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Misfit Mothers

Memoirs by Mothers of Children with Disabilities

Through my children I learned everything I know about my helplessness, but also about my ultimate strength. As mothers we test our own survival when we raise children—we strengthen our core.
—Sallie Bingham (1991: 96)

Over the past 30 years literature by women has moved from the margins to the mainstream of literary culture. Little-known writers from earlier eras have been given new attention and a many contemporary writers have flourished. Still, even in 2003, certain aspects of human experience remain largely “off the map.” Motherhood, for one. The vast majority of women worldwide, past and present, have been mothers, yet the subjective experience of motherhood has seldom been explored in literature, not even in autobiography, presumably the most personal and candid of genres. As late as 2000, Jo Malin observed, “Texts that are sited in the writer’s identity as a mother are rare” (See also Suleiman, 1986; Rich, 1976). According to literary scholar Brenda Clews (2001), we are just now (since the mid-1990s) entering a stage where “the maternal text” has begun to be written.¹

Yet I have discovered six book-length autobiographical works (literary memoirs published between 1967 and 2000) firmly sited in the authors’ identities as mothers.² This essay argues that these memoirs shed light on what it means to reach full human development, suggesting four stages of growth that might be applied to the maturation of all adults, not just the mothers of children with disabilities: First, each mother must let go of the dream child, i.e., the idealized “perfect” child, and of her idealized image of herself. Second, each mother must reinvent her role as a mother by acquiring new knowledge, language, and skills. Third, each mother learns to “think like a mother,”

involving many changes in thinking, feeling, and decision-making. Fourth, for many, this new consciousness leads to fighting for social change in hopes of creating better conditions for all people with disabilities.

On the surface, each memoir appears to focus on a child's life (as the subtitles suggest: "one child's courage," "a daughter's life," etc.). In fact, each also tells the story of a mother's life, especially her inward experience of self-in-relation—the mother's subjectivity. Each author writes of her caring for a child with a serious brain-based disability, including autism, Down's Syndrome, and lissencephaly. (To use the professional terminology, the children are "exceptional" because they have "special needs.")

As she chronicles her child's development, each author reveals her own. I call these authors "misfit mothers" because they do not fit stereotypes of mothers as passive and serene. Nor do they fit the existing categories of the adult life cycle; these categories are typically framed in terms of the education and career path of a solitary working in the public sphere (Levinson).

One researcher has pointed out that when a woman becomes a mother, she develops a mindset fundamentally different than the one she held before:

There are many books written about the physiological and practical aspects of motherhood, but far less is written about the mental world where the new identity is formed. Becoming a mother is accomplished by the labor each woman performs on the landscape of her mind, labor resulting in a motherhood mindset, a deep and private realm of experience. (Stern and Bruschweiler-Stern, 1998: 3)

One need only visit any bookstore to find shelves crowded with books on birth, the physical changes of pregnancy, "parenting," and child discipline. But one would be hard-pressed to find descriptions of the "motherhood mindset." It is as if our society assumes that such a mindset does not exist, or else develops without conscious thought. The authors of these memoirs must consciously "labor on the landscape of the mind" because each has been thrust into a crisis with high stakes—her child's very survival. Each author manages to overcome a child's grim prognosis.

A developmental model for mothers

These memoirs suggest four developmental stages of growth: First, each mother must let go of the dream child, i.e., the idealized "perfect" child that most mothers hope for. This often involves a period of intense grief and shame when she learns of her child's disability, and may also involve the letting go of illusions regarding herself and the larger world. This "letting go" must occur before the mother can accept and renew her commitment to the real child. Second, each mother must reinvent her role as a mother. This reinvention involves acquiring new knowledge, language, and skills, in addition to carrying out the day-to-day nurturing and training that we usually equate with moth-

ering. Third, each mother learns to “think like a mother.” The word “think” only partially suggests the many changes in perception, thinking, feeling, and making judgments that occur. These changes involve hard work over many years that leads to a new kind of consciousness. And finally, fourth, for many of these mothers, this new consciousness leads to fighting for social change in hopes of creating better conditions for all people with disabilities.

