

Disability Studies Quarterly  
Fall 2002, Volume 22 No. 4  
pages 81-101 <[www.cds.hawaii.edu/dsq](http://www.cds.hawaii.edu/dsq)>  
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Sex, Disability And Motherhood:  
Access To Sexuality For Disabled Mothers

Corbett Joan O'Toole  
The Disabled Women's Alliance

Abstract

There is limited research into the sexual lives of mothers, particularly mothers with disabilities. This article examines the barriers to sexuality facing mothers with disabilities. These barriers include: stereotypes that disabled mothers are not sexual, lack of resources for essential aspects of parenting, and difficulty in creating time for personal and private adult activities. Recommendations are presented based on the experiences of disabled mothers.

Introduction

"Hot sexy mama" are three words that disabled mothers will never hear strung together - except perhaps from their lovers. Both the literal and figurative components of that phrase are culturally precluded from mothers with disabilities. While nondisabled women may hear this phrase directed to them, whether it is desired or offensive to them, disabled women never hear it. As Judy Heumann, disability rights leader and Assistant Secretary of Education under President Clinton, said in 1982, "I don't know if I am offended by sexist comments or not as they have never been directed at me."

This paper explores access to sexuality for physically disabled mothers. First is a review of the literature to create a data profile of disabled women and disabled mothers. As part of this, I examine the statistics, lack of research literature on this topic, cultural assumptions about sexuality, motherhood and disability, and the challenges faced by disabled mothers in their quest to be sexual beings. I then discuss issues for disabled mothers, including scarcity of information and of resources, and the barriers disabled women face to having a sex life and how to solve them. Specific issues for single mothers are also examined. I outline issues related to raising sexually healthy children and access to sexuality for disabled mother's children. Finally, I outline suggestions to increase access to sexuality

for disabled women including areas for further research and discussion.

Perhaps the most relevant context for the entire paper is this short but startling statistic from *The Mother's Guide to Sex* (Semens & Winks 2001, p.ii)<sub>1</sub>: "If you're partnered, you're probably not surprised by the statistic that parents living with children spend only about twenty minutes each week being intimate with each other." Creativity and flexibility are essential elements in order to create and maintain a sex life while raising children and through much life experience disabled mothers have had plenty of opportunities to practice both skills.

This paper operates within conflicting contexts. First, that a great many women with disabilities<sup>2</sup> are successfully parenting. Second, that the knowledge that they have gained through parenting is useful in discussions of parenting, disability, gender, and sexuality. Third, that disabled mothers are creating sexual lives for themselves. Fourth, that neither disability research, sexuality research nor parenting research has included mothers with disabilities. Fifth, that this paper, and the related resources, are an important beginning in a dialogue among many stakeholders.

Wates (1997), a disabled parent researcher in the United Kingdom, articulates a common challenge to beginning a new dialogue: "Disability is so closely associated with dependence and social isolation that it is hard for people to imagine a disabled individual at the centre of family life in the role of primary carer..." (p.2). These "exclusions are unconscious; all the same they convey to disabled people that their presence is not expected in the domain of pregnancy, birth and parenthood. When I told people I was researching the subject of disabled parents I noticed that people often thought I was talking about parents of disabled children" (p.4).

The review of the literature shows that disabled mothers are overlooked in research and statistics on both disability and motherhood. A U.S. national study specifically focused on disabled parents (Barker & Maralani 1997) and compared it to a national data set, the Survey of Income and Program Participation conducted by the U.S. Census Bureau. A similar examination was done in the United Kingdom and published in various publications by Michele Wates (1997; 1999; 2002).

The Barker & Maralani (1997) review focused only on studies done on a U.S. population. It is argued that the lack of research interest in this topic is deeply embedded in cultural assumptions about sexuality, motherhood and disability. Block (in-press) and others (Llewellyn 2002) argue that the focus on controlling the reproduction of and parenting by women with intellectual disabilities is really just a wedge into controlling the reproduction of women whom society deems unacceptable for any reason. The review also includes accounts by women with disabilities on how they challenge these assumptions and often related negative public

policies.

Disabled mothers face many issues that can inhibit or prevent them from effective parenting. Some of these include the overwhelming scarcity of information and resources on mothers with disabilities. With the availability of the internet, a number of disabled mothers have created websites and listserves that allow disabled parents to exchange information and resources. While disabled mothers encounter numerous barriers to parenthood, they also find effective solutions that are identified. This section also includes a discussion of issues that are particular for disabled mothers who are not currently partnered.

