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Reproductive Technology and Disability: Searching for the "Rights" and Wrongs in Explanation

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Several years ago I worked as a lawyer representing psychiatric patients on the grounds of a large medieval-looking turn-of-the-century mental hospital in British Columbia. Soon after starting my new job I met Ann, a woman who shortly after her admission as an involuntary patient had informed her treatment team that she was pregnant. She had always wanted to have a baby. When she told her doctor about her pregnancy, he decided that this idea was part of her delusional system and prescribed anti-psychotic drugs to control her pathology. In fact she was pregnant and the medication given during the first trimester of pregnancy had teratogenic effects. Now she was carrying a fetus with a disability. The doctors told her that it would be best to have an abortion in the circumstances. She agreed. This client began my thinking about disability, reproduction, parenting and the role of medical control.

This paper is about women, disability and reproductive rights, specifically new reproductive technologies.¹ The discussion examines the ways that a "rights" analysis informs the position women with disabilities take to reject new reproductive technology, particularly pre-natal testing. By way of contrast, some women who define themselves as "reproductively disabled" because of their difficulties in conceiving or bearing children argue for their right of access to reproductive technology, especially

* Assistant Professor, Faculty of Law, University of British Columbia, with thanks to Susan Boyd, Christine Boyle, Nitya Duclos, Isabel Grant, Roberta Hamilton, Nancy Hansen, Susan Russell, Jim Russell and Lynn Smith, all of whom read earlier drafts of this paper and made helpful suggestions. This article is not to be quoted without the permission of the author.

1. I am using the distinction between old and new reproductive technologies that is outlined by Renate Duelli Klein, "What's 'New' About the 'New' Reproductive Technologies" in G. Corea, *et. al.* (eds), *Man-Made Women*, (London: Hutchinson and Co. (Publishers) Ltd., 1985) p. 64 where new reproductive technologies include pre- and post conception sex selection techniques, the full range of 'test-tube' techniques, as well as the increasing number of antenatal tests such as amniocentesis and chorionic villi sampling. However, as medical intervention in women's reproduction increases, various older "technologies"—often those that have been organized, if not controlled by women, for centuries—themselves seem "new" because they are stamped with the approval of medical expertise. Abortion and birth control are examples. Artificial insemination has traditionally been used by lesbians who wish to become pregnant without engaging in heterosexual sex. It too is often considered "new" as it becomes restricted through medicalization.

in vitro fertilization (IVF).² Arguments in support of each of these divergent political positions rely on the concepts of “disability”, “rights” and “choice”. How do the same principles lead to such different conclusions?

My thesis is that women with disabilities bring a critical view to the meaning of “choice” in reproductive rights, because of a heightened sensitivity to group-based concerns and equality rights, rather than to the situation of the individual case. The life experience of disability is characterized by discrimination and presentation of false choices. The disability community argues that the “choice” to continue with a particular pregnancy following a pre-natal diagnosis when it discloses a disability constitutes a false choice because of the social and economic context of the decision, as well as the medical milieu. Women with disabilities reject a medical model of disability and tend to be sceptical of medicine and science because of the role these have played in their own lives. For these reasons the disability community rejects reproductive technology at this time because it is likely to further disadvantage people with disabilities.³ The community also rejects a medicalized discourse as inappropriate to explain the issues surrounding reproductive technology.

Women who claim a reproductive disability also use language of “choice”, but conclude that restrictions on reproductive technology are restrictions on their reproductive choice and autonomy. Reproductive technology, especially *in vitro* fertilization (IVF), represents an apparent solution to a particular woman’s disadvantage. In arguing for access to technology, women who claim a reproductive disability have adopted the group-oriented disability discourse to gain access to resources for individuals. The focus is on the difficulties of an individual who has “chosen” to become pregnant, who has been unsuccessful and is aware that the new technology will allow her new ways of pursuing her choice. Medicalization

2. Certainly not all persons not able to bear their own genetic child would describe themselves as reproductively disabled. Christine Overall in *Ethics and Human Reproduction: A Feminist Analysis*, (Winchester: Allen and Unwin Inc., 1987) has used the term “involuntarily childless” to describe women who wish to bear or adopt children but are unable to do so because of biological or social reasons. I do not mean to focus on infertility in this paper. The broad sketch of reproductive disability is included to provide a contrast with women with disabilities and to demonstrate the power of disability rights language.

3. See Canadian Disability Rights Council, *Final Recommendations to the Royal Commission on New Reproductive Technologies*, July 5, 1992, (prepared by Sandra Goundry), for an argument by disability activists to reject new reproductive technology. In this paper, I am indebted to the work of Sandy Goundry, Shelagh Day, Gwen Brodsky and Maria Barile who articulated the position of the Canadian Disability Rights Council (CDRC) and the Disabled Women’s Network (DAWN) for presentation to the Royal Commission on Reproductive Technology.

of the discourse is helpful in making this argument because of a characterization of infertility as a treatable medical issue and the value we place on universal health care.

I am conscious of the dangers of imposing these categories on women.⁴ Women with disabilities are not a homogeneous group and suggesting that there is one life script or shared view on matters is misleading. Because of the host of other differences in the lives of disabled women, no single voice can properly speak for what would be a stereotype of a disabled woman's experience. There is a similar vast array of differences among women who describe themselves as reproductively disabled. I use the distinction only to explore the sites of the life cycle where the social nexus of gender and disability is most apparent.

In this paper, I first describe the problems in defining disability. Secondly, I sketch some broad differences between women with other disabilities and those who claim a reproductive disability. Thirdly, I outline features of the reproductive technology debate that underlie these positions. These features include appropriation of disability rights discourse by some women who claim a reproductive disability, the interpretation of "choice", and the medicalization of the debate. Finally, I distinguish how women with disabilities and women who claim a reproductive disability use rights discourse through a differential emphasis on equality rights and rights to autonomy.

I. *What Is Disability?*

What is a proper definition of disability? Just what we are referring to, or whom, is not clear. My main objective here is to outline why this question matters. This section provides a framework for what women with disabilities mean by "disability", suggesting why women who are involuntarily childless would embrace the term "disabled".

Many writers adopt some version of the World Health Organization's distinctions among the terms "impairment", "disability" and "handicap".

4. Feminist theory has relatively recently begun to grapple with the "difference question", the acknowledgement that feminist theory must account for differences among women along such dimensions as race, class, sexual orientation and disability. See for example, Elizabeth Spelman, "Inessential Woman: Problems of Exclusion" in *Feminist Thought*, (Boston: Beacon Press, 1980):

Most philosophical accounts of 'man's nature' are not about women at all. But neither are most feminist accounts of 'woman's nature' or 'woman's experiences' about all women. There are startling parallels between what feminists find disappointing and insulting in Western philosophical thought and what many women have found troubling in much of Western feminism. (p.6)

"Impairment" is defined as a deviation in physical or mental structure or process; "disability" is a loss of function; "handicap" is a social phenomenon determined by the socio-cultural factors which surround and interpret a condition.⁵ According to that taxonomy, impairment, (founded in anatomical or physiological alteration) may or may not be correlated with disability (a variation in ability to perform certain tasks) which may or may not result in handicap.⁶ There are at least two problems with these semantics. First, the categories are probably artificial and unhelpful because they are interdependent and give no clues as to causality. Arising out of a medical model, this view implies that impairment or disability comes first and the condition is then processed through a social lens. But disability may well be the result, rather than the source of a social phenomenon. For example, an individual may be described and treated as "mentally handicapped", not because of her abilities or her brain structure, but because of certain idiosyncracies. On account of the social power of the label however, she may not perform certain tasks that she is able to do, or may eventually lose the ability to perform the tasks. The second problem with the concepts of "impairment" and "disability" is that they appear to be neutral words because of their medico-technical associations. While this type of language appears to have no particular point of view, medical terms are imbued with social judgments about what is "healthy" or "pathological" and "normal" or "abnormal". This thinking reflects an underlying value that favours abilities, but the social bias is masked by categorization and language that purports to separate "objective" from "social" phenomena.