Letting go of the dream child and committing to the real child

First, each mother goes through a period of intense grief and shame when she learns of her child’s disability. All six describe the crucial stage of grieving the loss of their own imagined child—the perfect child they dreamed of. Martha Beck, for example, learns during mid-pregnancy that her child has Down’s Syndrome. The next few months bring an intense and painful grief process. She describes a time when, still pregnant, she stops an elevator between floors in order to be alone:

[I] covered my face with my hands, trying to control myself. I felt as if some evil ogre had killed my “real” baby—the baby I’d been expecting—and replaced him with an ugly, broken replica I was suddenly seized by a rage so strong that I wanted to bash in the elevator walls I mashed my hands against my eyes and shook so hard that the elevator compartment trembled on its cable. (1999: 197)

Others write of pounding pillows and mattresses, throwing objects, and verbally lashing out at spouses and doctors. Rage grows out of an intense sense of loss and in every case it is accompanied by a sense of shame—the sense that somehow the author has failed as a mother. As her once-lively toddler sinks into a vortex of silence, Beth Kephart often feels she is somehow responsible for his Pervasive Developmental Delay (PDD): “[I]n the dark at night, I lie awake and wonder, worry about the instincts I am lacking ... horrified that love alone may not be enough” (1998: 54).³ She is close to despair. “I can’t believe how deep the hurt goes—or how black things look, how broken” (1998: 63). Unfortunately, this shame is often reinforced by professionals who work with the mother.

In time, the grief leads to a recommitment to her child. As Beck searched a bookstore for parenting guides, “I realized that I was not looking for information on how to transform my child into a prize that every parent would envy. I needed to transform *myself* into a parent who would accept her child, no matter what” (italics hers, 1999: 195). Kephart reached a similar point after her son’s diagnosis with PDD: “I pound the books ... with my fist. I pledge to the boy and his father ... that I will not, no matter what, confuse my child with a label.... I will not lose sight of the gift that my son is, will not let go of my expectation—my surety—that Jeremy will find his way in the world” (1998: 85).

For each mother, this commitment is not a passive resignation to the inevitable but rather a deliberate choice to commit not to the child she dreamed of but to *this actual child*. She sees the child as imperfect yet still precious and lovable. Often spirituality is part of this process of grieving and recommitment. For most of these authors, this phase of letting go also involves letting go of many illusions—about oneself, about professional helpers, about society’s view of the disabled, and more. Miriam Edelson (2000), for example, is heartbroken about her inability to breastfeed her son or to love him without ambivalence. Beck (1999), Park (2001a, 2001b), and Kephart (1998) are all disillusioned by friends who shun them because of their children’s disabilities.⁴ Joan Richards (2000) is shocked by the way she is dismissed by her son’s doctors, even though she is their professional peer.

Reinventing the maternal role

Second, for each author, acceptance and commitment lead to a determined and tough-minded advocacy for her child in the face of a sometimes hostile environment. All the authors write of their love for their children—the tenderness, protectiveness, and fascination that we often associate with mothers. Such tender feelings help the mother to provide day-to-day nurturing, protecting, and care. In addition, she must acquire a set of skills that includes “political literacy,” assertiveness, communication skills, and the ability to be a “broker” for her child.

James Wilson and Cindy Lewiecki Wilson, parents to a disabled adult child, observe that when a child is diagnosed with a disability, he or she is “immediately inserted into a complex array of institutions and inscribed by their medical, legal, educational, and social discourses” (2001: 9). These institutions tend to objectify the disabled person. The mother—if she is to fend for her child—is forced to make sense of this “social apparatus of disability.” Wilson and Lewiecki Wilson use the term “political literacy” to describe knowledge of the specialized terminologies, the power structure of various institutions, and how to access and navigate the “complex array of institutions” that may include hospitals, clinics, schools, and social service agencies. Political literacy also involves learning about laws affecting her child.

Initially, the need for “political literacy” is overwhelming, as in the case of Miriam Edelson (2000). Her son Jake is hospitalized in infancy with a rare brain deformity that causes seizures and other baffling symptoms. She and her spouse must decide if Jake should receive a feeding tube, undergo major surgery, be permitted to be resuscitated, be placed in residential care—all within a short period of time and with little information or counsel. All of these are highly charged decisions with huge ethical, financial, and emotional consequences. In the midst of the initial crisis and in the years following, Edelson works hard to become “politically literate”; she learns about the legal and ethical issues, figures out the medical terminology, collaborates with other caregivers, and challenges authority figures when necessary.

