority group models a rejection of the medical model with its "focus on impairment as the defining characteristic of life as a disabled person." They agree that "it is social barriers which create disability, and that the difficulties of living as a disabled person are due to discrimination and prejudice, rather than impairment" (Shakespeare, 1998: 670). Yet in seeking to prevent or mitigate the pain they anticipate their child experiencing from this discrimination, most mothers nevertheless act within the medical model's perspective "that the human being is flexible and 'alterable' while society is fixed and unalterable," and with the model's emphasis "upon adaptation to the environment" and individual effort (Llewellyn and Hogan, 2000: 158).

The bind in which mothers and children find themselves is exemplified in the experience of Jean Barbarino, a single mother whose own mother often cares for Jean's young son with cerebral palsy while Jean is at work. Jean resents the pressure to change her child, and is frustrated that the child's impairments, features of his anatomy, are assumed by most people to be transitory. Speaking of her boyfriend (the child's father) she says

I've got his father who insists.... "Gee, this kid ought to be walking. He ought to be doing this by now." "How much longer are they going to be doing the physical therapy on him?" [she mimics] Then I got my mother on the other side. "Boy, I hope this kid starts walking in the summertime. I don't know what I'm going to do if he doesn't start walking." EXCUSE ME PEOPLE HE MIGHT NOT WALK!

Nevertheless, Jean cannot bear to actually say as much to her mother, who she describes as a simple woman who wouldn't understand.

Jean is painfully aware of negative reactions to impairment. The day before our interview Jean had asked her live-in boyfriend, the boy's father, to sign Social Security benefits papers which indicated the child's diagnosis; it bothered him so much to admit that his son was disabled that he left home without signing the papers, and had not yet returned. Asked about whether she had sought respite services, Jean commented, "I don't need somebody to come in to help me out so I can get out. I just want to be able to take him with me." She seeks, in other words, to include her son in the social life of which she believes he should be a part. The obstacles to this goal are matters both of anatomy and prejudice, as well as of Jean's position in a class-stratified society. The child's body is so stiff that Jean is unable to separate his legs enough to carry him on her hip like most other children his age. Jean worries about the social exclusion she foresees for him. She talks at length about her current struggles to locate and afford a stroller that would accommodate her son's unique body so that he might participate in everyday outings; at the same time, she fights to get her county to pay for more physical therapy to help enable him to learn to walk. Thus to the outside world, including her own mother, she masks the permanency of her son's differences, while she simultaneously strives for societal change, her son's fair share of resources, and a biological cure through therapy.

"I see the situation disabled people are in," explains disabled writer and activist Cal Montgomery, "as unjust, not tragic. Created and sustained by society—which is to say, by all of us—and therefore potentially changeable." Writing in the online disability journal *Ragged Edge*, she explains "I'm not interested in changing myself into the sort of person society automatically enables; I'm interested in changing society so that it enables all its members." Yet by Montgomery's own admission, "the process of making the world better is not an easy one. Even imagining the kind of world you're shooting for is hard to do" (Montgomery, 2004). Through the experience of mothering a disabled child, many women do come to reject the medical model on the grounds that it denies full personhood to their child, yet ironically they appear to be acting on the medical model by seeking to have their child

overcome or minimize disability, i.e., to change into the sort of person society enables. The goal of overcoming disability in this case may not exclusively be, as some disability rights advocates suggest it is, because mothers themselves still hold to a normative standard of development or because they struggle, as indeed many do, with limited resources; it may also be because mothers worry that their cherished children will face social ostracism and prejudice well before societal attitudes can be changed. "The process of making the world better," after all, "is not an easy one." To a woman striving to be a good mother, the promise of individual cure may sometimes appear more immediately realizable than does a welcoming society.

In representing a child as a "giver" a mother establishes the child as morally superior to others, but she nevertheless also believes that the gift her child has given may have come at the expense of the child's social acceptance. Caring for and publicly representing her child on a daily basis, she predicts that impairment will be an experience not only of bodily or cognitive limitation, but of social construction as the disabled "Other," in which her child will feel the pain of being out of place in the world. A mother can therefore simultaneously morally elevate her child's personhood to or beyond that of typical children, be truly grateful for having been given the gift of unconditional love, and still wish for, and work toward, her child being cured.

#### Mothers and Critiques of the Social Model Within Disability Studies

In understanding how mothers of children diagnosed with disabilities can hold this paradoxical position regarding their disabled children, it becomes necessary to address in a more nuanced manner the ways in which disability is caused by discrimination rather than anatomy. The Disability Rights Movement, with the social model as its "theoretical linchpin," has set as a major goal to remove restrictions and increase access to social contexts from which disabled people have been denied (Shuttleworth, 2002: 113). This has led to a focus on the removal of structural barriers in the public domain; in the United States, arenas such as employment opportunities and access to public facilities can, and in many instances, have, been addressed through legal means. The Americans with Disabilities Act (ADA) is perhaps the most significant

example. But, as Shuttleworth argues, within other domains, such as in what in American culture are considered the private interactions of love and friendship, oppression is less easily amenable to change through public policy.

In love, personal prejudices reflecting social attitudes toward disabled people, cultural meanings of disability and hierarchies of desirability are... given free rein. Access to this interpersonal context for disabled people thus cannot rely on the rule of law or public policy. As one man with cerebral palsy phrased it, "I don't give a flying fuck about the ADA because that's not gonna get me laid."