5. A similar formulation is found in the United Nations Declaration on the Rights of Disabled Persons, passed in 1975 which defines a disabled person as:

Any person unable to ensure by himself or herself wholly or partly the necessities of a normal individual and/or social life, as a result of a deficiency, either congenital or not, in his or her physical or mental abilities.

6. Susan Wendell in "Feminist Theory of Disability" (Summer 1989), *Hypatia*, Vol.4, No.2, criticizes the U.N. distinctions among the terms impairment, disability, and handicap, and prefers simply to use the term "disability" to emphasize that disability is a phenomenon socially constructed from biological reality. Wendell suggests that social oppression may be the only thing that disabled people have in common. She suggests defining disability as a position from which a disability politics might emerge rather than a set of attributes that are objectively identifiable. (See footnote 5 of Wendell's article).

The disability community rejects a medical model of disability and instead, emphasizes social factors.⁷ Disability activists say that the “normality-abnormality” continuum is not helpful in understanding disability except to the extent that normality is understood as a social interpretation. Disabled people often write about how painful it is to deal with the responses of individuals to their disability and they say that these reactions are often more difficult than the condition itself. Jenny Morris, a woman with a disability, writes about ordinary reactions in ordinary situations:

“Strangers in the street have a range of responses to us, from the ‘How marvellous you are!’ through ignorance to the very obvious fear of the alien nature of disability. Our common experience is that it is unlikely that we can go out in public, to the shops, the theatres, the library, to pick our children up from school etc. without encountering some reaction from a total stranger. Libby says, ‘Some days I get really angry at the way people stare at me in the street. I feel like saying ‘I don’t have three heads, do I?’ but most of the time I accept it—after all I stare at disabled people myself. I am nearly always self-conscious in public. I don’t like being in situations that attract too much attention. I hate it when mothers grab their toddlers out of the way, saying ‘Mind the lady, darling’, even though I know they’re only trying to be considerate”.⁸

Apart from the responses of individuals to disability, the ways in which physical structures, cultural events, and services are organized reflects what the disability rights movement refers to as an “ableist” bias, which means that the specific needs for inclusive environments for people with disabilities are not even considered. This systematic preference for people who are considered to be able is reflected in the architecture, cultural forms and service delivery of our society. For instance, going to a restaurant that has a welcoming atmosphere to a person with a mobility impairment does not mean a back door beside the garbage cans. It means that the restaurant has a ground floor entrance or a ramp as the main entrance, not as a second thought. Once inside the building, an accessible bathroom means more than a bar beside the toilet. It means a very large bathroom to allow a wheelchair to move around and a sink at an

7. Note for example an explicitly socio-political definition of physical disability which is offered by the Union of Physically Impaired Against Society (UPIAS) that states:

Disability: the disadvantage or restriction of activity caused by a contemporary social organization which takes no or little account of people who have physical impairments and thus excludes them from participation in the mainstream of social activities. Physical disability is therefore a particular form of social oppression.

8. Jenny Morris (ed.), *Able Lives: Women's Experience of Paralysis* (London: The Women's Press, 1989), p.74.

appropriate level, as well as an unencumbered route through the restaurant to the bathroom. At the tables, sugar and condiments are well within reach from a sitting position. These details are often invisible to those who are "able" and who have been socialized in a world oriented to the able.

Besides attention to structures and services in order to include people with disabilities we need different social understanding of what dependence and accommodation mean. In this vein, Morris describes the particular way that our society views the dependence of people with disabilities when they require certain services even though we all depend on a host of services constantly in our daily lives:

For example, we all depend on water coming out of the tap when we turn it on, while a disabled person such as Ann Mathison depends on someone to help her get dressed in the morning. However, when non-disabled people talk about water coming out of the tap, the issue is whether the water company is reliable; when they talk about Anna being dependent on an assistant, the issue for them is what they see as her helplessness created by her physical limitations.

If water does not come out of the tap, the problem is identified as a failure on the part of the water company. However, the nature of the problem when Anna's assistant fails to help her get dressed when and how she wishes is determined by the structure within which the service is provided. If Anna pays her assistant and the assistant fails to do her job properly, Anna may sack her and get another (if she is both confident enough to do this and certain that she can recruit another assistant.) If, however, Anna is in an institution then she is unlikely to have the power to decide when and how she gets dressed. Neither is she likely to have the power if the assistant is provided by her local authority and is answerable to a Home Care Organization rather than Anna herself. When Anna does not have control over the provision of her personal care, the problem is considered to be her own dependence and her demands which do not fit in with the service provided.⁹

As a concept, disability is a social category mainly organized by those with power, although people also control it by self-identifying as disabled. Its construction is founded in part on our society's view of what are

9. Jenny Morris, *Pride Against Prejudice: Transforming Attitudes to Disability* (London: The Women's Press, 1991), pp 137-38.

the important "differences" between people.¹⁰ A formulation where everyone is identified in a binary way as either "disabled" or not promotes a view of persons with disabilities as uniform, but the term "disability" is not universally accepted by those with physical or mental impairments. Michelle Fine and Adrienne Asch ask:

Why should a limb-deficient girl, a teenager with mental retardation, or a blind girl have anything in common with each other, or with a woman with breast cancer or another woman who is recovering from a stroke? What they share is similar treatment by sexist and disability-phobic society. That is what makes it likely that they will be thrown together in school, in the unemployment line, in segregated recreation programs, in rehabilitation centres, and in legislation.¹¹

As the disability rights movement has asserted itself as a political force, the specific language considered to be appropriate and respectful in identifying specific disabilities has undergone many changes. As they felt more empowered, disabled people have begun to name themselves rather than have others label them, pointing out distinctions where they think these are important.¹²

While I attempt here to report examples of how women with disabilities describe or define disability, very few of these voices have actually been heard. I suggest that there are two reasons for this lack of voice: first, the limited opportunities for disabled people to be heard, and second, the purpose for which disability is usually defined. Disabled people have had

10. Martha Minow in *Making All the Difference: Inclusion and Exclusion in American Law* (Ithica: Cornell University Press, 1990) has described the emphasis on "difference" in disability as characteristic of legal thinking based on an abnormal/normal persons approach. This dichotomous thinking is carried over in a rights approach to disability. Her analysis points to the limitless actual differences that exist between people but where the significant social and legal "differences" are defined by those in power. The central tension in the rights approach is between affirmative action or special entitlements to right historical wrongs for oppressed people alongside the similar treatment for all perspective. Minow's approach to difference as an aspect of relationships emphasizes connectedness between persons rather than divisions.

11. Michelle Fine and Adrienne Asch (eds), *Women with Disabilities: Essays in Psychology, Culture and Politics*, (Philadelphia: Temple University Press, 1988), at p. 6.

12. With thanks to Lynn Smith for pointing out the similarities between this development in the disability rights movement and a similar moment in the development of feminism at which time feminists began advocating strongly for changes in language toward gender-neutral and inclusive forms. In a similar fashion other oppressed groups have struggled with referents to themselves. For example, First Nations people have been referred to as "Indian," "aboriginal" and "First Nations". Disabled people alter language as part of the process of social transformation. Distinctions between "hard of hearing" and "deaf" reflect important political concerns to that sector of the disabled community. Recently the term "mentally retarded" has been replaced by "mentally handicapped", "intellectually handicapped" "intellectually challenged" and "developmentally disabled". These seemingly fine distinctions underscore different aspects of a person's situation, including the permanence of the condition and its context.

little opportunity to portray their own experiences within the general culture or within radical social movements for reasons that are in part, quite concrete. Often these limitations amount to issues of access to the arenas of communication. Stairs present powerful barriers for people with mobility impairments to speak at public meetings and the print medium poses similar obstacles to people with visual impairments. Whatever descriptions we have of disability in art, culture, and politics have come largely from the viewpoint of the non-disabled.¹³

Second, the most common reason motivating a definition for disability is to adjudicate entitlements to benefits. These include entitlements under insurance plans, both state-organized such as workers compensation or disability welfare benefits, and disability benefits under private insurance plans. The resulting definitions are organized and shaped by strong economic incentives to keep costs down. Although the elements necessary to establish disability are far from standardized, a common feature of this disability labelling is that professionals, almost always doctors and almost always non-disabled, determine whether a person has a disability and its extent. Doctors, physiotherapists, and psychologists determine disability through laboratory procedures, psychological tests and other methods of assessment.