Robert Naseef, father to an autistic son, runs into repeated bureaucratic barriers and gradually learns that “A parent is the most effective case manager for his child because he knows his child best.... Accepting this responsibility is key to getting the best program and services for your child.... You need to know how to navigate the service system ... and to develop skills of advocacy and assertiveness” (1997: 187). Edelson elaborates on the need to “navigate”:

To access the assistance they need, families must navigate extensive government and agency bureaucracies and cope with filling out umpteen forms for an alphabet soup of programs. This requires a fairly good educational background and a lot of *chutzpah*, in addition to the patience of a saint. [To provide home care] the managing of budgets, payroll and deductions also demands mathematical and accounting literacy equivalent to that exercised in running a small business. (2000: 76)

Sometimes the “navigator” role leads to becoming what Edelson calls “the broker.” She writes, “It is often necessary for one parent to stay at home to coordinate the various therapies the child needs. This ‘broker’ role can itself be a full-time job when coupled with the child’s personal care and ongoing roster of therapeutic and medical appointments” (2000: 75). It is most often the female parent who assumes the broker role, which may bring with it economic dependency, split gender roles, social isolation, over identification with the child, and vulnerability to divorce. Married couples with a seriously disabled child are far more likely to divorce than other couples. For all these authors, the child’s disability caused great upheavals in their jobs or careers.

It is important to note that there is nothing natural or instinctive about “political literacy” and that many mothers never acquire such skills. In fact, often professional helpers actively discourage mothers from asking too many questions. Edelson (2000), for example, observed that at Jake’s pediatric hospital, the only acceptable attitude on the part of parents was gratitude. Virtually all the writers describe encounters with doctors who try to infantilize them by scolding, blaming, and talking down to them. Beck’s Harvard doctor pressures her to abort, a renowned psychiatrist suggests that Park is at fault for her daughter’s autism, and Richards is dismissed when she pleads for pain relief for her hospitalized son. As Edelson observes, these roles are far more difficult for those who do not speak English or who lack education or *chutzpah*.⁵

Thinking like a mother

Third, out of this new motherly role—involving hard work and learning over many years—evolves a new kind of thinking that accompanied by many changes in perception, thinking, feeling, and the ability to discern and make judgments.⁶ Although one might easily write a book on this change in consciousness,⁷ I will limit myself to four aspects that stand out in these memoirs: intelligent love; a belief in the value of all life; a sense of

interconnectedness with other beings; and an ethic of care.

“Intelligent love” is the phrase that Clara Claireborne Park uses to describe the acute sensitivity that grows from a deep love for a child and a deepening understanding of a child’s needs.

Parents can accomplish much through intelligent love. [Despite what doctors believe] intelligence and love are not natural enemies. Nothing sharpens one’s wits for the hints and shadows of another’s thinking as love does.... [A poem by William Blake] describes love that “seeketh not itself to please /Not for itself hath any care, / But for another gives its ease, / And builds a Heaven in Hell’s despair.” There are millions of parents who practice this love daily and know that love is a technique as well as an emotion. (2001a: 197)

The phrase “intelligent love” calls to mind the word “attunement” that is used to speak of the mother-infant bonding of early infancy; attunement suggests the attentive observation, eye contact, mirroring, non-verbal communication, and the way a mother may synchronize her own daily rhythms to those of her infant’s. Attunement is comparable to acquiring a new language by immersion—a learned skill rather than an instinct. Attunement to a young child fosters “intelligent love.”

Thinking like a mother also involves seeing a child in terms of preciousness and not just deficit, and may lead to a belief in the value of all human life. Kephart writes,

Until I had Jeremy, I didn’t understand the expression “child of God.” But now I do. I understand God’s alive in him. That my son’s a spiritual presence grander in his architecture than I will ever be.... He has completed me, wrenched me in and out of myself, forced me past my boundaries. (1998: 167)

On a similar note, Brydon Gombay, in her study of mothers of disabled children, observes that “nurturing their children often leads to a profound recognition of the value of all human life” (2000: 17) and a strong will to protect it.

This new consciousness also involves a sense of the shared human condition. Regarding disabled children, Aristotle prescribed, “Let there be a law that no deformed child shall be reared” (*The Poetics* VII. xiv). He set the tone for Western civilization, seeing the disabled as abnormal or monstrous; therefore he believed they should simply be allowed to die—or at least to be excluded from society. In contrast, these writers emphasize a shared humanity. Park writes,

I have come to see mental health and illness, soundness and defect, not as the separate entities but as a continuum. The needs of defective and

sick children are more imperious than those of the well, but they are not different in kind. Sick children need to be accepted, supported, comforted, corrected—like well children.... And they need to be respected. (2001a: 192)

Wilson and Lewiecki Wilson emphasize that “disability” is a condition that unites almost all human beings: “All people who live long enough are likely to experience disability ... or to be closely related to someone who is disabled. What has been labeled abnormal actually occurs regularly and frequently and, yes, normally” (2001: 10).

