# ACCIDENTAL ACTIVISTS:

## MOTHERS, ORGANIZATION AND DISABILITY

by

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A dissertation submitted to the Graduate Faculty in Social Welfare
in partial fulfillment of the requirements for the degree of
Doctor of Social Welfare, the City University of New York

2006

UMI Number: 3213157

ProQuest Information and Learning Company
300 North Zeeb Road
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This manuscript has been read and accepted for the
Graduate Faculty in Social Welfare in satisfaction of the
Dissertation requirements for the degree of Doctor of Social Welfare

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# Abstract

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by

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This study explored how and why mothers with disabled children became activists, how their various encounters with social, health and educational services integrated with broader struggles for social justice and human rights, how this contributed to broadening their vision for their children's futures, and what they did with this new consciousness. The research examined the changing role of women in the Canadian Association for Community Living (CACL). CACL is an organization that was founded largely by women (in 1958), and over the years has been led by a number of key activist mothers. Right from the beginning it has been women whose advocacy for services for their children with disabilities has brought them into a broader relationship to the state.

Leading campaigns to close institutions and secure human rights, they learned to mother as activists, struggling in their homes and communities against the debilitating and demoralizing effects of exclusion. But for the most part they came to their activism “accidentally”, out of an event about which they had little choice, and certainly little foreknowledge. The research explores what “getting active” meant to these women who did what they did out of a sense of “gendered obligation”(Abramovitz, 1999).

The point of entry for this study began in “the everyday world” (Smith, 1987) of activist mothers with disabled children. The narratives of individual mothers themselves were a very important data source. Organizational archival documents and records of the Canadian Association from 1958-98 made the oral history aspects of this study viable.

Activist mothers recognized the importance of becoming advocates for change beyond their own families and they contributed to building an organization to place their issues on a more public scale. Yet the organization they founded has not been one that has necessarily recognized and profiled women’s contribution or been thought of in gendered terms. This study contributes to the scholarship on women’s activism and provides an opportunity to acknowledge the activist mothers for the contribution, courage and ability they devoted to their campaign for social justice.

# Acknowledgments

A dissertation is a hard task master. It is the daily trump card, consuming both waking and sleeping hours. As the research takes over, family and friendships once full blown are wedged into smaller spaces. The thesis advisor on the other hand, looms large as do the documents, the interviews, the reading and the writing. I began in 1998, late in my professional career, and during the 8 years of study I came to establish the first undergraduate program in disability studies in Canada and to co-direct a disability studies research institute at Ryerson University.  The doctoral program at Hunter equipped me to undertake this new academic challenge. To sit on the other side of the desk as a student, after so many years of teaching and facilitating workshops myself was a luxury. I read everything listed on the course outlines, required and recommended. Mike Fabricant taught the qualitative research course in which my thesis topic emerged. Mimi Abramovitz introduced me to a body of literature on women's activism that sent me outside disability to deepen my analysis and understanding about the field in which I practiced for 30 years. Her passion and commitment to feminist analysis provided the fixed arm of the compass. Her encouragement and guidance left me free to wander, explore, discover and then return and close the circle.

Many people let me know they were behind me. Michael Bach at the Canadian Association for Community Living gave me unlimited access to resources, and was eager to know what I was learning about his organization's past. Activist mothers of that movement and the focus of this study, welcomed and mentored me from the very first day I joined the staff of a local Association as a young woman in my 20's. They taught me what the textbooks could not and it is in a spirit of reciprocity that I have conducted

this work. Dean Sue Williams at Ryerson University knew what kind of pressure counted: she expected me NOT to be in the office on Fridays. My creative and dynamic sisters-in-arms in Disability Studies, Catherine Frazee and Kathryn Church, have made this chapter of my life the most exhilarating and satisfying yet. They were there through the ups and downs, on my side and in my corner, offering laughter and Bailey's and not necessarily in that order. Still other friends let me know they would be there when I could pick up the friendship ball I had to drop for a time. My father turned 90 and was proud that his life lesson 'you are never too old to learn' hit its mark with me. Sadly, my mother who died in 1993 missed this, but I came to realize how deeply she had seeded this work in me through her personal and unwavering commitment to her nephew Alvin who lives with a disability.

My son Maxim started and finished his degree in Urban and Regional Planning and placed 11th in the Canadian National Scrabble Championship. His remarkable achievements have been an important source of motivation for me. At times it seemed as though we were running along parallel tracks and I felt him setting the pace that helped me complete this marathon. My daughter Vida started her down PhD and for a time it looked as though we may finish together but she took time out to arrange her wedding. When I married in 1967 and moved out of my childhood home to set up one as an adult, I wished there had been a moment between to share an apartment with a girlfriend. Vida came to play that role in my life. As my "dissertation room-mate" she was the one I called to commiserate, vent, and share the sweet moments, too. Years between us evaporated as I drank in her worldly and knowledgeable counsel, and accepted her offers of wine and shoe-shopping excursions. The most profound and sustaining nature of my son and daughter’s support throughout this period has been how each has let me know, through the choices that they are making about their own lives, that they value the work I do.