(Shuttleworth, 2002: 113)

In movements predicated on civil rights, calls for geographical access to a community seem logical and appropriate. Interpersonal access to community, however, is another matter. "We consider it perfectly reasonable to demand that people put up with neighbors and classmates and coworkers that they might not want to include; but don't believe anybody has the right to demand that someone else be their friend" (Montgomery, 2004).

In revisiting the interview transcripts we see that it is precisely within the contexts of interpersonal relations, rather than structural access, that most mothers locate the most feared aspects of disability. Is she going to be alone the rest of her life? Will he get a date to the prom? Will another child hold his deformed hand? Will she be picked on and teased? Will people listen to her? In short, will my child experience love, friendship, and family? These are the questions that worry mothers. These worries derive from a focus on lived experience, the area critics within disability studies contend the social model has neglected. The "dominance of masculinist, anti-experiential perspectives in social modelist work has had the effect of privileging the 'restrictions on doing' dimensions of disability over its 'restrictions on being' dimensions," argues Carol Thomas (Thomas and Corker, 2002: 19). My research suggests that it is overcoming restrictions on *being* that underlies the efforts of mothers doing the work of nurturing disabled children.

The field of disability studies has successfully worked to demedicalize disability, defining disability as the outcome of oppression and

discrimination, and portraying the medical control of disabled people as politically motivated and dangerous. The medical model “buys into the assumption that people with disabilities are more concerned with cures than rights, are more plagued with their condition than with discrimination” (Linton, et al., 1995: 8).

The social or minority group models of disability on the other hand, have been liberating in directing action toward social and political change, and in wresting agency from the hands of the medical profession. “Nothing about us without us,” disability activists have argued in efforts to implement policy. And indeed, they have demonstrated that discriminatory practices and physical and institutional obstacles *can* be remedied (Asch, 1998: 78). In the United States, the Independent Living Movement redirected the medical model’s focus on impairment to address restrictive environments and social attitudes; the creation of Centers for Independent Living helped to develop a cross-disability identity and enabled people with disabilities to become role models for contending with discrimination (Kasnitz and Shuttleworth, 2001: 24–25). But some claim that the very success of the social model in Britain is now its weakness (Shakespeare, 2001: 11). A powerful tool, the social model effectively became, Shakespeare claims, a “sacred cow,” a litmus test by which disability activists are judged. In its strong version, the public presentation of the model is inconsistent with the real lives of disabled people. “Most activists concede that behind closed doors they talk about aches and pains and urinary tract infections, even while they deny any relevance of the body while they are out campaigning” (Shakespeare, 2001: 12). In *Disability Rights and Wrongs*, Shakespeare (2006) faults the British social model for its unsustainable distinction between impairment and disability, its claim that all disability can be removed by social change, and its downplaying of the role of impairment in the lives of disabled people. Like sex and gender within feminist analyses, in which sex refers to the biological and gender to social relations of inequality, the dichotomous framing of impairment and disability is now being challenged. Disabled people, Tom Shakespeare argues, experience the problems both of impairment and of disability, and a developed social theory of disability must encompass both aspects (1998: 671).

As scholars have more recently noted, while heavily reliant upon

constructed (Davis, 2002: 23). Shaken baby syndrome, for example, was identified as an impairment only after shifts in the pediatric field encouraged doctors to address developmental and behavioral issues of children; although child abuse has perhaps always been with us, the symptoms of this particular type of abuse was socially constructed as a medical syndrome in the United States during the 1970s (Evans, 2004: 161). Ilana Singh similarly argues that the medicalized categorization of behaviors as Attention Deficit Hyperactivity Disorder (ADHD) emerged within the context of patriarchal discourse and a specific culture of mother-blame. Diagnoses of and medication for ADHD remain a peculiarly American phenomenon (2004: 1193).<sup>3</sup> Similarly, dyslexia appears only in contexts of literacy. One might also argue that within the Chinese historical context the deformation of the natural foot, often including its paralysis, as a result of the practice of foot binding was the norm for wealthy women, and did not become an impairment until Westerners so defined it.<sup>4</sup> Other impairments that have also only recently been identified as such—including Asperger’s syndrome—suggest we might want “to question the clear line drawn between the socially constructed ‘disability’ and the ‘preexistent and somatic’ impairment.... Is the impairment bred into the bone, or can it be a creation of a medical-technological-pharmaceutical complex?” (Davis, 2002: 23). In light of these cultural and historical analyses, the distinction between impairment and disability blurs.

To accent both the relationship of impairment and disability and the need for their analytic separation, Shuttleworth and Kasnitz (2004) have recently begun to utilize the term impairment-disability. In defining impairment as “a negatively construed, cultural perception of a bodily, cognitive, or behavioral anomaly in terms of function or some other ethnopsychological or ethnophysiological status,” Shuttleworth and Kasnitz (2004: 141) imply that impairment, although referencing bodily or cognitive aberration, does not have an exclusively biological, pre-social existence.<sup>5</sup> Rather, impairment is always construed, experienced, and evaluated within a cultural context.

Acknowledging that articulating negative feelings about the experience of impairment may “play into the hands of those who feel that our lives are not worth living,” feminist disability scholars have also contested the dichotomous framing of impairment and disability; in

arguing that anatomy is not destiny, activists have too often “colluded with the idea that the ‘typical’ disabled person is a young man in a wheelchair who is fit, never ill, and whose only needs concern a physically accessible environment” (Morris, 2001: 9). Individuals who experience pain, or whose impairments result in a need for lifelong assistance with tasks such as eating or using the bathroom, may not easily recognize themselves in the social model. Nor do profoundly mentally retarded children, for whose lifelong care American parents feel they must plan, fit easily within this model. Regardless of accommodations, independence may not be a possibility for those with particular impairments; some people “could not survive, much less thrive, without constant and vigilant attention, without someone performing...nearly all the tasks of daily living” (Kittay, 2001: 566). Just as impairments may not exist solely in the realm of biology, not all disabilities are malleable social constructions.