Another aspect of thinking like a mother is a sense of interconnectedness with other creatures. Margaret Smith comments about her daughter:

Emma’s disability [epilepsy] links our family with families in the past, with families in the Third World, and with the animal kingdom, of which we all still form a part. Here, suffering and early death were and still are very real facts of life. Disability in the family has taught us all a powerful lesson: do not take life for granted. (1989: 170)⁸

Yet another aspect of thinking like a mother is the ethic of care that grows out of a fundamental belief in human value, dignity, and interconnection. Edelson explores this idea in her memoir:

The ethic of care arises from the notion that human interdependence is fundamental. We are persons to the extent that we relate to others. This differs sharply the views of theorists who have for centuries defined the self as independent, rational, self-interested, and autonomous. (2000: 152)

Edelson (2000) goes on to argue in favor of a feminist ethic of care which holds that bio-ethical decision-making should be rooted in specific contexts, guided by emotions, growing out of compassion and a belief in human dignity. Difficult decisions regarding abortion, feeding tubes, resuscitation, and other medical interventions should be approached through an ethic of care, writes Edelson.⁹

Fighting for social change

Out of this new consciousness, many mothers grow into a fourth stage, a commitment to changing society for the better. Having become much more sensitive to and knowledgeable about the injustices encountered by their individual children, many mothers go on to work on behalf of the needs of others with disabilities. They see clearly the narrowness of the Western view of human value and success—measured in terms of dollars, test scores, or accomplishments; they question the way our society offers little respect and few

rights to the disabled. These mothers also have gained a hard-won understanding of how institutions, policies, and laws may harm the disabled—even when they are intended to help.

Out of such insights, all six of these writers have committed themselves to helping those with disabilities. First, most obviously, all have written books that serve as guides to others, especially parents. Kephart's (1998) book, for example, has helped medical professionals to systematize a therapeutic approach to children with PDD. Similarly, Park's (2001a, 2001b) books provide extensive documentation kept over many years of how her daughter Jessy came to terms with autism; these have been used by researchers to better understand and diagnose autism. Parents and professionals alike now regard these books as groundbreaking guides.

Some of the writers have gone beyond writing to educate through other means. Robert Naseef (1997), motivated by his son's autism, retrained as a psychologist and now runs workshops to train parents and professionals to work together to help children with "special needs" as diverse as autism and ADHD. Edelson (2000) developed TV and radio documentaries to draw attention to the needs of "medically fragile" children. Beck (1999) has spoken to professional conferences for MD's on the bio-ethical decisions associated with medical technologies such as prenatal testing and sonograms; she believes that doctors cannot ethically encourage the "therapeutic abortion" of a fetus with Down's Syndrome if they lack a realistic view of what Down's Syndrome actually is and of the realities of parenting such a child. (Often doctors project their own exaggerated fears onto the fetus and thus paint an overly bleak picture of her or her future prospects.)

Most of these writers have focused their efforts at public education and activism on a specific type of disability. They are also part of a growing chorus of voices that have called attention to larger issues of human rights. Activist mothers have led the way to better and more just treatment of people with disabilities, including more inclusive public education, changed workplace policies, the community living movement for mentally retarded adults and the mentally ill, and more. They have formed national organizations such as ARC (formerly "Association for Retarded Citizens") and the National Alliance for the Mentally Ill (NAMI). In the United States, the efforts of activist mothers have contributed to powerful federal laws such as the 1975 *Education for All Handicapped Children Act*, the 1990 *Americans with Disabilities Act*, and the 1990 *Individuals with Disabilities Education Act*. Reforms have also occurred in the fields of criminal justice, medicine, and social work. Such progress supports the belief of philosopher Sara Ruddick (1995) that the practice of mothering (with its central themes of protection, nurturance, and training) can contribute to a more peaceful and just world.

Though much remains to be done to improve opportunities of those with disabilities, immense progress has occurred. Whereas in earlier eras a child with a serious disability would have been left to die or else hidden away, today such

a child has far more opportunities for a happy and meaningful life. Progress would not have occurred if not for the efforts of determined and intelligent mothers motivated by a passion for justice. The words of theologian Elizabeth A. Johnson might readily be applied to these “misfit mothers”:

Love [is] the shape in which divine power appears ... [love rooted in] the experience of women who know the breakthrough of their own strength, usually under duress: the nurturing power of a mother who enables her children to grow to full personhood ... the justice making vigor of women who know wrongs, both personal and structural, and stand as strong witnesses to resist and remake, deriving energy that they critically turn toward the well-being of others. (1992: 269)

Conclusions

These mothers—the six authors of the memoirs in my study and others like them—truly are “misfit mothers.” Through a process of relating to, thinking about, and coming to understand their “special needs” children, they have grown into mature adults who are remarkably active, enlightened, and courageous. These “memoirs of misfit mothers” chronicle in candid and unsentimental terms the authors’ full human development under difficult circumstances. Having come to terms with great sorrow and injustice, these women have grown far beyond the expectations they once held for themselves. All would echo the sentiments of Kephart, who writes, “[My child] wrenched me in and out of myself, forced me past my boundaries” (1998: 167). Closer attention to these life-stories would benefit not just mothers but all people who desire to grow into full humanity.