There is one important caveat to this political position of disability as a social construction legitimated by a medical model as it is expressed by activists. Understanding disability solely as discrimination, or as an objectification of the other, names important processes that should and can be ameliorated by true social commitment. However, this is an incomplete statement. What is missing here is the subjective experience of being disabled, and the extent to which social change can alter it. Jenny Morris reminds us that:

A feminist perspective on disability must focus, not just on the socio-economic and ideological dimensions of our oppression, but also on what it feels like to be unable to walk, to be in pain, to be incontinent, to have fits, to be unable to converse, to be blind or deaf, to have an intellectual ability which is much below the average...

While the negative parts to the experience of being Black or gay in a white, heterosexist society can be identified as wholly socially created, there are

13. See Deborah Kent, "In Search of a Heroine: Images of Women with Disabilities in Fiction and Drama", in *Women with Disabilities: Essays in Psychology, Culture and Politics*, *supra*, note 11. For a work that relies on the voices of people with disabilities, see Jenny Morris, *supra*, note 8, who draws on the work of disabled writers, filmmakers, playwrights, poets and others to convey the subjective reality of disability, an experience that is little represented in the dominant culture.

negative aspects of being disabled which would persist regardless of the kind of society in which we live.¹⁴

With an emphasis on 'objective' measurement and professional interpretation, neither the subjective nor the social reality of disability are given much weight.¹⁵

I will use the term "disability" to reflect the three alternatives contained in the *Americans with Disabilities Act* of 1990: having a major functional restriction as a result of a physical or mental impairment, or having a history as such, or being perceived to have such a condition.¹⁶ This legislation acknowledges that disability may have a medical basis, that having had a disabling condition in the past may create the same barriers as a current condition, and that the social and political context of any condition is critical. But I have also incorporated the subjective reality of disability as spoken by women with disabilities. I will argue subsequently that those women who claim a "reproductive disability" attempt to place themselves in this framework so that a properly founded

14. Morris, *supra*, note 8, pp. 70-71.

15. For a clear example of how medical approval is needed to define disability, and its specific link to restricting entitlements to state benefits, see the definition of "handicapped" in s. 2 of the Regulations pursuant to the *Guaranteed Annual Income for Need Act*, R.S.B.C. 1979, c.158:

'Handicapped person' means an individual 18 years or older who, at the discretion of the Director, has been designated as handicapped due to the individuals being mentally ill or mentally retarded as defined in Section of the Provincial Mental Health Act, or due to the individual, having a physical injury, amputation, or physical malfunction of the body. Such designation shall be made only after a qualified medical practitioner has confirmed that the disability is permanent and there is no remedial therapy available for the individual to significantly lessen the disability, and provided the disability is sufficiently severe that:

- the individual requires extensive assistance or supervision to manage normal daily functioning, or
- as a direct result of the disability the individual requires unusual and continuous monthly expenditures for transportation or for special diets or other unusual but essential and continuous needs.

For purposes of these regulations, the foregoing definition excludes an individual who, regardless of any physical or mental disability, has not tried nor completed all possible medical treatment to overcome the disability. The definition also excludes an individual whose reason for being unemployable is due primarily to causes other than those stated in the first paragraph of this definition.

16. *Americans with Disabilities Act* of 1990 Pub L No 101-336, 3(2), 104 Stat 327, 330 (1990)

A person with a disability

- (1) has a physical or mental impairment that substantially limits the person in one or more major life activities; or
- (2) has a record of such physical or mental impairment; or
- (3) is regarded as having such a physical or mental impairment.

claim of disability leads to an entitlement. If infertility is found to be a disability it may follow that there is an entitlement to the benefit of reproductive technology, most commonly IVF.

II. *Women With Disabilities v. Women Who Claim a Reproductive Disability: Points of Nexus of Gender and Disability in the Life Cycle*

Despite their shared use of the term "disability", the life experience of women with disabilities is predictably different from women who claim a reproductive disability. Such factors as the history of institutionalization of disabled people, together with segregated education and job markets, nearly ensures that women with disabilities experience the world in a fundamentally different fashion than women with fertility problems. Because of the different ways gender identity develops, likelihood of membership in an alternate family or living arrangement, relative income or employment levels and degree of confidence in medical or technological solutions, these women are likely to express different attitudes about reproductive technology.

First, in all likelihood, women with disabilities acquire the 'disability' label earlier in life than women who claim a reproductive disability, so the social construction of disability is more likely to shape the individual's self-concept.¹⁷ As young girls and adolescents struggling with their identities as women, including the accompanying questions of sexuality and reproductive capacity, women with disabilities report that they have grown up outside the particular experiences that typically characterize heterosexual gender identification.¹⁸ Martha Saxton, a woman with spina

17. Major exceptions to this projection of life-cycle differences are cases where women develop disabling conditions as a result of an accident or through the onset of a progressive degenerative disease, such as multiple sclerosis. Socialization at puberty in these cases would not differ in any systematic way because of disability. See for example Jenny Morris, *supra*, note 8 which reports the results of a questionnaire study of such matters as sexuality and intimate relationships, and motherhood, as the subjective experience of women with spinal cord injuries acquired at different stages of life. For an interesting account of the ways in which gender affects strategies for coping with multiple sclerosis as an example of an adult-onset condition, including issues such as marriage and continuity of employment, see Susan Russell, "From Disability to Handicap: an Inevitable Response to Social Constraints?" (1989), 26 *Can. Rev. of Soc. and Anthropol.* See also Bonnie Klein "'We Are Who You Are': Feminism and Disability", *Ms* (November-December 1992), Volume III, No. 3 for an account of her onset of disability in her mid-forties because of a stroke and her difficulties in identifying with other women with disabilities.

18. See Adrienne Harris and Dana Wideman "The Construction of Disability and Early Attachment" in Michelle Fine and Adrienne Asch (eds), *supra*, note 11 for a critique of the use of psychology, particularly psychoanalytic theory, to explain gender identification generally and in particular, gender identification for girls with disabilities.

bifida, discusses her special confusion about sexuality and gender during adolescence. Although her family raised her to think of herself as 'normal' she says:

I wasn't sure if the teenage magazines, the scenes at the movies, the clandestine discussions with other girls really applied to me.¹⁹

Rather than being relieved at missing these often turbulent and unpleasant times, women with disabilities report that their gender, sexuality, and capacity to be mothers²⁰ were simply ignored.²¹ In contrast, those women who describe themselves as reproductively disabled can only encounter this after the condition is discovered, usually well into adulthood. By this time the struggles with puberty and adolescence and initial sexuality have

19. Martha Saxton, "Born and Unborn: the Implications of Reproductive Technologies for People with Disabilities", in Rita Arditti, Renate Duelli Klein and Shelley Minden (eds), *Test-Tube Women: What Future for Motherhood*, (London: Pandora Press, 1984) p. 305. For a review of several empirical studies of disability and the development of heterosexual behaviour around adolescence, see Harilyn Rousso, "Daughters with Disabilities: Defective Women or Minority Women?" in "The Construction of Disability and Early Attachment" in Michelle Fine and Adrienne Asch (eds), *supra*, note 11 where the authors study heterosexual behaviour of women disabled before adolescence and after adolescence, and found later development for those with pre-adolescent disabilities. Parental expectations were seen as critically important by the women.