Although physically disabled women are a sizeable portion of the population of disabled mothers (26%) (Barker & Maralani 1997), they have been the subjects of only limited research. This paper is constrained by the lack of research on disabled mothers, the lack of research on the intersections of disabled mothers and sexuality, and the lack of comparative data between mothers with physical disabilities and either mothers with non-physical disabilities or nondisabled mothers.

This research deficit may be due to the invisibility of disabled women in our culture entirely (except for individual heartwarming stories of overcoming adversity), the unimaginable idea of disabled women being mothers since that notion confronts our stereotypical notions of motherhood, and/or the inconceivable thought of disabled women as sexual beings (Ketz 2001). While individual stories of having a culturally recognized sexual identity abound in first-person accounts, the cultural image of a disabled woman is one of asexuality. She is often compared to a nondisabled norm. While many researchers have challenged the representativeness of this norm, disabled women are definitely measured against it.

As Fine and Asch wrote in their landmark book (1988):

Women with disabilities have not been "trapped" by many of the social expectations feminists have challenged. They have not been forced to get married or to subordinate paid work to childbearing or housekeeping. Instead, they have been warned by parents that men only "take advantage"; they have been sterilized by force or "choice," rejected by disabled and non-disabled heterosexual or lesbian partners, abandoned by spouses after onset of disability, and thwarted when they seek to mother (p.29).

The training against motherhood begins when a woman is diagnosed as disabled and continues throughout her childbearing years (O'Toole & Doe in-press). It encompasses: lack of sexuality education (Rouso 2001); family expectations and training for celibacy (Rouso 2001; Nakanishi 1998); training nondisabled people to regard disabled women as unfit partners (O'Toole 1999); lack of access to sexual and sexual

health information (Waxman & Saxton 1997); training for abuse prevention, but not positive sexuality (O'Toole and Brown in-press); sterilization and institutionalization for sexually active women (Block in-press); high divorce rates if a formerly nondisabled wife becomes disabled (Barker & Maralani 1997; Fine & Asch 1988); removal of children if a disabled woman becomes pregnant (Kirschbaum & Olkin in-press); and public policies that prohibit disabled women from parenting (Waxman & Wolfe 1999).

These proscriptions encompass women with physical disabilities (O'Toole & Doe in-press); visual disabilities (Kent in-press); cognitive disabilities (Block in-press); hearing disabilities (D'aoust 1999) and other disabilities (Wates & Jade 1999). They are practiced in Asia (Nakanishi 1998), Africa (Longshaw 1997), Australia (Mascall 2001), Europe (Wates & Jade 1999), Latin and South America (Block in-press; Berman-Bieler 1997), as well as North America (Waxman & Wolfe 1999).

Whether mainstream culture recognizes that they exist or not in the United States alone over 6 million disabled mothers are raising children. Nearly one-third of all disabled women of childbearing age are mothers with children living at home (Barker & Maralani 1997). Over 1.2 million of them are doing it as single parents.

It is amazing that so many disabled women become mothers since disabled women are neither trained for nor expected to be sexual members of societies (O'Toole & Doe in-press). Looking towards the cultural images of disabled women for a base of positive sexual imagery is confining. In nearly all images, disabled women are presented as asexual beings.

When cultural images of disabled women are presented, it is as a singular, indistinguishable mass. Differences between women - the color of their skin, types of disability, partner relationships, geographic context, parenting context, socio-economic context - are obscured. They assumed to be the same - no differentiations are presented or explored. Their individuality is masked both in research and culture. Although occasional specific sexual images of disabled women occur, these are rare. In discussing the particular experiences of disabled lesbian mothers, O'Toole and D'aoust (2000) faced a similar research problem:

The experience of disabled lesbian mothers are as diverse of the wider populations. The problem, then, is that these diverse issues have not been examined in ways which respect the natural multiplicity of conditions. Usually the add on or layered effects of oppression is discussed without considering the reciprocity and interaction among factors (p148).

In reviewing the very limited literature on disability, motherhood and sexuality, it must be noted that the excellent *Mother To Be: A Guide to Pregnancy and Birth for Women with*

*Disabilities* (Rogers & Matsumura 1991) has one of the only published accounts of sexuality for disabled mothers. Because of the extremely limited already-published work in this area, a great deal of this paper is either a compilation of related research or based on interviews with disabled mothers done for this article or for previous work<sup>3</sup> (O'Toole & D'aoust 2000; O'Toole & Brown in-press; O'Toole 2001).

Who are disabled mothers?

Although there are many studies on children with disabilities, the lives of these children as they grow up, partner, and become parents are less examined. This leaves a gaping hole in the knowledge of professionals and, more importantly, in role models for children with disabilities (Kirshbaum & Olkin in-press). The literature on disability focuses on interactions between specific disabilities, disability-related medications and sexual performance. While some disability resources look at pregnancy, it is nearly always from a medical perspective (Rogers & Matsumura 1991).