I have earlier shown how American mothers just finding out about their child’s disability have generally acted more to change their children than to change society—that is, they have directed their efforts toward impairment within the medical model vehemently opposed by disability rights activists. Yet I would like to suggest here that many mothers who have experienced nurturing a disabled child over a period of time have developed a discourse that may *converge* with the current efforts within disability studies to address issues of embodiment without losing the political agenda of human rights.

The problem with the current social model of disability, Hughes and Paterson have argued, is that like biomedicine, the social model treats the body as a “pre-social, inert, physical object, as discrete, palpable and separate from the self” (1997: 387). In this essentialist stance toward the body, impairment is presented as a private issue, devoid of public meaning, while disability is disembodied. Some disability scholars and activists therefore have called for “giving impairment a sociological agenda—as a culturally informed and meaningful quality of existence” (Paterson and Hughes, 1999: 602), for taking a “more nuanced view, simultaneously defending the moral value of disabled people’s lives, but also recognising the differential impact of impairments” (Shakespeare, 1998: 670). As both caregivers for impaired bodies and advocates for their disabled children’s full personhood within an unjust society,

mothers of disabled children may be well positioned to contribute to this new understanding.

Disability scholars Kevin Paterson and Bill Hughes are particularly concerned to explain the *interconnectedness* of impairment and disability in the lived experience of disabled people. Following Leder’s analysis of pain, they argue that in everyday life our experience is characterized by the disappearance of the body from awareness; however, in situations of disease or pain the body becomes present to us in a dysfunctional manner, it “appears as a thematic focus of attention, but precisely in a dys-state” (Leder, 1990: 84, quoted in Paterson and Hughes, 1999: 602). Instead of disappearing, in the context of pain the body “dys-appears.” Applying this analysis to disability, Paterson and Hughes argue that in a disabling social environment, one in which there are physical barriers to accessibility or in which an individual faces prejudice, for example, the impaired body is brought to consciousness; there is a simultaneous recognition of both the external barriers and the internal body. In such settings “the body undergoes a mode of ‘dysappearance’ which is not biological, but social” (1999: 603). Impairment in this sense is an inherently intercorporeal phenomenon. The authors illustrate this process using the example of speech impairment.

The body of a person with speech impairment “dysappears” when faced with (socially produced) embodied norms of communication. Since these norms largely reflect the carnal information of nondisabled people, the relationship of disabled people to them is one of significant disadvantage. The “dys-appearance” of the impaired body is structured by this disadvantage. Exclusion from and disruption to communication is not therefore a matter of the ability of an impaired person to communicate, but about conventions and norms of communication, which are (*a priori*) hostile to non-conforming forms of physicality.

(Paterson and Hughes, 1999: 603)

The criterion of time, in particular, makes the body of the speech-impaired person, in this case that of one of the authors, “dys-appear.” Asked a question by someone during a ride in a lift (elevator), the author points out that the option to answer was not available to him, because the “duration norm” of the communication was not commensurate with (his) carnal needs” (606). Just as the architectural conceptions of space



have been largely uninformed by the carnal information of wheelchair users, communication norms—codes of movement and timing—are primarily informed by non-impaired bodies; in such contexts, the body “dys-appears” in the experience of the person with speech impairment as a consequence of oppression.

Mothers of disabled children describe a similar phenomenon in relation to their experience of their children’s impairments. In numerous interviews, mothers described how when alone, their child appeared to them (mothers) as “normal.” “When I look at my daughter,” the mother of a child with Cri du Chat syndrome (a genetic disorder) commented, “it’s like, I don’t see the strange, like ‘what is this?’ I see my daughter, you know, who’s going to need a little extra help.” Darlene Mulligan similarly no longer sees her child with Down syndrome as unusual.

She is normal to me. She requires extra paperwork, she requires a lot of extra doctors that I’ve got to keep track of. I have to buy five more Christmas presents than I would normally have had to do. She is a high maintenance child, is what I would term her, but otherwise, she is normal.

Acknowledging that there may be contexts in the future in which her daughter’s difference will be made to matter, Alice Brooks states that “until then, I’ll live in my little fantasy world and enjoy her for what she is.”

It was in two contexts that a child’s impaired body “dys-appeared” to a mother. The first context involved encounters with typical children and their parents. This excerpt is from an interview with the mother of a young boy with cerebral palsy:

It bothers me sometimes when I go to the grocery store and there’s a kid that you can tell is about Peter’s age, and is sitting independently in the cart, and you know, I’ve got him fastened in an infant carrier, you know, which is a *big* baby in an infant carrier. And I know that I get looks like I’m a crazy mother or an over-protective mom.... And he catches a lot of stares, and they’ll say, “oh, isn’t he adorable,” but then, you know, when you say he’s a year old, they’ll look at you like, gee, he looks and acts like maybe six months old.