20. For other personal accounts of the development of the disabled woman's view of herself as a potential mother or as a sexual being, see, for example, Maria Barile, a woman with a disability who says in "New Reproductive Technologies: Socio-Economics versus The Rights of Women with Disabilities" in *Four Discussion Papers on New Reproductive Technologies*. Prepared by CRDC and DAWN (1990), *supra*, note 3:

Many women with disabilities are socialized to believe that they are unfit to be good mothers, especially with regard to the child-bearing process. Some of us are wrongfully led to believe that spasticity during delivery, for instance, could kill the baby or that a pregnancy could not be carried to term. These myths have been and continue to be embedded in the minds of young girls with disabilities and appear to be very real to many of them. (p.24)

See also Mary Jane Owen, "A Romp Through Metaphor Land", *Disability Rag*, January/February 1987, p. 11 in which college students were asked to free associate about the term 'disabled woman'. While words signifying dependency were frequent responses (eg. 'sorry', 'almost lifeless', 'grey'), words associated with sexuality and motherhood were almost entirely absent.

21. Nasa Begum in "Disabled Women and the Feminist Agenda" (1992), 40 *Feminist Review* 70 describes how certain areas of feminist concern impact differently on disabled women. These include gender roles, body image, and sexuality. With respect to gender roles she argues that the attainment of traditional gender roles for disabled women may be seen as a real sense of achievement. Quoting from Rousso, *supra*, note 19 at p. 159:

I pushed myself to the very things that my parents said I could not have. I was determined to prove that I was a 'normal' woman. I deliberately sought the most handsome man to parade me around. And although I did not consciously intend to do it, I became pregnant out of wedlock at 17, which was extremely affirming for me. One of my proud moments was parading around the supermarket with my belly sticking out for all to see that I was indeed a woman, and that my body worked like a normal woman's body. (at p. 74)

concluded with the accompanying consequences for gender identity. Disability has not been relevant in a developmental way to the sexual, female or reproductive self.²²

Women who have been disabled for much of their lives are more likely to be living in an arrangement that is an alternative to the traditional nuclear family.²³ Although many feminists conclude that the traditional nuclear family is an oppressive institution, "the struggle against the family may be different for those who are excluded from the outset".²⁴ A larger proportion of adult women with disabilities are single rather than married or in a couple relationship. Adult women with disabilities live more often with their parents, and describe their feelings of being restricted and over-protected.²⁵ For many women with disabilities, an alternate living arrangement in adulthood is a variation or extension of an institutional environment that continues from childhood,²⁶ and arrangements where unrelated adults live together in a group home are more common within the disability community than elsewhere in our society. As well, the special relationships that develop between people with disabilities and their attendants are somewhat unique. In contrast, women who describe themselves as reproductively disabled are more likely than disabled women to be married, in heterosexual relationships, and living in a traditional family both as child and as adult.

Second, women with disabilities are overwhelmingly poor and under-employed. The combination of segregated education and systemic discrimination in employment has a devastating effect on the income and employment prospects of women with disabilities. Often education has

22. I do not mean to imply that reproductive disability does not create pain, or feelings of failure to the individual. Indeed, women with fertility problems describe processes similar to a grieving reaction for their situation. My point is simply that the differences in the acquisition of disability in the life-cycle of women will have different consequences.

23. On appeal to the Supreme Court of Canada in *Canada (A-G) v. Mossop* (1990), 71 D.L.R. (4th) 662 the Canadian Disability Rights Council successfully argued to be an intervenor, in part on the basis that disabled people had an interest in a case about the definition of "family" and same-sex benefits because people with disabilities so often live in unusual groupings of individuals.

24. Begum, *supra*, note 21, p. 75.

25. See for example, J. Campling, *Images of Ourselves*, (London: Routledge and Kegan Paul, 1981), p. 17.

26. While a full discussion of the effects of institutionalization is much beyond the scope of this paper, it is useful to bear in mind a finding that there are five common descriptions of institutional life approached in diverse ways. These are: loss of liberty, social stigma, loss of autonomy, depersonalization, and low material standards. (See K. Jones and A.J. Fowles, *Ideas on Institutions—Analyzing the Literature of Long-term Care and Custody*, (London: Routledge and Kegan Paul, 1984). The relatively recent movement toward de-institutionalization of children and adults with disabilities should have a significant effect on living arrangements for people with disabilities.

been interrupted when required resources were no longer available. In contrast, there is no reason why the education attained by women who claim reproductive disabilities should correspond to that of the general population.

Third, women with disabilities and those who claim a reproductive disability have different orientations to medicine and technology. Infertility was conceptualized as a disability in the same era as the development of certain of the new reproductive technologies and the whole purpose of *in vitro* fertilization is to treat infertility. Therefore a woman who claims to be reproductively disabled is likely to actively seek out medical solutions to her problems and has adopted a disability label, in part to ensure access to medical technology.²⁷ By comparison, many women with other disabilities have likely developed a well-founded distrust of medicine and science. A negative body image by disabled women may be derived from, or at least reinforced by doctors' treatment, perhaps most critically during adolescence,²⁸ and women with disabilities may well conclude that:

Our bodies have been the targets of medical abuse. We have been hospitalized and have spent years in doctors' offices and still our bodies have not cooperated. Some of us live in chronic pain and some with chronic unpredictability and others with chronic stares. We have felt the personal invasion of surgeries and endless diagnostic procedures.²⁹

27. See D. Wells, "Ectogenesis, Justice and Utility: a Reply to James", (1987), *Bioethics* 1(4) who argues that the inability to produce one's own genetic children is *prima facie* a disability in the same way as near-sightedness, and that failing to treat infertility would be as foolish as failing to treat nearsightedness. The analogy is faulty because improving vision is perceived to be a desirable objective in a more universal sense than the ability to reproduce one's own genetic offspring.

28. See, for example, this description by J. Campling *supra*, note 25, about the effect of medical treatment on body image:

Having a disability made me very aware at an early age of the messages I was receiving from the larger society about how I was supposed to look and how you're supposed to be. Also, as the doctors poked and studied me endlessly, I learnt more quickly than some non-disabled that I am seen as an object ... I was made to walk naked ... and then lie on a mat while in turn they (5 male students) examined my body, opening and closing my legs, poking and prodding here and there and making comments. I was at the age when I was developing from a child into a woman ... I started to lose my self respect. (p.10)

29. "This body I love—finding ourselves" in Susan Browne *et al.* (eds.), *With the Power of Each Breath: A Disabled Women's Anthology*, (Pittsburgh: Cleis Press, 1985), p. 246. For a general discussion of the way that the medicalization of disability has affected women with disabilities see Nancy Hansen in "Surmounting Perfect Body Syndrome: Women with Disabilities and the Medical Profession," in Houston Stewart, Beth Percival, Elizabeth Epperly (eds.), *The More We Get Together*, Canadian Research Institute for the Advancement of Women (Charlottetown: Gynergy, 1992).

All too often, the “magical cure” solution that medicine or science offered failed miserably and women with disabilities may well view medicine as a series of false promises. Lesley Hall writes:

When I was sixteen I paid my last visit to an orthopaedic surgeon. He wanted to carve me up, perform a miracle on me and transform me into a normal person. But this time, I intended to say no. I thought of how I should tell him this. After six years, I was tired of the miracle cures that never worked...

I went into the doctor's office hoping that I would have the guts to reject this operation. It was a carrot that the medical profession kept dangling before my eyes.³⁰

In short, women with disabilities often find that they engage with a world where the particular combination of gender and disability results in consequences that are different than they would be for non-disabled women or men. The result of the gender-disability nexus is crystallized in matters of sexuality, reproduction and motherhood. In the following section, I argue that the life experiences of women with disabilities informs not only their conclusions about reproductive technology, but also results in their rejecting a liberal and medicalized framework for discussing the issues, while women with claims of reproductive disabilities argue their case within the medical discourse.