As Wates (1997) points out it is sometimes the lack of questioning that is the genesis of the research gap: "The numbers of disabled parents [in the UK] are unknown and have to be guessed at because originators of official statistics have never thought to correlate disability with parenthood and thus the relevant questions have never been asked" (p.3).

Approximately 11% of all American families are parented by one or two parents with disabilities. That translates to 10 million families with children living in a home in which a parent has a disability (Barker & Maralani 1997). Of this number, there are more disabled mothers than disabled fathers.

A rough extrapolation from the data indicates that approximately 4.8 million disabled mothers are partnered and over 1.2 million disabled mothers are single. Disabled mothers of color are far more likely to be single parents than white disabled mothers. It is interesting to note that more than one-third of all disabled parents in a national study are raising children under the age of six (Barker & Maralani 1997).

Yet Kirshbaum (Kirshbaum & Olkin in-press), the leading researcher in this field, reminds us that far too often the focus is on looking for dysfunction and ignoring competencies in families of disabled parents: "Much of the research on parents with disabilities has been driven by a search for problems in these families." Research "reveals the widespread belief among professionals that disability severely limits parenting ability and often leads to maladjustment in children" (Buck and Hohmann 1981).

According to a landmark study of disabled parents commissioned by Through the Looking Glass, an information and support organization for parents with disabilities and their families as well as professionals, the following is true: "Disabled women are more likely to be single parents or

divorced than disabled men. Also more likely to have a partner or spouse who is disabled." (Barker & Maralani 1997) Parents with physical disabilities have an average of 2.2 children of whom 27% are children with disabilities. Parents with disabilities are more likely to have adopted children with disabilities (41%) than to birth them (23%) (Barker & Maralani 1997).

Disabled mothers who are the most successful at building and maintaining a sexual life are those who are able to extrapolate what they need to know from a wide variety of sources (Berman-Bieler 1997). They might look at general information on sexuality and disability for suggestions of positions or alternative techniques. Resources on the impact of parenting on the sexual lives of nondisabled women may give them assurance of their universality of their own experiences. Access to specific communities of support, such as lesbian, disability-specific, neighborhood, may provide important outlets to discuss pressing issues and gain new information.

### Myths and assumptions

There are numerous myths about sexuality and motherhood including four articulated for all mothers by Semens and Winks (2001): Sex is for procreation; moms are not sex objects; dads are sexy, moms are not; all parents are Ozzie and Harriet. In addition to these, there are numerous myths that address (and attempt to culturally enforce) the sexuality and reproduction of disabled women.

When was the last time that you saw a mother, any mother, presented in a positive sexual light? These images are rare.

Sexuality for mothers is presumed to be in one of three contexts: 1. doing her wifely duty within a marriage; 2. as a release from the burdens of childraising (often used to indicate either an impending divorce or a sign of mental instability); or 3. hidden masturbation - used as necessary but always meant to be invisible.

In other words, mothers are presumed to only have sex with their permanent, male partner and only for procreative or recreative (for him) purposes. All other expressions of sexuality by mothers are seen as suspect.

That the statement above are myths and not reality are reflected in these quotes from Semens & Winks (2001): "Most mothers can testify that the desire for a fulfilling sex life didn't disappear when they had children; it simply got buried under an avalanche of conflicting demands on their time and attention." (p.ii)

To further explore the four myths articulated by Semens & Winks (2001) for all women, we need to look at their implications for both gender and disability. In the first myth, sex is for procreation, the basic presumption of any sexual union is to create new life. Yet numerous historical and research studies demonstrate that most couplings are designed for satisfaction not procreation. This myth also presumes that all couplings are heterosexually oriented between partners who are capable of procreating. Any number

of partners belie this myth either because of lack of procreative capability or same-sex couplings.

The second myth, that mothers are not sexual objects, often moves nondisabled women into a realm that is all-too-often frequented by women with disabilities, that of not being perceived as a sexual being.

The third myth, dads are sexy but moms are not, feeds into a continuous cultural reinforcement of men's need for sexuality but not women's. When nondisabled mothers refuse to stay within this confinement, they are seen as unfit. "Mothers who make their sexual needs a priority are deemed oversexed, promiscuous, or even neglectful; fathers who do so are simply exerting their conjugal rights." (Semens & Winks 2001 p.16) Disabled mothers and fathers are used to being seen as asexual often to the extent of the societal presumption that their children are adopted. But it is also true that while a disabled woman may be seen as irresponsible for creating a biological child, a disabled man sees an increase in his sexual status.