Ann Meadows, the mother of an autistic boy described her visit to an indoor playground with similar feelings

I took him to Discovery Zone with my niece. She has a nine-month-old baby, and we just decided to go over one day, and there was another little boy there his age, and this little boy is running and jumping and saying, “watch this, mommy,” and “no, I want to go here,” and “I want to eat now,” and Max, of course, isn’t saying much anything, just screeching.... and, of course, I have to devastate myself. I had to ask how old he was, even though I knew. I knew it was going to be close. I was hoping she’d say he was three, he’s just very small, and she said that he was like only a month older than Max, and then she asked, obviously, the next question is well, “how old is your son” and I told her, and she just kind of looked at him funny and like, gee, he doesn’t say anything at all, and I just kind of took him and went the other direction, not trying to be obvious about it, but...

Jenna Mosher similarly talks about comparing her child to that of a neighbor:

It’s still hard. Not as hard, but like there’s a little boy.... he was outside running around with a little suit of armor on with a sword, and I couldn’t believe that he was four. He was younger than Daniel, and that—it startled me more than it upset me—although for some reason the birthday party was hard.

The second context in which mothers describe their child’s impairment as becoming more visible to them is that of the doctor’s office. Becky Romano tells of hearing her son described by the doctor as the physician explains his chromosomal abnormality:

I mean, I think my son was so handsome and then he just ripped apart his face. He has all these dysmorphic features. His eyes are wide spread. He has no bridge in his nose. His ears are too low. He’s got all the features of like a Down’s child, but he doesn’t have a Down’s face.... He’s got like what they call a shawl scrotum, and he’s dwarfed in size, and all of that. I’m now sitting there absorbing all of this the first day that he tells me all of this and I’m like, “take me to Boston, please!” So I thought to myself—it was awful. The torment I went through. I felt like I wanted to wring my own neck because I would look at my son and find myself picking, oh, my God, he does look like that. It was awful. Then I would look at his portraits on the wall and I would say oh, my. So every Christmas picture

I took after, I would say, he's got that look. I would look at him a certain way when he was sleeping at night, and I said, "Becky you've got to stop this because you can't let doctors say this to him."

In all of these cases, mothers describe their negative experience of their child's impairment not as deriving from an essential, pre-social feature of the child's body itself, but as an intercorporeal phenomenon. The impaired body, when cared for and nurtured by the mother on its own terms is normal, not brought to consciousness. "The impaired body 'dys-appears,'" however, "as a consequence of the profound oppressions of everyday life. It is stunned into its own recognition" or in this case into recognition by the mother, "by its presence-as-alien-being-in-the world" (Paterson and Hughes, 1999: 603). This then helps explain mothers' apparently contradictory views toward their disabled children:

My sister-in-law just had two twin boys, two twin boys perfectly normal, and you think, okay, everybody else in your family had normal, healthy children, why you, and then you say to yourself, "you're being foolish. You're just feeling sorry for yourself. Get on with it," you know what I mean? You do feel like sometimes, what did I do wrong? But then if you look at her, she is wonderful. She's, you know, she's happy and she's a normal child to me.

(Alice Brooks, mother of a child with Down syndrome)

I can handle Alexis when I really go in a broad spectrum and look down at everything and go what is life about? And there's different people, and so what. Alexis is different and your life is going to be a little different, and you look down on everything, and it's like all right, what's the end result? That we're supposed to love each other and take care of each other and help each other and help each other to have a good time and enjoy life, right? Generally, and then all the other things start coming when I get back down into my little, little area, and I start looking around and going, the Joneses, they go do this and they can go to the beach and they're doing this, and their kid is running around, why can't I do that, and poor Alexis, and then I get wrapped up in this poor little thing again, that I think instead of looking at what is the whole thing really about, I start looking at little things that I think are important. that even though

if I could have that one thing, there would be another thing. Do you know what I mean?

(Jane Sawyer, mother of a daughter with multiple disabilities)

Intercorporeal encounters, Paterson and Hughes suggest, become demands for disabled people to normalize themselves, to express themselves carnally in a manner conditioned by ableist norms of bodily comportment (1999: 608). The narratives I collected suggest that mothers feel these demands, not only for their children, but for themselves, as societal norms hold *them* accountable for their non-conformist children.<sup>6</sup> In everyday encounters outside the home, on neighborhood streets, in grocery stores and in doctors' offices, impairment is produced as experience, albeit differently, for both disabled child and mother.

Some mothers, particularly as they first experience a diagnosis of disability, for their own comfort or in the hopes that their child's mind or body can be changed to no longer dys-appear as alien in the world, seek to intervene within the child itself; and/or they may attempt to make the child appear "normal" by lying about the child's age or dressing the child so as to hide orthotics or a child's drooling. Yet after the experience of mothering a disabled child over time, most mothers in the study claimed to have undergone profound changes in their own understanding of personhood and disability. "If you were to say this to me before I had Peter, or while I was pregnant that he would have cerebral palsy, you know, he wouldn't be quite normal, I'd say 'oh, no, I couldn't handle that,'" Angela Petrocelli reflects. "But now that you see him, and you get an expression from him, he still smiles at you, still has a favorite book, and he has a lot of things that normal kids, it's okay now. You feel like you walk in a room in the morning and they're smiling and, you know, I mean I can't change what happened, and I—to me, he's fine. I mean, I know he's not, but he's, you know, he's fine." Lucy Baker, mother of a mentally retarded boy remembers that "for a long time, even after he was diagnosed, both my husband and I almost didn't want to—almost admit to some people." Being able to talk comfortably about it *now* is helpful to her "because that was the hardest thing just knowing that it was something that you're almost ashamed of, you know, not—not anymore, but, I mean, we definitely were—had

that feeling at first, you know, that it was something bad and that people would look down on us for it.”