III. *The Discourse*

1) *Appropriation*

Long before the technological advances that led to the development of new reproductive technologies and the accompanying socio-political questions, people with disabilities lobbied for a more inclusive society. Their arguments, expressed recently in rights language, included such principles as accessibility, reasonable accommodation, dignity, respect, and full participation in social life for people with disabilities. While these principles have not yet achieved the universal realization hoped for,

30. Lesley Hall, “Beauty Quests—A Double Disservice, Beguiled, Beseeched and Bombarded—Challenging the Concept of Beauty” in Diane Driediger and Susan Gray (eds.), *Imprinting Our Image: An International Anthology by Women with Disabilities*, (Charlottetown: Gynergy, 1992), p.135.

the concepts have been noted and accepted by some courts.³¹ To some extent, then, the courts have used human rights legislation and Charter provisions to echo in law the desirability of a society in which all persons participate in social life regardless of ability. Increased costs to governments or private parties should not easily defeat the right of people with disabilities to be included.³² More importantly for the purpose of this paper, the ideas of disability rights have trickled into popular consciousness. Although their absence is still much more evident than their presence, disabled people are more visible in society now than in the past, as are the specific entitlements that have followed rights arguments. Wheelchair ramps, close-captioning on television, elevator buttons with Braille numbers are necessary entitlements in an inclusive society. Children with disabilities are beginning to attend regular classrooms at age appropriate levels.

In this context of growing social awareness and developing jurisprudence on disability rights, individuals with fertility problems have appropriated a disability rights discourse to gain access to resources and services forged by earlier efforts at advocating very different disability issues. While I propose here that the term "reproductive disability" builds on the efforts of the disability movement, I am neither suggesting that there has been a planned and conscious takeover of a discourse, nor that any appropriation is morally reprehensible, but rather that there has been

31. Few discrimination cases based specifically on disability issues have reached appellate courts in Canada, although several important decisions by courts and human rights tribunals extend to disability issues. For example, in *Saskatchewan (Human Rights Commission) v Canadian Odeon Theatres Ltd.* (1981), 122 D.L.R. (3d) 381, the court decided that persons who use wheelchairs must be given an appropriate seat in a movie theatre, not necessarily the same seat that is offered to any other able-bodied patron. The notion of formal equality was rejected. In CDRC etc. statutory disqualification from voting on the basis of incapacity to control finances constituted discrimination because it was not an appropriate test of capacity for the specific situation. See also *Woolverton et al. v. B.C. Transit operating "HandyDART"*, Decision of the B.C. Human Rights Council (unreported), August 13, 1992 in which scooter users alleged discrimination because they were required to transfer from their scooters to seats when using HandyDART, a parallel transit service for persons with mobility restrictions. Despite expert evidence about safety concerns and an argument that this risk presented an "undue hardship" to B.C. Transit, the party providing the service, the respondent was found in violation of the Human Rights Act.

32. Although the issue of costs to governments on disability related issues has not yet been litigated, increased cost has not generally been found to justify violations of rights. See *Re: Singh and the Minister of Employment and Immigration*, [1985] 1 S.C.R. 117 where the court found that increased cost to government did not save the government's failure to grant an appropriate oral hearing to refugee claimants. In *J.C. v Forensic Psychiatric Services Commission et al.*, (February 28, 1991), S.C.B.C., No. A873287, the court found that the expense involved in providing equal housing for men and women patients did not constitute a defence to discriminatory treatment by gender.

a sense of identification with a particular social category that has attracted entitlements by the use of rights discourse. In pursuing their project, women who claim a reproductive disability draw on both the symbols and actual victories of a different political movement. As a result of their differences in life stories and in social location from women with disabilities, women who claim a reproductive disability transform substantially the discourse they borrow, especially on the questions of “choice” and the role of medical debate.

2) “Choice”

References to autonomy and “choice” are pervasive in discussions of sexual and reproductive matters.³³ Rape and forced sterilization are some explicit examples where choice is absent for women and a pro-choice position on abortion or the availability of a midwife rather than a doctor to attend during pregnancy are rallying points for advocating the right to choose for individual women. “Choice”, however, occupies a very different niche in the argument on reproductive technology by women with disabilities and those who claim a reproductive disability. Women with fertility problems address what they perceive as an absence of choice when they lament the difficulties in access to IVF. By way of contrast, women with disabilities bring a more critical perspective to what “choice” means to them within the context of reproduction and disability.

Reproductive choice for women with disabilities has a very particular meaning derived from an historical context that includes lack of information about birth control, forced sterilization and prescriptions of unsafe contraceptives. Because women with disabilities have experienced disadvantage in a range of contexts, they are likely to have a somewhat jaded view of the meaningfulness of individual choices in the abstract. In all probability, choices have already been more restricted in their own lives. Barriers to physical facilities, education, employment, information, and

33. In a talk at Queens University in 1992, Diana Majury has described the pull of the concept of “choice” and the negative reactions to restrictions on choice in various feminist discussions, including reproductive technology. The effect of restrictions on access to abortion are far more serious than the effect of restricting choice regarding access to IVF. Restrictions on abortion result in defined negative outcomes both for society and for the individual such as higher teenage births, and physical and psychological damage to women. Any risk associated with abortion is relatively low except when the abortion is coerced. In contrast, limiting “choice” by restricting reproductive technology (referring here mainly to IVF) has virtually no negative impact at the societal level. At the individual level the restriction on choice means that some women may not be able to bear their own child, and given the scarcity of white, able-bodied newborns, may not be able to adopt a baby.

social relationships are some of the particular areas of the experience of discrimination where the notion of individual choice has fallen away.

Urging extreme caution in the use of pre-natal diagnosis, disability rights activists worry that the existence, availability, or use of pre-natal testing limits, rather than enhances, true reproductive choice because of social attitudes toward disability.³⁴ While these tests purport only to provide additional information to the woman about her pregnancy, certain diagnoses lead almost inevitably to the termination of the pregnancy and disabled people say this reflects a value judgement on their own lives as "not worth living", thereby exacerbating the existing discrimination against disabled people.³⁵ The disability community argues strenuously that the enormous fear of disability,³⁶ the incorrect belief that most disability arises from inherited conditions³⁷ and the reliance on medical information to understand disability all support the moral rightness that a pre-natal test revealing disability should lead to an abortion.³⁸ The disability rights community says that any "choice" about a specific pregnancy is more apparent than real in these circumstances but the appearance of "choice" is consistent with "ableist biases" and a dominant ideology that values autonomy and individualism.

34. Janice Tait, "Reproductive Technology and the Rights of Disabled Persons", (1986), 1 Canadian Journal Of Women and the Law, describes the discomfort with "choice" as a slogan taking on new meaning in reproductive technology:

The choice is often represented as that between having a "healthy baby" or a "defective child" by physicians who pioneered the "improvements". And what shall be termed a "defect?" Down's Syndrome? Spina bifida? Wrong sex? What about cleft palate and hare lip? If the technology fails to detect the "defect" what status will the newborn have if she comes into the world disabled?

35. Statistics indicate that 90% of pregnancies are terminated after amniocentesis reveals a disability. See M. deWachter, "Prenatal Diagnosis", in D.J. Roy (ed.) *Life Technologies and Public Policy*, (Montreal: Institute for Research on Public Policy, 1986).

36. Fear of disability is tenacious in our society. For a gripping account of the anxiety associated with having a disabled child by a disability activist herself, see Anne Finger, *Past Due: A Story of Disability, Pregnancy and Birth*, (Seattle, Washington: Seal Press, 1990). See also Rayna Rapp, "XYLO: A True Story", in Arditti *et al.* (eds.), *supra*, note 19, pp.313-327.