The fourth myth, all parents are Ozzie and Harriet, imposes a strong cultural image on nondisabled parents regardless of their actual lifestyle or partnership(s). When a nondisabled mother is in the grocery store with her child, the presumption will often be made that she is doing her wifely duties as part of a male/female couple even when her attire or behavior belies this. The same assumption is rarely made about a visibly disabled woman doing the same job.

Myths for women with disabilities combine gender and disability stereotypes to create specific paradigms/boxes

Myth #5: Disabled women are asexual

Disabled moms are having sex lives, but most people would never realize it (Wates 1997). The nearly total invisibility of the sexual lives of disabled mothers creates the misimpression that disabled mothers do not have sexual lives, that sexuality is not on the radar of disabled mothers and that sexuality is not an appropriate topic of discussion for disabled mothers.

A fundamental challenge for disabled mothers is that nondisabled mothers are held as a norm and disabled women are measured against it. But as Michele Wates reminds us: "it does not make sense to go after a supposed normality that involves us in continuous and uncomplaining struggle" (Block in-press).

An intrinsic part of the problem is that disabled people, whether they are mothers or not, are presumed to be asexual. Widely documented and strongly societally reinforced, this belief creates numerous myths about disability, sexuality and especially mothering. The training for asexuality begins early:

Growing up with cerebral palsy, my sexuality was rarely acknowledged or, if it was, it was often invalidated. I

learned not to ask questions about sex or talk about boys I liked because I would get teased by adults or older children - my questions or comments about sex were "silly" and my "crushes" were "cute." Just like my disability, I got the message that sexuality - particularly my own - was not a topic for discussion. Needless to say, it was enormously damaging to my self-esteem (J 2001).

Contrary to pervasive societal stereotypes, disabled mothers are having fulfilling sexual lives (Rogers & Matsumura 1991). They are using their resourcefulness to create openings for their own sexual expression. They are finding opportunities for sexual expression with themselves and with partners. They are refusing to allow denial of access to sexual information to stop their sexual expression.

Myth #6: No one wants to partner with a disabled woman.

If you think about it, it is amazing that disabled women have sexual partners at all. The cultural pressure against partnering with disabled people, whether you are disabled or not, is very strong.

Both disabled girls and their potential partners are trained from a young age. Disabled girls are trained not to be partners and their potential partners are trained not to see them as desirable mates. As Nora Groce (1997) documents, this is a world-wide perception. In a cross-cultural examination of gender and disability she reports:

There is often little expectation that a girl with a disability will live independently or will marry and establish a household of her own. As one often does not become a full adult in the eyes of the community until marriage, lack of marriage keeps many disabled females forever in the status of dependent child. (This does not mean that many girls and women with disability do not establish relationships, become sexually active or bear children, only that their activity is often not acknowledged by the societies in which they live) (p.3).

The training of nondisabled people is often very specifically designed to create an abhorrence or at least a distancing between nondisabled and disabled people. Children are taught that people must be "protected whenever possible from that awful experience of association with disability" (Blakford 1993, p.290).

Even within adult communities this message is pervasive. While some types of sexual contact with disabled women are seen as interesting or even kinky, sexual partnering with a disabled mother is definitely not on anyone's radar.

When partners choose to be with disabled women, they face enormous and continuous examination and obstacles. They are often assumed to be unable to "catch" a nondisabled partner, to be a caregiver to the disabled woman, and/or to be

responsible for any children she has. Megan Kirshbaum and Rhoda Olkin, researchers, refute some of this:

...division of family labor was found to be more equal in couples where the wife had a disability. That is, husbands tended to contribute to the childcare and household tasks that their wives were physically unable to do. Despite the common assumption that husbands of women with severe disabilities might feel burdened by childcare and household tasks, these men directly reported being quite satisfied with their role arrangements. A majority of the mothers with disabilities, however, rated improved availability of funding for adaptive equipment and disability-related assistance services, as well as improved accessibility in housing, as likely to increase their satisfaction with the division of family labor (Kirshbaum & Olkin in-press).

The impact of the strain of a new disability on an existing nondisabled relationship often exacerbates pre-existing tensions and may result in divorce - primarily if the woman becomes disabled. Researchers far too often stop at this point in the woman's life. Further research would indicate that many of these newly disabled women, many of whom are mothers, go on to create new partnerships with more flexible mates.

Myth #7: Disabled women do not want children

Disabled women are assumed not to be, and not to want to be, mothers (Rogers & Matsumura 1991). They are seen as not quite right for the job of bearing and raising children (Wates 1997). This in turn reinforces their undesirability as sexual partners. But Kent's (in-press) experience contradicts this:

I loved being pregnant. Unlike those Victorian ladies who went into confinement, disappearing behind whispers and closed doors the moment their "delicate condition" became apparent, I wanted the world to take notice of my bulging belly. I seized every opportunity to walk the streets, to ride the city buses, to present myself in public. I reveled in the anticipation of motherhood, and somewhere too, I felt an exhilarating sense of defiance (Kent in-press).