“Otherness” Paterson and Hughes argue, “is not an objective property of certain kinds of bodies, but rather the product of social processes that produce a hierarchy of identities” (1999: 609). Mothers in the study generally came to reflect on their own prior “othering” of disabled people, as well as on the existence of this hierarchy that devalues the identity of their child and their own identity as mother; many, claiming a transformation deriving from love for their disabled child, came to assert the full personhood of their child regardless of the permanence of disability, and to reject the hierarchy of identities as arbitrary or unjust. “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,” concluded Jenna Mosher. As for Lucy Baker, 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.”

### Reflections on Normal

If these are, after all, just our children, what is the place of impairment and disability in their lives according to mothers? And what is the meaning of a cure in relation to a disabled child’s identity? A common medical model discourse to which mothers are exposed is that their child’s true identity has tragically been trapped by an impairment separate from the self. This message was exploited in the New York University Child Study Center’s well-intentioned, but ultimately short-lived and demeaning 2007 campaign for public awareness about children’s untreated psychiatric disorders. The ad campaign took the form of “ransom notes,” in which disabilities were portrayed as kidnappers, holding children hostage. One ad ran “We have your son. We will make sure he will not be able to care for himself or interact socially as long as he lives. This is only the beginning.” The note is signed “Autism.” The text of another ad reads, “We are in possession of your son. We are making him squirm and fidget until he is a detriment to himself and those around him. Ignore this and your kid will pay.... ADHD.” Yet another states “We have your son. We are destroying his ability for social interaction and driving him into a life of complete isolation.

It’s up to you now.... Asperger’s Syndrome” (<http://thegimpparade.blogspot.com/2007/12/ransom-notes-campaign.html>).

The ad campaign, discontinued in response to criticism from both disability rights and parents’ organizations, had played on parents’ fears and the broadly accepted notion that a normal child lies within or elsewhere, tragically trapped and in need of rescue through strategies that intervene to return the child to normalcy. As Penny Richards comments on the blog “The Gimp Parade,” similar “replacement thinking runs through a lot of parent-support-group chatter—as in ‘I want my life back’ (no, this is still your life; you might wish it was running closer to your expectations, or just closer to the average, but that’s a different complaint), or age-normed ideas such as ‘he’s sixteen, he would have been driving now if not for...’ (well, maybe, maybe not—a driver’s license isn’t a universal birthright)” (<http://thegimpparade.blogspot.com/2007/12/ransom-notes-campaign.html>, retrieved December 24, 2007).

The experience and ambiguity of mothering has led some of the women in the study to openly challenge the medical profession’s binary categorization of normal and abnormal. “We’re doing everything you’d do for a regular child, but maybe a little bit later,” comments the mother of a girl with Down syndrome. “I say regular as opposed to normal. Somehow normal just doesn’t—there is no normal.” A mother of a girl identified with cerebral palsy similarly complains, “I think the hardest thing is when you go to the doctor and so many doctors will use the term abnormal or not normal. What is normal, you know?... You can call her atypical or whatever, but you don’t use the word normal because what’s normal to you isn’t normal to somebody else.” Teenage mother Maria Peters, whose son is blind, mentally retarded, and has cerebral palsy, reflects that as this is her first child, “it’s just like I got used to it.... You know what I’m saying? This is normal. To me. And maybe not normal to anybody else who has a kid.”

Kim Boland complains that because her mother-in-law hasn’t been around kids with Down syndrome, “she doesn’t really know, but she’ll say things like ‘those kids.’ Well what exactly is ‘those kids?’ He’s a little boy.” It is specifically through the experience of mothering children whose bodies are not typical and having family life informed by their non-typical carnal needs, that the opposition of normal and abnormal is revealed not only as oppressive to those who don’t fit the mold, but

also as an arbitrary construction. The term normal, these mothers argue, should either be discontinued, or expanded to include those currently excluded from the domain of full persons. There are, they argue, many ways to be normal.

In taking this stance, mothers, though labeled as being in "denial" about their children's abnormalities, are nevertheless reassessing the concept of the normal in a manner consistent with biologists and anthropologists' revisions to the concept of race; that is, in which race is no longer seen as a natural, biological category. Functional determinists make the claim that "functions take place in a uniform mode at a relatively uniform performance level by a statistically distinctive portion of the members of a species. These are the normals" (Amundson, 2000). But, Amundson claims, "like the concept of race, the concept of normality is a biological error. The partitioning of human variation into the normal versus the abnormal has no firmer biological footing than the partitioning into races. Diversity of function is a fact of biology" (Amundson, 2000). Examining current scholarship in physiology and anatomy, he concludes that the concept of species normality should be replaced by a concept of individual normality or responsiveness. The concept of responsiveness, he suggests, represents individual normality, and replaces the statistical and comparative basis of normality with an assessment of the relation between individual performance and needs. "There is no need for a species design" (Amundson, 2000).

It is this idea that some mothers claim to have learned from nurturing a child whose body or behavior, when measured by a universal standard, falls outside the statistical norm. Children, they argue, cannot be compared, nor can the experience of mothering. What's normal to one person, is not normal to another. Both articulating that "there is no normal," and acknowledging that the concept of normality is oppressively linked to both social opportunity and cultural valuation, mothers' acquired knowledge can contribute to a new ethics which would incorporate disability rights within a broader conception of personhood and human value. This is a point to which I will shortly return.