37. The incorrect assumption that there is a higher probability of disability with a mother with a disability is true for only a limited number of conditions. The hereditary nature of certain disabilities is, however, a widely held notion. In 1927, Justice Oliver Wendell Holmes Jr. wrote for the U.S. Supreme Court approving compulsory sterilization for mentally handicapped persons against their will because "three generations of imbeciles is enough," in *Buck v. Bell*, (1927), 274 U.S. 200.

38. See Ruth Hubbard, *The Politics of Women's Biology*, (New Brunswick; London: Rutgers University Press, 1990):

Women are expected to implement the society's eugenic prejudices by 'choosing' to have the appropriate tests and 'electing' not to initiate or to terminate pregnancies if it looks like the outcome will offend. (p.197)

A woman who claims a reproductive disability will be more inclined to assume, in a liberal sense, that she has the right to make individual choices in life. It follows that the injustice she perceives in her situation arises from the discovery that the choice of biological motherhood seems unavailable to her. The frustration and sense of injustice is increased by any impediments (such as cost or limited resources) to the choice to avail herself of assistive technology.

3) *Medicine*

Although the disability rights community along with the feminist communities have called for a moratorium on *in vitro* fertilization, and women who claim reproductive disabilities want a right of access to that technology, all understand any version of reproductive "choice" to be limited by the role of medicine and the state in reproductive technology.³⁹ Despite their general agreement that medicine controls or limits women's reproductive decisions, women with disabilities go farther in their critique of the medical model and its relationship to power, by rejecting medical discourse as inappropriate to frame their arguments about reproductive technology. Ironically, women with reproductive disability claims advance their position more effectively by using medical discourse. Women with disabilities refuse to accept the parameters of a medical debate mainly because of the perceived connection between eugenics and medicine. As well, they see an incompatibility between reproductive issues as defined by women and the objectives of medical scientists in pursuing reproductive questions.

From their particular concern about pre-natal diagnosis, disability rights activists liken the effects of reproductive technology to the most horrific modern program of eugenics, the Nazi program of racial hygiene. While it is true that the decision as to who should live and who should die

39. Some of the feminist critique of the increasingly intrusive role of medicine, law and the state in women's reproduction are reflected in: Sheila Martin, "The Control of Women through Gender-Biased Laws on Human Reproduction" in Richard F. Devlin (ed.), *Canadian Perspectives on Legal Theory*, (Toronto: Edmond Montgomery Publications Ltd., 1991). For a Charter analysis of forced Caesarian sections, see Isabel Grant "Forced Obstetrical Intervention: A Charter Analysis" (1989), 39 U. of Toronto L.J. An amusing but telling anecdote is related in Gena Corea, *The Hidden Malpractice: How American Medicine Treats Women as Patients and Professionals*, (New York: Morrow, 1977) which describes a 1972 raid of the Feminist Women's Health Centre in Los Angeles that was conducted by 10 police officers and a detective. Carol Downer, the originator of the self-help concept, pleaded guilty to fitting a diaphragm, for which she was fined \$200 and put on probation for two years. During the raid, the police tried to confiscate some yoghurt, known to be a gynaecological remedy, but they released the substance when one of the collective members informed them that it was her lunch.

was made by the men of the state in Nazi Germany, the justification for the decisions was given by doctors and scientists. In other words, the particular form of the eugenics movement could not have been carried out without a collaboration between the state and medicine/science. According to the disability rights perspective, reproductive technology provides a new way to perpetuate programs of population purification. With the expanded capabilities of amniocentesis and chorionic villi sampling,⁴⁰ certain disabling conditions can be detected but not changed with the tools of current medicine and technology.⁴¹ Disability activists say that this technology allows for a particularly insidious version of eugenics because it exists in an environment in which principles of equality of opportunity are said to be important, where science and medicine are assumed to be value-free and where the bias toward the ablest goes largely unexamined.⁴² Yet the search for perfect babies is what legitimates vast amounts of medical research monies to expand the range of pre-natal diagnosis, where the focus of research is usually removed from

40. Amniocentesis is a procedure that samples the amniotic fluid at approximately the sixteenth week of pregnancy using a syringe applied externally to the abdomen. The results of amniocentesis are not available until nearly the 20th week of pregnancy. Chorionic villi sampling is a tissue sample taken from the 8th to 10th week of pregnancy by the insertion of an instrument vaginally. Both techniques are performed in conjunction with ultra-sound to locate the position of the fetus. Certain genetic conditions of the fetus such as Down's Syndrome, may be diagnosed with these procedures. Each carries a certain risk of miscarriage.

41. Some of the pre-natal genetic diagnoses constitute disabling conditions from birth such as spina bifida, while other diagnoses are genetic conditions that do not appear until middle age, such as Huntington's disease. Unlike the corrective measures that result from an Rh disease finding, there are no measures that can change the genetic endowment of the fetus to eliminate Down's Syndrome or Huntington's disease. According to Yvonne Peters, in "New Reproductive Technologies: a Threat or a Benefit to Equality" in CRDC and DAWN Discussion Papers, *supra*, note 20:

This broad scope of prenatal testing not only encourages a form of eugenics but also promises to control and manage disabilities from the womb to the grave. (p.17)

Pre-natal diagnosis may mean an increasing medical tracking or state-control throughout life as techniques are developed to detect conditions that appear later in life.

42. In discussions preceding amendments to the Criminal Code about abortion in 1967, representation by the Canadian Medical Association to a committee of the House of Commons set out the grounds for a legal abortion and contained a provision permitting legal abortion if the fetus was defective in some way. This position was taken before the use of amniocentesis but it was the medical establishment's position that doctors could assess whether the fetus was defective by clinical experience. In the end, Parliament did not give such discretion to doctors and this ground was dropped from the amendment. See Janine Brodie, Shelley Gavigan and Jane Jenson, *The Politics of Abortion*, (Toronto: Oxford University Press, 1992).

women's health issues.⁴³ In this context the information derived from pre-natal diagnosis is presented as objective data from which a woman is expected to exercise 'free choice' in deciding whether to continue a pregnancy.

Although pre-natal testing is accompanied by genetic counselling to assist women in making a decision about pregnancy, the counselling is usually in a hospital and carried out by medical personnel. The disability community says that appropriate "counselling" associated with pre-natal diagnosis should not be limited to medical, rehabilitation or psychological information but should include contact with people with the particular diagnosis or with their parents in order to convey the experiential component of disability which would speak not only to practical advice but also to the joys and sadnesses of the experience. Medical facts are simply insufficient upon which to understand or decide.⁴⁴

Besides the eugenic component of prenatal diagnosis, the disability community stresses that emphasis on medical detection techniques re-orients the discussion of disability in a harmful way. Pre-natal testing aims to eradicate disability in biological terms and thereby diverts public attention away from the eradication of disability discrimination. Any expectation that prenatal diagnosis techniques will effectively eliminate disability distracts discussion and resources away from the many other causes of disability and away from discrimination, social matters that society can do something about.⁴⁵

43. Patricia Spallone, *Beyond Conception: the New Politics of Reproduction*, (Granby, Mass.: Bergin and Garvey, 1989), describes the divergent interests between the scientists who develop reproductive technology and women who will be affected by it. She argues that virtually any basic research question can be conceptualized as leading to important answers about health matters *some time in the future* and she explains that scientists do this in applications to granting agencies all the time. However, the more important reason for research is: "No 'test-tube' babies, no prize-winning research". (p. 107).