Historically, the reproductive abilities of disabled women have been controlled. The existence of disabled mothers challenges strong cultural notions of who can be an appropriate mother (Wates 1997).

Whether through institutionalization, social control, sterilization, or removal of children disabled women's ability and fitness to be mothers has been undermined and challenged (Block in-press). As outlined by the statistics above, despite this overwhelming social control a significant number

of disabled women are mothers (Rogers & Matsumura 1991).

If disabled women have children, a strong cultural message is that they will have defective children and "pollute the gene pool" (Block in-press). But these myths are not born out in fact: "Fears that disabled women would produce children with similar conditions (nearly always groundless since the vast majority of disability is not hereditary) have mingled with convictions that they would harm, deprive, or burden children they attempted to rear" (Fine & Asch 1988 p.21).

Myth #8: Disabled women are unfit to be mothers

When disabled women have children, they are seen as having violated a powerful societal taboo. A high number of them have had their custody challenged (Barker & Maralani 1997). Many more have had non-legal, but powerful interventions. From this disabled mothers learn that their right to raise their children will always be challenged (Wates 1997). And that being a sexual woman who is also a mother with a disability is potentially dangerous.

Disabled mothers have good reason to worry. In this study of predominately white, well-educated parents with disabilities the right to parenthood was often challenged:

Parenting has been the last frontier for people with disabilities and an arena in which parents are likely to encounter prejudice. Researchers have found that parents with disabilities experience prejudice about their rights or abilities to parent. In a national survey of almost 1,200 parents with disabilities, about 15% of the parents reported attempts to remove their children. Indeed, about 7% of over 300 undergraduate psychology majors did not think people with disabilities should be parents at all.

It seems that the stigma attached to disability encompasses a threat to the right to parent for persons with disabilities. Thus the legal rights of parents with disabilities, especially in custody decisions, is a fundamental issue for all parents with disabilities (Kirshbaum & Olkin in-press).

Kent (in-press) remembers being a visibly disabled woman with a small child. She recounts her personal perspective of how this experience imprinted her:

The exhaustion and isolation I felt are common to many, if not most, new mothers in middle-class America. Yet I had one added burden sighted mothers did not share. I knew that wherever I went people were observing me, wondering about me, at times doubting my abilities. All too many people, both strangers and acquaintances, questioned my capacity to care for my daughter and to keep her safe.

Because sex and motherhood are seen as mutually exclusive

categories (except for reproduction), when disabled mothers make their sexuality visible they are vulnerable (Wates 1997).

In evaluations of the fitness of mothers, sexual expression is always a significant factor (Lewin 1993). Women are judged by their sexual behaviors. Discussions of types and frequency of partners are always part of both social and legal discussions of a woman's moral fitness to be around children.

If a disabled mother practices non-marital sexuality, she increases her risk. Lesbian mothers, alternative sexuality mothers, mothers who dress sexy, mothers with multiple partners, mothers with vibrators next to their beds, mothers who deviate in any way from a very rigid norm are highly suspected to be unfit. For disabled mothers, being suspect is very dangerous. One mother talks about how her sexual behavior would impact her and her daughter's lives:

As a lesbian I have found that some parts of the Deaf community are tolerant, accepting and even supportive of various sexual orientations, while part of the leadership and the grassroots are as homophobic as mainstream society. I was nervous about how [my sexuality] might impact [my child's] membership in the Deaf community. I was scared to date Deaf women, and even interpreters, because the community is so small that just a single night spent with someone would be generally known by the next day (D'aoust 1999, p.117).

## Issues for disabled mothers

### Scarcity of Information

If disabled mothers had to rely on preexisting material on disability, motherhood and sexuality to guide them, they would never have a sex life (Wates 1997). The breakthrough book, *The Mother's Guide to Sex*, was just published in 2001 and it was written by two vibrator saleswomen.

This lack of information has significant impact on disabled mothers' resources to solve new sexual challenges (Rogers & Matsumura 1991). All mothers are tired while raising children. Most mothers have to learn new techniques to carve out time for themselves. But when disabled mothers are presumed to be asexual, challenged for their parental fitness, and denied any resources on sexuality, it becomes more challenging to make space for a sexual life.