The medical model functions, and children are monitored, labeled, and deemed eligible for intervention services, within a statistical paradigm developed in Europe in the nineteenth century. Over the last one hundred fifty years, people have been "encouraged to strive to be normal, to huddle

under the main part of the curve" (Davis, 2002: 105). Yet a number of mothers in the study describe a personal transformation in terms not only of rejecting the binary of normal/abnormal, but of embracing the very qualities in their child that are labeled by society as abnormal. The child's impairment is in this interpretation not relegated exclusively to a biology separate from the self, but rather is understood as integral to the child and infused with meaning. Reflecting on her child's impairment (agenesis of the corpus collasum), Lorraine Hamilton asks "You have this child that you love so much and if they didn't have that, who would he be?" A cure would in this case be the equivalent to the replacement of one child with another; to love this particular child is thus to love the impairment-disability, for they are inseparable. As Peggy Hoffmeister comments about her autistic son during her second interview,

Rather than think about what would he be like if he didn't have this, I just accept that, well, he does have it and this is the way he is, and this is—and it's not as if he has a disorder that could be magically lifted away to reveal some different boy because that's not—that's a part of his personality. This isn't something like your hair is dyed green, but it will grow out and your own self will be revealed. This is him. I mean, his hair is green. Well not really, but anyway...

Pam Karcher describes an event that epitomizes the endearing qualities of her son Mac, qualities she understands to be inextricably linked to Asperger's syndrome and are the origin of his nickname of "Wacky Macky,"

I mean, all children do cute, strange things and everyone thinks their child is the best, but ... he really does do the strangest things that just crack me right up. I mean, we are just hysterical. We have him on tape. He has this little rubber pretzel.... It's a teether, but he wanted it on his head. Now this is when I was first suspecting something, but now I think that this is part of that trait within him, but he wanted it on his head and it wouldn't stay on his head. And we have this like on tape. And he's getting all mad and he's really getting mad, and we're cracking up at him in the car. We're driving up to Niagara Falls and he's trying to get this pretzel to stay on his head. It keeps falling off. And we have the whole thing on tape. I'm like, "we should send this in to 'Funniest Home Videos'" because I've

seen much less funny things win \$10,000, I'll tell you right now. And he finally gets it up there and he's like—he's staring at it like this, his eyes are crossing, and it's almost like "okay, nobody move!" And he just stayed like that and then he looks at you and he's like—he was just so proud of himself because he got the—and then every now and then he'd check to see if it was still up there and it was just so funny. And I'm like, that's like just little, weird little Mac stuff that makes him like so unique.

In these conceptualizations, a self that is intimately integrated with impairment is also linked to social value and to the uniqueness, rather than exchangeability, that characterizes individuals as full persons. Here "anomaly presents as originality rather than deviance" (Silvers, 2002: 240). Full personhood, rather than "otherness" is thereby extended to a broader range of humanity. In these mothers' conceptualization, the performance of independence in meeting needs is irrelevant; a condition of complete dependence is acknowledged as within the range of normal.

Let me give a concrete example of such a redefinition of normal as it played out in the interaction of my teenage disabled daughter with two non-disabled friends who had come to spend the night. I had set up air mattresses and sleeping bags on the living room floor, got DJ washed up and in her pajamas, and given the girls the movies we had rented for the weekend. At 1 a.m. I peeked in on them, was promptly kicked out, and went up to bed. I awoke the next morning to find DJ dressed. "How did she get dressed?" I asked the girls. "She woke up and said she had to go to the bathroom, so we put her on the toilet" was one girl's casual response. "Then she said she wanted to get dressed, so we got her dressed, but we couldn't find her bra." "Oh," I said, trying to sound casual myself, "It's in her white set of drawers." "I *told* you to look in there!" exclaimed one girl to the other triumphantly. For these girls, as well as for DJ herself, it is obvious that impairment causes difference; her impairment precludes DJ going to the bathroom by herself for instance, in turn setting up different practices of modesty and intimacy. Yet it's very true that with the same body in a different context, with different friends or with children who are not close friends, DJ would have been much more disabled than she was in this context.

The interesting question is what enabled these girls to respond this

and being. Few American adults have grown up with friends who would have put us on the toilet as if it were no big deal. What do these kids know that growing up, my friends and I didn't? Although none of them would describe the situation in these terms, the relation of impairment to disability here hinges on all three girls' concepts of normal. That is, DJ and her friends define her as different, but as normal for *her*. By extension, they too are both different and normal: if you are friends with DJ, it is normal for you to assist her in translating her speech, using the bathroom, and eating. It is also normal for you to get to park closer to the movie theater using the handicapped parking tag, to get out of study hall to have lunch with DJ, and to look forward to having access to her parents' adapted wheelchair van when you get your driver's license. Implementation of a public policy of inclusion had provided *some* children, at least, the opportunity to redefine the meaning of normal, as has mothers' daily participation in the care of their disabled children.

Mothers' descriptions of how they have come to understand and value their unique children articulate a position consistent with a "cultural model" of disability, in which impairment is both human variation interacting with environmental obstacles *and* socially mediated difference that lends identity and phenomenological perspective (Snyder and Mitchell, 2006: 10). Snyder and Mitchell distinguish this model from the British social model, which is more committed to the dichotomous representation of impairment as a designator of biological difference and disability as social process. Instead, Snyder and Mitchell suggest that social obstacles and biological capacities both impinge on the lives of disabled people, with the result that these differences have significant bearing on how disabled people experience their lives (2006: 6). They give a reading of the Oedipus Rex story in which the limping Oedipus can answer the sphinx's riddle precisely because of his experience with mobility impairment. In the cultural model they propose then, embodiment is critical as a source of meaningful materiality. Social obstacles and children's biological capacities have significant bearing as well on how women in this study come to experience motherhood and give meaning to disability.