¹In 2001, Clews suggested a three stage process: 1) the mother is spoken for (by artist, writer, doctor, etc.), 2) the mother is written about by a daughter (1970s-1990s), and 3) the mother herself finally speaks.

²Martha Beck (*Expecting Adam: A True Story of Birth, Rebirth, and Everyday Magic*) is a graduate student at Harvard when she learns the fetus she is carrying has Down’s Syndrome. Despite strong pressure from the medical community to abort, she carries the child to term. This memoir focuses on the many changes in values and perspectives that occur during her pregnancy. When Miriam Edelson’s (*My Journey with Jake: A Memoir of Parenting and Disability*) first child is a young infant, she learns that he has lissencephaly, a rare brain deformity that will severely limit his mental and physical capabilities. This memoir tells of her relationship with her son, coming to terms with his disability, and efforts to improve health care for disabled children. Her son Jake is ten and living in residential care as she writes. Beth Kephart’s (*A Slant of Sun: One Child’s Courage*) son Jeremy is two when she realizes he

suffers from a mystifying autism-like disability, PDD-NOS (Pervasive Developmental Delay, Not Otherwise Specified). This is an evocative account of her relationship with her son. Through determination and love Kephart and her husband help him overcome this serious condition. Part memoir, part parenting guide, Robert A. Naseef's *Special Children, Challenged Parents: The Struggles and Rewards of Raising a Child with a Disability* tells the story of raising an autistic son (now an adult). He also offers many insights and resources for parents of children with various kinds of physical and mental disabilities. Clara Claiborne Park's two books, *The Siege: A Family's Journey into the World of an Autistic Child* and *Exiting Nirvana: A Daughter's Life with Autism*, tell about the life of Park's daughter, Jessy, beginning with her diagnosis of "childhood psychosis" at age three into adulthood; Jessy is now forty and an artist. Park is an English professor who tracks and documents her daughter's intellectual and emotional development in detail. Joan Richards (*Angles of Reflection: A Memoir of Logic and a Mother's Love*) is an historian of science who writes of her son Ned's physical challenges: first, a brain tumor that he recovers from, then a odd injury to his elbow (while they are living in Germany) that heals improperly, resulting in his spending long stretches of time in a German hospital. Her experiences with her son and with bureaucratic hospitals awaken Richards to a feminist consciousness.

³PDD-NOS (Pervasive Developmental Delay-Not Otherwise Specified) is a set of symptoms that includes social, language, and behavioral impairments; the disorder is little-understood and is sometimes used as a catchall term to "diagnose" symptoms that do not fit elsewhere. Like autism, PDD often manifests itself around the age of one or two years.

⁴Shunning and social isolation are more likely when the disability is one that is stigmatized and misunderstood, such as mental retardation or mental illness. People have more compassion for disabilities that are clearly physical in nature.

⁵Even as they encounter arrogance, the writers all express tender appreciation for the kindness and compassion they receive, sometimes unexpectedly, from others: a nurse, a speech therapist, a day-care director, a neighbor, etc. Affection, trust, loyalty, and wisdom grow from these relationships that sometimes demonstrate an impressive level of respectful collaboration.

⁶In her important book on maternal identity, Ramona Mercer asserts that much of maternal competence (even under normal circumstances) is "dependent on the woman's cognitive abilities: to project into the future, to consider alternatives and problem-solve, to know what information she needs and where to obtain it, to communicate effectively, to trust others, and to establish nurturing relationships with others" (1995: 303).

⁷See Sara Ruddick's (1995) classic book, *Maternal Thinking: Towards a Politics of Peace*.

⁸This belief in the interconnection with other humans and animals echoes the ideas of David Hay and Rebecca Nye, who have researched the spirituality of early childhood. In *The Spirit of the Child* (1998), they argue that "relational

consciousness” is common among young children, before they have been socialized into seeing themselves as rational and autonomous.

⁹Most of these authors also write about other decisions they must face, such as whether to have another child. Stretched to the limit by caring for a “special needs child,” they are reluctant to give birth to another who runs a genetic risk of disability. This decision leads to conflict in the family.

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