There are numerous websites, books and articles that separately address disability, sexuality and parenting. But there is almost no overlapping information that examines the three as interrelated issues (Rogers & Matsumura 1991; Wates 1997) Disability resources talk about the interactions between specific disabilities and pregnancy. Sexuality and disability resources talk about the right to be sexual and techniques for being sexual. But they are almost always focused on traditional heterosexual relationships and

heterosexual behaviors and presume that people do not have children. (Sexualhealth.com; Rogers & Matsumura 1991)  
Disability and parenting resources focus on encouragement, pregnancy health information, and infant care techniques and equipment but ignore sexuality. (Rogers & Matsumura 1991)

The exceptions to this are rare. Denise Sherer Jacobson's book (1999), *The Story of David*, recounts not only her journey to adopt a child, but also explicit discussions of sexuality and sexual practices between she and her also disabled husband.

*Mother to Be* (Rogers & Matsumura 1991) has two pages on resuming a sexual life after pregnancy. While it offers some specific suggestions, it is focused only on disabled mothers who have recently birthed children. It also has a strong presumption of a permanent heterosexual relationship - she refers to all partners as "husband". (This is being changed for the second edition.)

The Disabled Parents listserve ([www.disabledparents.net](http://www.disabledparents.net)) is currently the only place that a woman with a physical disability can get sexual information and discuss her sexual life without concern of judgment. Although some lesbians contribute to this list, there is not an ongoing discussion of non-heterosexual practices for mothers with disabilities.

Nearly all the available information on sexuality and disabled mothers presumes that they are white, heterosexual and married. It is extremely difficult to get any information about disabled mothers of color, lesbian mothers with disabilities, or disabled mothers with alternative sexual practices.

### Scarcity of Resources

Dealing with the enormous scarcity that comes with parenting - especially parenting for the first time - can be overwhelming. Nearly all new mothers react to child rearing by putting their own needs on the back burner. In a telling exercise, author and educator Cheri Pies (1988) asks women thinking about becoming mothers to make a pie chart of their current lives. She then asks them to turn the paper over and make a new pie chart with the addition of one child. Nearly all the participants immediately delete any time by themselves, with their partners or with friends. So what they were left with was the chores necessary to get through a day to only meet an imaginary child's needs. If this is what people are planning for, imagine how hard it will be to change that mindset when a flesh-and-blood child is present.

Yet researchers consistently find that parents who do not ignore their own needs while providing for their children's needs provide the best family environment (O'Toole & Doe in-press). As one disabled mother states: "I can have it all. But only what is really important to me. And only if I plan for it. And only if I don't try to have it all at the same time" (L 2001).

One of the decisions that many mothers with disabilities

make, particularly if they are alone with a young child, is to have the child sleep in the same bed or same room with them. For many mothers this allows them to do childcare tasks more easily. But it also makes it much harder to have intimate time with a partner.

In some cases, the presence of a child in a parent's bedroom is considered suspect. In legal cases, a nondisabled norm has sometimes seen this choice as an indicator of unfit parenting (Krishbaum & Olkin in-press). So disabled mothers may be reluctant to discuss this openly, instead framing it as an issue for the child. Untangling this situation can involve changing the child's routine, finding different ways to accommodate disability-related needs, and rearranging tasks to create time for intimacy.

One of the biggest challenges to a disabled mother's ability to have intimacy is that the increased demand on her is not matched by an increase of resources to her. She may face a lack of money to buy needed adaptive equipment (Barker & Maralani 1997). She may need to design a new personal transportation system since paratransit systems do not carry baby seats and the law requires children to be transported in them. She may need assistance with childcare activities, such as bathing, but is prohibited from using her PAS funds for this. She may need to find childcare that is accessible by transportation, finances, and physical plant. In nearly all cases she will be searching out information and resources that, if they exist, are scarce. All of this directly impacts how much time and effort she has to put into creating and maintaining an intimate life.

#### Making Space for Intimacy

Do disabled mothers want a sexual life? Most answer yes. But the constraints of managing disability and motherhood often make it hard to find time. And if the nondisabled parents are only finding 20 minutes a week, then what happens for disabled mothers?

One of the best resources for disabled mothers is their experience in managing their disabilities and lives. As Michele Wates & Rowen Jade write: "A proven ability to overcome problems has got to be a more useful life skill than a trouble free life" (from their public speech notes).

It can be argued that mothers with disabilities bring more resources to creating motherhood on their own terms than nondisabled women. They have already had to negotiate with partners about sexual intimacy. They can do it again. They have already learned to survive with limited information and resources and they can use those skills for this new challenge.

For most mothers with disabilities, this new set of challenges is welcome. Their decision and ability to parent was not without challenges of its own. They have already faced resistance and found a way through it. Now as long as they can stay away from the purview of Child Protective Services, they can create the life they want.

This life will have some new challenges for disabled mothers to continue to be sexually active beings. They will need to create solutions that work for them and their family.