As I have discussed elsewhere (Landsman, 1998, 1999), mothers who have nurtured disabled children over time describe their children as both their greatest joy and greatest sorrow. They do not portray

them as passive gifts, as in the common phrase “God gives special children to special parents” which keeps intact the categories of normal and special, ensuring that the speaker remains safely entrenched in the category of normal and free from the Other’s “tragedy”; but rather as active givers, most often of the gift of knowledge of unconditional love. To accept the gift is often described by mothers as a long and sometimes reversible process, an ongoing physically, emotionally and financially painful struggle. But to do so is also to allow, in the life of the mother, exactly that which Paterson and Hughes claims disablism prevents: for impaired carnality to make its mark on the design of social space and time.

#### Conclusions: Mothers and Disability Rights

The implications of having impaired carnality make its mark, not only in the home of the disabled child but in the larger society, are not lost on mothers. In practical terms for parents, it means for instance that the work place would accommodate mothers’ and fathers’ schedules of personal assistance to their disabled children. Denise Rivers, mother of a child with hydrocephalous, explained that she lost her job as a medical transcriber at a local hospital because she missed too many days at work. “I don’t think the system is set up right for mothers.” she states. “You know, I had eight years in this place and because my child—I happen to have a sick child and I lose my job, where somebody else had a, you know, normal child, they wouldn’t have lost their job.” It might mean as well that mothers’ work as nurturers of disabled children would be valued as much as that of those who nurture children without impairments. “You know, I’ve had people say to me, ‘well you’re not going to waste your life just devoting your whole life to her are you?’” complains a mother of a child with cerebral palsy in her second interview. “I don’t think that’s a wasted life.... I think people who haven’t been there don’t know what to think so therefore they say stupid things.”

Many people “who have been there,” this research suggests, identify meaning in subtle actions that are unintelligible, and indeed often undetectable, to those attuned exclusively to communication norms informed by “normal” carnality. A shift in the tone of a cry, the relaxation of a muscle, a cock of the head or a glint in the eye:

mothers have learned to read such behaviors as a child’s expression of self. Such wisdom, gleaned from intimate experience in non-typical encounters, is not routinely recognized as knowledge; rather, mothers report that it is dismissed as wishful thinking, as denial. Personhood, as anthropologists know, is a reflection not of inherent qualities, but of cultural valuation. Engaged in everyday acts of caring and experiencing protocols of communication informed by impaired carnality, mothers not only come to discover, but to establish, their child’s personhood. As we have seen in the previous chapter, mothers often redefine a child’s dependency as a source of reciprocity. In this way, mothers and disabled children are engaged in relations of mutual giving and interdependence. The disabled child’s personhood, largely negated by society, emerges in relationship with the mother, and so too a mother’s transformed self emerges in relationship with the child.

If others had the benefits of their experience, these mothers suggest, impaired bodies of all types would not “dys-appear,” but rather be incorporated into a less judgmental world in which each person had his or her valued place. Speaking of the personal impact of her experience raising a mentally retarded son, a mother states,

I try and have it make me more understanding of not even just other children and other parents that have gone through this, but really everybody. You know, everybody has something whether it is a disability or really—it just seems like everybody has some sort of disability. You know, it may not be necessarily be a physical one, but something, so it’s—we just try and be—it certainly doesn’t always work but—more understanding and more compassionate of everybody, you know, whether it’s a crabby neighbor or, you know.

Ann Meadows is a mother whose child has pervasive developmental disorder, on the autistic spectrum. She tells a similar story in which her experience mothering a child with a non-normative mode of interaction has been generalized to affect her understanding of other children and beyond that, to other people:

People have to realize that not every child is perfect, and that even the children that aren’t perfect, still have things about them that are great, no matter what. No matter how bad a child is. I was telling you about the

friend that I just met and she brought her son over, and he came into the house screaming and ran from end to end, but he's gorgeous, and he was just so adorable, you know, and I guess maybe if it hadn't been for knowing Max and understanding that some children are different, I don't know if I would've been able to see that. I would've just looked at him and go, "oh, God, how do you deal with it?" but I looked at him and I saw that he was an adorable little boy, and then he calmed down and I got to see that there is something in there besides the problem, and that people have to look past what's wrong with the child to find out what's right.... I think that people just have to learn to—and even not only children, but other adults, too. You have to decide that everybody has something. Well, okay, maybe not everybody; there's mass murderers out there. But most people have something that's really great about them, and you have to learn to find it.

Mothers' experiences of their children's bodies as alien in the outside world have led some to attempt to change those bodies, to normalize them. In so doing, these women participate in the medical model of disability even as they interpret disability as the consequence of oppression. While seeking to change the protocols of intercorporeality that provide the basis for judgments about their child's performance within the context of physician evaluations, many mothers feel powerless to change those protocols *outside* the doctor's office, in the larger society. The medical model these mothers uphold presents the impaired body as trapping the real child; here the impaired child is always an unfinished product requiring medical expertise to become fully human (see Dreger, 2004: 125). But caring for, knowing intimately, and loving deeply their children's differentially impaired bodies has led many mothers to envision a future in which *no* type of body would be alien in the world; all would have a place and none be made to "dys-appear." As Kim Boland explained in an excerpt presented earlier, "if everyone in the world had one person in their family that had a problem, that had Down's syndrome or you know cerebral palsy, or whatever, people wouldn't be so quick, the world wouldn't be such a mean place...." Describing how her experience as a mother of a disabled child led to a broader understanding of racism and prejudice in general, she continues, "You really think about it today and it's all along the same lines.... I guess it's really opened up another world for a lot of people."