44. The way in which information is disseminated is important. For example, see Ann Finger: "Claiming All of our Bodies, Reproductive Rights and Disability," in Browne, S. Connors, D. Stern N. (eds), *supra*, note 29 for an insightful view of the way in which information is disseminated when a disabling condition is found in the fetus. For example, a disabled woman chose to have amniocentesis in order to determine whether the fetus had Downs syndrome or spina bifida. The woman had no intention of aborting the fetus in those circumstances, but wanted the information because of her own special needs. She was shocked by the assumption at a group counselling session that anyone would abort such a fetus. Calling the clinic after the session to voice her objections, she was informed that the clinic felt it should present as *negative* a position as possible.

45. As well, an increased attention to genetic causes of disabilities de-emphasizes the wide range of environmental contributors to disability such as traffic and work-place accidents. In its final report to the Royal Commission on New Reproductive Technologies, *supra*, note 3, the CDRC suggests that the major cause of infant disability is poverty-related—that is, poor maternal nutrition (p. 5). See as well Anne Finger, "A Lot to Learn", March/April 1990 *The Disability Rag* 28.

On the other hand, women who claim a reproductive disability place their arguments within a medical discourse in this debate. Accepting a medical discourse here means three things: first, accepting a medical model of disability; second, formulating the problem as an allocation of medical resources; and thirdly, appealing to the social value of universal health care. By placing their arguments on entitlement to IVF within a medical framework, women who claim a reproductive disability accept a medical definition of disability: impairment is viewed as "fixable" or at least alleviated by medical intervention. This argument is premised on a right to infertility treatment as a right to health care, an argument with a special appeal in Canada because of this country's history and its pride in universal health care.⁴⁶ Questions about rights to treatment and moral dilemmas about allocating medical resources are current and newsworthy topics for the discipline of bioethics.⁴⁷ Medical ethicists, health care economists, as well as writers in the popular media, are accustomed to discussing such questions as the criteria for selecting transplant recipients, the appropriateness of "no resuscitation" orders, and other questions about distributing medical resources. Access to reproductive technology is a similar issue in this familiar category of questions.

To date, medical personnel have assumed control over decisions about who gets access to the technology and how pre-natal diagnoses are communicated to women⁴⁸. Not surprisingly, there are indications that the medical establishment has been widely accepted as the legitimate authority to exercise power in this realm. For instance, in its report on reproductive technology, the Warnock Commission recommends compulsory counselling for anyone who wishes *in vitro* fertilization, and

46. Canada's commitment to universal health care is now echoed in the *Canada Health Act*, R.S.C. 1970, c. C-6.

Section 3 provides:

It is hereby declared that the primary objective in Canadian health care is to protect, promote and restore the physical and mental well-being of residents of Canada and to facilitate reasonable access to health services without financial or other barriers.

47. Questions of "distributive justice" in the sense of allocation and access to services attract much more attention with respect to medical services than, for example, with respect to legal services. See Paul R. Tremblay, "Rebellious Lawyering, Regnant Lawyering and Street-Level Bureaucracy" (1992), 43(4) *Hastings Law Journal* 960 who posits that health care is viewed as more of a right than legal care and that cost is therefore a more pressing concern. Further, medical care is more visibly controlled by government while legal care is more likely seen as the responsibility of families. My point here is simply that the access questions of reproductive technology fit into an existing and familiar debate within bioethics.

48. See Recommendations 10-12 in the CDRC's final recommendations to the Commission on New Reproductive Technology, which speak to a formal Code of Ethics that has a "disability-positive" underpinning for the professionals who are involved in reproductive technology and the dissemination of information about pre-natal testing.

genetic counselling is already a mandatory component of pre-natal testing in Canada.

The argument that women now advance for access to IVF has some similar features to the struggle for access to abortion in Canada. In the 1960's, access to abortion was broadened by amending legislation. While the change obviously benefitted women because abortion was more available, the motivation for increasing access came not to protect or liberate women but to serve the interests of doctors.⁴⁹ Doctors said that they were performing abortions on a regular basis as medical care for women and argued successfully that their professional medical treatment be "de-criminalized". Ironically, as has been true on the issue of abortion, the "medicalization" of reproductive technology may serve the interests of women who claim a reproductive disability. But medicalization does not serve women with disabilities well. In short, women with fertility problems have adopted disability rights language to further their claims to entitlements and have adopted medical discourse in argument despite the fact that the disability rights movement has concluded that such a discourse is inconsistent with its interests.

IV. *Rights Arguments: Rights to Equality v. Autonomy*

Women lobbying for access to IVF because of a claim of reproductive disability argue access as a "right". Women with disabilities call for the greatest care in reproductive technology, especially pre-natal diagnosis, and argue in part that the "rights" of disabled people are threatened by reproductive technology. How do rights arguments allow this variety of conclusions? What predictions can we make about the "success" of presenting such rights arguments?

In general, the disability community focuses on two different formulations of rights: equality and autonomy.⁵⁰ Equality rights are conceived as a group right, a collective right of a disadvantaged group. Remedies such as employment equity programs, fully accessible public transit

49. See Brodie *et al.*, *supra*, note 42. The real purpose behind the provisions of the Criminal Code was to protect doctors from criminal liability, rather than to reflect in law reproductive rights for women. Similarly, in *R. v. Morgentaler*, [1988] 1 S.C.R. 30, in which the Supreme Court of Canada struck down the criminal sanction against abortion, four of the judgements focus on procedural problems in availability of medically approved facilities for abortion, rather than on any woman-centred critique of the legislation.

50. The distinction between rights to autonomy and rights to equality is somewhat misleading because the concepts both arise from a base of individualism. Rights to autonomy are clearly individualistic. Equality rights are based on a comparison between individuals by both drawing out similarities between individuals to form a category or group, and distinguishing members of the category from members of other categories.

systems and integrated education benefit the disadvantaged group as a whole by altering the conditions that lead to systemic discrimination. The right of autonomy means recognizing the differences that exist between individuals and that an individual's life and decisions should be treated with dignity and respect. An example of the right to autonomy would be an acknowledgement, for example, that a person with a mental illness should have the right to consent or to refuse a recommended medical treatment. These different objectives are somewhat paradoxical because they emphasize, differentially, the concerns of the individual and collective aspirations. Women with disabilities reject reproductive technology insofar as it threatens group-based or equality concerns, mostly by the use of prenatal diagnosis. As a result, the disability community generally leaves for another day the autonomy concerns of the individual with a disability who might benefit from reproductive technology because she is having difficulty becoming pregnant.⁵¹

The value of pre-natal testing as an aid to reproductive choice is especially problematic to women with disabilities but the significance of pre-natal testing and the demand for perfect babies is not limited to the interests of the disability community. Arguably the issues around pre-natal testing affect all women because of the symbolic connection between women and motherhood in our culture⁵² and the strong belief that mothers are responsible for the way their children turn out.⁵³ Declining the test that would have disclosed a disability and subsequently giving birth to a child with a disability, or giving birth to a child with a disability after receiving information that the fetus had a disability, means that

51. This is a matter of emphasis, however. In the final CDRC Report to the Royal Commission on Reproductive Technologies (*supra*, note 3), Recommendation 1(d) refers to the availability of reproductive technology on an equal basis to anyone who wants it as a human rights principle, and Recommendations 13 and 14 state more specifically that there be no disability-related eligibility criteria for access to reproductive technologies. Restricted access to reproductive technology for women with disabilities constitutes discrimination in two ways: by restricting access to the technology on the faulty assumption that disability is most likely to be genetically based, and secondly on the basis that women with disabilities will not be good mothers.

52. Because of the tenacious connection between the vision of women and motherhood in our society, the construction of motherhood becomes important to all women even if they have decided not to have children. See, for example, Martha L. Fineman, "Images of Mothers in Poverty Discourses" (1991), 2 Duke Law Journal 276.