The solutions presented throughout the remainder of this paper emerged from the experiences of mothers with disabilities.

You have to make time for sex

With kids, if you and your partner don't talk about it before hand, the few opportunities you have can disappear before you get started. Some people like to play with the challenge of time constraints. For them, the fun it is to catch stolen moments in new places or at new times. Perhaps during a baby's nap or a child's visit to the neighbors. For other parents, it becomes important to carve out specific adult-only time. So they hire a babysitter or arrange a childcare trade for their preferred time.

A new body means new opportunities

For most physically disabled moms, a significant change is in how their body has changed with childrearing. Whether it changed from a pregnancy or from post-adoption childrearing, her body is now experiencing new stresses. All mothers are tired. They do not get enough sleep. But for mothers with physical disabilities, the additional physical care required for parenting takes its toll. Mothers may have to find new ways to do formerly routine tasks. This change may also impact her (and her partner's) pre-parenting preferences for sexual positions and behaviors. In some ways, disabled moms are given a new body with a child. And they do not ever get the old one back. This may mean a need to discover new sexual practices (both alone and partnered).

You need to negotiate with sexual partners all over again

Whether a partner is new or old, having a child forces mothers with disabilities to redefine all parts of their lives. In some ways, disabled women have an advantage. As a disabled woman from Australia reminds us: "I think we're lucky," she says. "We have to be far more open with our partners than other people do. I have to take my clothes off in front of my husband and he has to position my body. It encourages more openness in a sexual relationship" (Mascall, 2001, p. 4).

Not only is a disabled mother functioning with a new body, she also has new challenges juggling her life as mother and partner. At the most elementary level, disabled mothers need to talk openly with their partners about the changes in their lives and how it is impacting their sexuality. Some women find the burden of childrearing to be a relief from a sexual contract that they were unhappy with, but unable or unwilling to renegotiate. Other women find that before children sex was getting predictable and they enjoy the challenge of having to be more creative with sexual opportunities.

Because partners of disabled women are directly impacted by the negative sexual stereotypes about the undesirability of disabled partners, some amount of thinking and negotiating has already occurred. In a study of disabled lesbians and their partners, Axtell (1999) found: "Disability and chronic illness didn't necessarily figure into the way participants articulated their identity as couples, but did affect their relationships in a number of ways. Participants described effects on their sexual relationships, their financial stability, and their planning for the future" (p 63).

Disabled women and their partners have unique resources to draw on as they create a sexual life while parenting. In a discussion of heterosexual couples where one partner has a disability and who lived together, Kirshbaum and Olkin (in-press) report: "In fact, couples, regardless of [type of] disability, on average reported happy marital relationships and high satisfaction with their division of family labor, e.g., with the division of childcare, household tasks, and family decisions."

#### Single mothers

A significant portion of mothers with disabilities are single mothers. In addition to the challenges and solutions already presented, these mothers have other issues to consider.

#### Sleeping arrangements

One of the biggest secrets of single mothers is that their kids often sleep either in the same room or the same bed with the mother. Like partnered mothers with disabilities, this may be because it makes night time childcare easier for a disabled mother. Or it may be a habit, common to many nondisabled single mothers, of keeping a child nearby at night. In addition, disabled single mothers are likely to be impoverished (Barker & Maralani 1997) so there maybe only one bedroom in the house.

Whatever the reason, disabled single mothers are not going to have control over their sex life until this issue is addressed. Some mothers share childcare (including overnights) with other single mothers. This allows them to schedule a sexual partner during their child-free time.

#### Talking to children about partners

Single disabled mothers also have the challenge of how to talk about their sexual partners with their children. Some mothers choose to introduce their partner(s) to their children. Other mothers choose to keep their sexual partnerships private from their children. Other mothers present all adults who come into the home as "friends" and do not involve the children in the specifics of each arrangement.

Each route has direct implications on a single disabled mother's availability to be a sexual partner. Partners, particularly those who are not parents, often have difficulty understanding the constraints on a single disabled mother's

time and energy. Some mothers may prefer to have permanent partnered relationships, but find themselves outside the flow of dating. Other mothers consciously choose to have more casual relationships or even stop dating for a while. As one single disabled mother said:

[I don't want] to sacrifice any hope or dream of a love life just because I'm a parent. I've had one relationship (long distance) during parenthood and I called it off because I didn't have the energy or level of interest required to feed the relationship. I don't think I was in love anyway. I do feel way less need to be in a relationship than I did before I was a parent. I'm open to the possibility, but not pining. I don't necessarily make the choices that I assumed I would (B. 2001).