What is this world to which mothers are opened up? And to what vision could the experience of mothering disabled children contribute? Can mothers' experiences move beyond the domain of inspirational stories of "special parents for special children" and be made to speak to challenges posed by scholars of disability studies and activists for disability rights? Might they contribute to possibilities for engagement of disabled people in valued domains of love and friendship? The power behind the concept of disability, Lennard Davis proposes, is that it "presents us with a malleable view of the human body and identity" (Davis, 2002: 26). He uses the term "dismodern" to describe the new perspective to which disability studies scholarship can and should lend itself. "The dismodern era ushers in the concept that difference is what all of us have in common.... That technology is not separate but part of the body. That dependence, not individual independence, is the rule" (Davis, 2002: 26). Many disability rights activists are themselves now publicly claiming that independence is a deception, interdependence the reality.

"We all need each other to live well," writes Bill Rush (Interdependent Living), a journalist and peer counselor with cerebral palsy, as he exposes the interdependence that belies any American's claim to self-sufficiency: the use of manufactured goods, food purchased in grocery stores, indoor plumbing, and the like. Acknowledging this broad interdependency, Tom Shakespeare's critique of the social model (Shakespeare, 2006) claims that biological limitations will nevertheless affect some people such that they will always remain dependent in every context, unable to reciprocate equally. We need to have a model of disability that addresses *this* difference without denying value and dignity. In their statements that there can be no standard by which to judge children, that all forms of oppression or hierarchy based on physical or mental markers are invalid, and that mothers are indeed gifted by their child's dependency and the knowledge of unconditional love it brings, mothers of disabled children come close to expressing the ideal that "aims to create a new category based on the partial, incomplete subject whose realization is not autonomy and independence but dependency and interdependence" (Davis, 2002: 30).<sup>7</sup>

Whether pursuing cures, attempting to minimize visible markers of disability, utilizing early intervention services, or crying as they describe

their fears and hopes to a researcher, mothers in the study expressed a desire to have their disabled child, one they themselves once might have interpreted as “other,” participate in social life. The social life they envision is itself specifically American. Yet in reconceptualizing the normal, or in rejecting the concept altogether, they also critique American values.

In the new way of thinking toward which Davis argues disability studies should move, “We are all nonstandard” (Davis, 2002: 32). Rather than an American minority group, disability may thus be understood as a form of human variation (see Asch, 2004; also Colligan, 2004), “the most human of experiences, touching every family and—if we live long enough—touching us all” (Thomson, 2004: 76). This is not to suggest that a universal biological condition of frailty and vulnerability become the basis for citizenship. The latter, Hughes argues, may constitute a theoretical means of ameliorating the existential negativity associated with being disabled,” but it does so “at the expense of disability identity” (Hughes, 2007: 673). It is not the disabled body, but the “normative, invulnerable body of disablist modernity that is the problem” disability studies needs to address (Hughes, 2007: 681). In a movement based on such understandings, might not the beliefs of mothers of disabled children both that their children are profoundly different and that “there is no normal,” find a home? Paterson and Hughes among others have asked us to examine not only how structural barriers produce oppression, as the social model has been so effective in explicating, but also how oppression “is manifest in corporeal and intercorporeal norms and conventions, and can be read in and through the ways ‘everyday encounters’ can go astray” (1999: 608). It is here that mothers’ knowledge—not inherent, but acquired through the intimate experience of nurturing non-typical, different, dependent children in everyday encounters—may begin to converge with the perspective of this more nuanced disability scholarship and with activism to promote justice for all people.

## Epilogue: Personal Reflections

It is my daughter DJ’s last day of school before summer vacation. This morning I watch her maneuver her bright yellow power wheelchair with its joystick control toward the special lift-equipped public school bus that pulls into our driveway, as she listens to a CD of a currently popular rock band on Sony Discman headphones that rest over her fashionably pierced ears. (The iPod, so much in vogue, requires too much manual dexterity for her to control). She and her father have already had today’s obligatory disagreement over the volume of the music. Hanging off the back of the wheelchair, her pink backpack bulges with her laptop computer, splint, the notebook used for communication between me and her aide, algebra and English books to return, and a yearbook for friends to sign; her Dynavox, an augmentative communication device, also hangs somewhat precariously on the overburdened chair. I move in quickly to grab a kiss; having raised two kids before her, I know how fleeting are such opportunities. As the bus aide follows protocol to secure the wheelchair, I look through the bus window; I watch DJ’s jerky movements, her arms “flapping” and her body rocking in joyous response to music, temporarily oblivious to the world outside that created by the headphones. And I ponder, what is the role of impairment and disability in the making of this very unique, yet very American girl?

Later that day, I will contain my anger and hold back the tears as I argue with the administrator of a summer youth program at a local college who proposes a refund of my deposit because while DJ’s one-on-one aide is welcome and her adaptive computer keyboard is compatible with their system, there is no way to get DJ into the science building where her chosen courses are scheduled. Apparently eight steep concrete steps are to prevent her participation. Too bad, but it’s an old campus. In an environment constructed in accord with conventions informed by non-disabled carnality she is simply not