53. The recent movement toward international adoptions reflects the demand for perfection. The reason seems to be that the number of "perfect" and "pristine" local babies has diminished. There are still babies locally who are described as disabled or older children who are available for adoption. There seems to be more willingness to deal with the legal and bureaucratic problems of international adoption and other issues attendant with adopting a child from a different country than the willingness to accept a less than perfect child.

mothers can be blamed for the ways that their children turn out at an earlier point than ever before.⁵⁴

While the disability community has argued its issues in "rights" language, asserting "rights" may not be useful to predict or to achieve particular outcomes,⁵⁵ whether the rights are based on individual concerns such as autonomy or privacy or based in collective concerns such as equality. A rights analysis almost always involves deciding between competing rights⁵⁶ or the state controls how resources are dispensed, or

54. Barbara Katz Rothman in *Recreating Motherhood: Ideology and Technology in a Patriarchal Society* (New York: W.W. Norton & Co., 1989) argues that the ideology of motherhood leads to a commodification of reproduction where the child becomes the product of the reproductive process. The commodification leads to an evaluation of womanhood that depends on an evaluation of motherhood. Presumably, the quality of the product (the child) becomes an important component in evaluating the person as a mother and as a woman. Susan Penfold and Gillian Walker, *Women and the Psychiatric Paradox*, (Montréal: Eden Press, 1983), Chapter VI, suggest that the eugenic tendencies in the thinking of medicine in the early 20th century was followed by an undercurrent of motherblaming for a host of economic, political and social problems around World War I. The authors do not draw any causal links between eugenics and motherblaming but that question remains open. There are few tools in any situation that can predict what our children will be like when they grow up. Ruth Hubbard reminds us, *supra*, note 38:

With all the prenatal tests in the world, we cannot know what our children will be like, whether they will be healthy and able-bodied and remain so, and what sorts of people they will be when they grow up. We have the best chance of successful parenthood if we are prepared to accept our children, whoever they are, and do the best we can to help them accept themselves and, hopefully, us too ... Sparing no expense to develop techniques for diagnosing disabilities prenatally, so as to prevent the birth of children who have them, accentuates the stigma to which people with disabilities, as well as their families, are exposed. (p.169)

55. See for example, Joel Bakan, "Constitutional Interpretation and Social Change: You Can't Always Get What You Want (Nor What You Need)", in Devlin, *supra*, note 39.

56. The competing rights of fathers and fetuses in the field of reproduction have been widely discussed. These are especially problematic when the state intervenes, especially on behalf of the fetus in issues of abortion, forced Caesarian sections, or legislation to control the lives of women during pregnancy. See, for example *Paton v British Pregnancy Advisory Services Trustees*, [1979] Q.B. 276, aff'd at [1987] 1 All E.R. 1230 (sub. nom C. v. S.) and *Paton v. United Kingdom* (1980), 3 E.H.R.R. 408; *Re: Baby R* (1988), 15 R.F.L. (3d) 225 (B.C.S.C.).

other factors are at play,⁵⁷ so that regardless of the strength of a rights argument any prediction about outcome must be guarded. Still, rights cannot be forgotten because of their pervasiveness in the ideological and symbolic realm. Rights are popular and bring a claim into "a linguistic currency to which everyone has access".⁵⁸ Particularly for the most oppressed in our society:

the conferring of rights is symbolic of all the denied aspects of their humanity ... rights imply a respect that places one in the referential range of self and others, that elevates one's status from human body to social being.⁵⁹

Just as women and slaves have used rights discourse to legitimate their struggles, so now are prisoners, the homeless and people with disabilities.

Infertile women invoke rights discourse, in part by adopting a disability label, and then use the language of equality to develop objectives of individual autonomy. With this position, women who claim reproductive disabilities have piggy-backed on a rights discourse that has provided some limited success for the disability movement. Unlike the equality concerns that inform the position taken by women with disabilities, this approach to reproductive matters is based on considerations of liberty and privacy.⁶⁰ Although a rights analysis is infinitely elastic and is certainly

57. Rights discourse has been widely criticized as a set of legal concepts which articulates a problem in a particular and limited way, obscuring the more important power relationships that underlie disadvantage. For a discussion of the ways in which a discourse and especially the discourse of law sets the boundaries for the discussion, see Carol Smart, *Feminism and The Power of Law* (New York: Routledge, 1989). For instance, law distorts the issues of sexuality that underlie rape and distorts the capitalist relations that underlay exploitation of women in employment. Similarly, legal rights of mental patients provides a distraction from the power of the psychiatric establishment to render patients powerless. A similar problem exists because of the discourse in which the debate on reproductive technology is set. With only a "yes-no" alternative to the question of reproductive technology, the frame of the issue assumes that there is only one feminist agenda related to reproductive rights. Clearly the right to have or not have children, to accept or reject sterilization, to birth or raise children as part of a lesbian partnership or as a single woman, are all matters within the struggle for reproductive rights. The particular formulation of the agenda depends on all of the differences between women.

58. See Carol Smart, *ibid*.

59. For a discussion of why rights are important to the most seriously oppressed groups in our society, see Patricia Williams, "The Pain of Word Bondage" in *The Alchemy of Race and Rights*, (Cambridge: Harvard University Press, 1991) at p. 153:

For the historically disempowered, the conferring of rights is symbolic of all the denied aspects of their humanity: rights imply a respect that places one in the referential range of self and others, that elevates one's status from human body to social being.

60. See Lynn Smith, "An Equality Approach to Reproductive Choice: *R. v. Sullivan*" (1991), 4 *Yale Journal of Law and Feminism* 1, who argues that the traditional view of reproductive choice is based on an individual woman's "right to choose" about matters relating to pregnancy, termination of pregnancy and medical treatment. An equality approach focuses on the economic, social and cultural concerns of pregnancy, child-bearing and child-rearing.

an imperfect tool for prediction, the rights argument advanced by infertile women is not only compelling, but is likely to work because of a particular combination: the use of “disability” as a symbolic underpinning of the argument, the way the questions fit within current discussions in the field of bioethics and the social position of the women who advance the argument.⁶¹ What is important here is that the women likely to advance rights arguments for the purpose of gaining access to reproductive technology are unlikely either to perceive themselves or to be perceived by others as part of an oppressed class in any other way. In advancing a claim to reproductive technology, some women are making demands on an economic and political system that has served them reasonably well, and these women can expect success, at least in comparison to women with disabilities.

IV. *Conclusion*

This paper has looked at the ways in which rights discourse is used to respond to reproductive technology. The concept of “choice” is an orienting point. As a sacrosanct component of feminist discourse on matters of reproduction and sexuality, women who experience reproductive difficulties call on the right to choose motherhood and claim a violation of the right when there is an obstacle to resources. The argument for the entitlement to resources is buttressed by identifying with the disability movement and by raising arguments framed in a medicalized discourse.

To persons with disabilities, an abstract notion of a right to “choice” is not helpful in explanation, nor is it true to life’s experience. “Choice” implies that an individual uses a particular calculus to decide and to affect outcome. Through the living experience of disadvantage, women with disabilities are sensitized to unravel a situation where it consists of false choices. Pre-natal testing, presented as material on which to make better and freer choices may be such a false choice. Women with disabilities accept neither a medical model of disability nor the medicalization of the debate about reproductive technology.

In the chimeric world of rights, disability rights activists use equality rights to argue against reproductive technology. The focus is on discrimination and group concerns, most importantly, the eugenic component and its connection to medicine. Women with fertility problems who wish

61. I would not suggest that the measure of success of the arguments should be so high a standard as universally accessible state-funded treatment of choice for infertility: rather, I suggest more limited private solutions to meet the requirements of the individual.

access to resources have adopted the equality rights discourse, cloaked with the right to medical treatment, in the service of individual autonomy. Rights which are so compelling in our society, yet so devoid of content, exist as an explanation within the power of law. Whether Ann, my client, who had certain legal rights in her situation, was able to continue her pregnancy (or was even *allowed* to be pregnant, despite the fact that she was) or not was determined not by law, or even by arguments in law, but by medical understanding, advice, and coercion to its patient Ann.