Single disabled mothers are more suspect

Single disabled mothers are more likely to have their ability to parent questioned. Without a partner, particularly a nondisabled partner, they are often perceived as questionable, potentially unsafe and possibly unfit. All disabled mothers know that once they are referred to Child Protective system, their life and choices will come under a bright microscope. All of their choices will be questioned by nondisabled people using nondisabled norms. Disabled mothers rarely measure up with that lens.

So many single disabled mothers choose to live a more circumspect life. They present a competent face when they are outside the home even when they are struggling. They do not turn to nondisabled parental assistance programs even when they need help and they teach their children to be wary of nondisabled people's questions about their home life. This may involve modeling compensatory behaviors in public situations (i.e., doing something a harder but more standardized nondisabled way so as not to arouse questions). They may keep sexual partnerships hidden from public view, be vague about any sexuality questions, and be extremely careful in all their relationships with adults.

Raising sexually healthy children

In discussions with mothers with disabilities, they frequently comment on consciously being open to discussions of sexuality with their children. They emphasize a positive approach to sexuality and responsibility.

As a parent, I try to convey to my son (now 14) that no topic is off limits for discussion. He sometimes would like me to be a little more discreet when we talk about sexuality (I did get my Masters degree in sex education) and I try to respect his boundaries. The most important thing I want him to understand is that I am an approachable parent. I also want him to be comfortable with the two topics that I was never comfortable with as

a child - disability is one, sexuality's the other (J 2001).

Disabled mothers who are raising disabled children are particularly concerned that their children have access to sexual information and positive sexual role-modeling during their youth. One disabled mother puts it this way:

Sometimes as a mother, I find myself consciously telling my daughter that she will have a lover, be a mother, raise a family. I tell her this not because I believe that these are her only options. But I tell her this because I know that nearly all of the rest of the world doesn't believe that she can do it. And she is peppered with this disbelief many ways every day (R 2001).

Sometimes there is concern that a child's disability will impact their sexuality and sexual choices as they age. Anticipating the transition to adolescence, this mother prepares herself in this way:

I'll acknowledge the possibilities, probably before a nondisabled parent would, but then be vigilant in his training so he doesn't have sex before he can handle it and all that goes with it, but if he does, then that he handles it appropriately. What a tightrope. I guess it's just that I know he'll be a sexual being, with desires, starting in several years and that he needs the same guidance as any nondisabled kid his age (B 2001).

#### Summary

Research in disabled mothers and their sexuality provides a wealth of ideas about resilience, communication, problem-solving, and maintaining a positive sexuality. If future research incorporates the resilience of disabled mothers, instead of focusing on the problems, beneficial work would result.

Inclusion of disabled mothers in studies of gender, sexuality, and/or disability would build the literature. Examinations of nontraditional mothers with disabilities are desperately needed. Long-term studies of motherhood and disability would give new perspectives and directions.

To a large extent the barriers facing disabled mothers and their families reside in the unexamined medical-model perspective through which they are usually viewed. Challenges to this model that include mothers with disabilities would provide a permanent reframing of fundamental myths that constrain disabled women's access to sexuality and parenting.

#### Endnotes

1. The author is indebted to two wonderful resources

which strongly influenced this article. *The Mother's Guide to Sex* provided a valuable blueprint for exploring these issues.

And author Judi Rogers, who is currently revising *Mother to Be*, provided invaluable direction and inspiration.

2. Throughout this article, I have chosen to use particular language. I chose "partner" over other alternatives because I want the readers to know that I am including all sexual partners. When I say "mother" I am referring to the primary caregiver(s) of a child. I chose to use "disabled mother" interchangeably with "mothers with disabilities" to show that some people have a cultural affiliation with the disability community. I chose to include in a general way people who are practicing alternative sexuality (such as BDSM) or non-traditional gender roles (such as transgendered people) to acknowledge the presence of these people within the term "mothers with disabilities" and to also acknowledge the increased risk to their rights to parent.

3. For this and other papers, interviews were conducted with disabled mothers across a sexual identity and disability spectrum. Twenty-two women were interviewed over a period of five years. Some of the interviews were conducted through email or on the telephone and some from interacting with these mothers in natural settings such as at home, at conferences, at community events. In addition, the researchers (O'Toole, D'aoust, Doe) used participant observation. Each of these researchers has access to mothers with different disabilities in different settings. Doe is a disabled mother. D'aoust is a Deaf lesbian disabled mother. O'Toole is a disabled lesbian mother. As a disabled mother, you have access to the culturally invisible world of disabled mothers, both lesbian and not. While in this environment the researchers observed and later recorded what they observed, what they learned and experienced during these contacts. All of this research was done in a participatory, non-invasive way and it was entirely unfunded.

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