Finally, the debt I owe to Leo is immeasurable. I could never have imagined thirty five years ago when he was writing his own thesis that I would ever want to undertake a doctorate myself. He gave back in spades whatever support and encouragement I may have offered then. He wrestled over details that worried me. He was helpful and willing at every stage, with every draft. That he cooked and made sure I had the space and time to work would have been enough to get me through. But then there was the email on February 14, 2001. First he quoted: “Just remember this: A kiss is still a kiss, A sigh is still a sigh, The fundamental things of life as time goes by.” Then he wrote: “It leaves out a few things like bread and wine, dignity, solidarity and democracy – but hey, it’s Valentine’s Day.” I knew then I would save the note to include here to acknowledge the part he played in this endeavor …and so much more.

# Accidental Activists: Mothers, Organization and Disability

## Table of Contents

# Introduction

## Background and Overview

Over the past two decades disabled people, influenced by the civil rights movement and the women's movement, began to describe themselves as a legitimately entitled minority group. In so doing, they laid the groundwork to mount a dramatic revision of the way disability may be understood. Disabled academics and activists began to place disability in a social, political and cultural context to examine the structural dimensions of the disability experience and proclaimed disability studies as a new academic terrain. They shifted the focus away from the more traditional emphasis on individual deviancy and pathology, towards an exploration of the socially constructed barriers (inaccessible architecture, exclusionary policies and practices, prejudice) as the "real" or sociological problems of disability (Priestley, 2001; Charlton, 1998; Oliver,1990;  Linton, 1998; Linton, Mello & O'Neill, 1995; Davis, 1997; Gill, Kewman & Brannon, 2003).[1]

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[1] In Mink (1999) Abramovitz describes a parallel phenomenon in her discussion of the rise of industrial capitalism in the early 19th century in which men were assigned to breadwinning in the workplace and women were assigned to care-taking in the home. "To inform men and women of their new roles and to convince them to adhere to them, the emerging domestic code became legitimized though social thought that viewed gender roles as biologically determined rather than socially assigned and by legal doctrine that defined women as the property of men" (p.237).  Disabled people, like other marginalized groups, including gays and lesbians, are challenging oppressive constructions of their identity within institutional settings and through codifications in law.

Increasingly, disability has come to be understood as a form of social oppression experienced by people with perceived impairments and manifested in discriminatory practices. This is frequently referred to as the “social model” of disability; it is distinct from the more traditional emphasis on biological impairment, termed a “medical model” of disability, which individualizes and pathologizes the disability as a deficit residing within the person. Disability rights activists believe that overemphasis on the medical model has detracted from full citizenship for disabled people. The development of disability activism based on the social model, characterized by the identification of disabling barriers and creation of enabling environments, combined with the academic perspective of disability studies, allows for an analysis of structural factors, on the one hand, and the agency of disabled people and their allies in changing those structures, on the other (Priestley, 2001).

While disabled feminist researchers and activists acknowledge the significance of social model analysis, many have contested the “maleness” of this approach and have found especially inadequate its tendency to deny the personal experience of disability. They have argued it made good political sense, initially, to marginalize the “embodied” experience of disability because biological arguments, traditionally, have been used to legitimate social exclusion. But they have urged disability researchers and activists to learn from feminist methodology, to locate movement politics in the famous feminist principle, that “the personal is political”, to give voice to the subjective experience of disability (‘what it feels like here’) rather than on objective barriers and structures (Morris, 1992, 1996; Thomas, 1999; French, 1993).

As with other domains of social inquiry, including social work, disability studies grapples with the relationships between individual lived experience and macro social analysis. Social workers struggle to understand and theorize relations between the “macro” and the “micro”, the “individual” and “society”, a theme famously illuminated by C. Wright Mills (1959, p.226) in the distinction – and interconnection - between the “public issues of social structure” and “personal troubles of milieu”. Such concerns are increasingly critical given the current restructuring and reshaping of the welfare state.

Significantly, disabled people themselves have often led this struggle for social justice, but among their allies are the hundreds of activist parents whose struggle at an individual level for their own son or daughter launched national organizations, including the March of Dimes, Easter Seals, Muscular Dystrophy Association, and Associations for Community Living. They all have, in general, focused on promoting quality of life and personal rights for people with disabilities and their families in the community.

These allies are typically represented in the literature as parents’ organizations or movements (Anglin & Braaten, 1978; Dybwad, 1990). However the reference to “parent” obscures the gendered nature of the role for it has been mothers who have been at the forefront. Only recently has their contribution begun to be recognized. The Fiftieth Anniversary project undertaken by the Ontario March of Dimes (1999) solicited personal stories to commemorate the “Marching Mothers” whose door-to-door efforts raised funds to find a cure for polio and built a highly visible, national organization.

> The first Mother’s Marches in Ontario were held in Toronto in the early 50s. From celebrity endorsements to local media campaigns to the ringing of fire alarm bells

> from the centre of town, everyone in the community got involved. Right after dinner, when "father was home", women went out to their neighbourhoods with their pickle jars or canvassing kits and made their calls (often socializing along the way). Homes welcoming Marching Mothers turned on their porch lights to signal their support (Hawke, 1999).

However many hundreds of mothers marched in the 1950s, Andrea Spindel (Executive Director, Ontario March of Dimes) claimed it took 40 years before a woman was elected president of the Ontario March of Dimes Board (telephone conversation, February 21, 2002). Informal and anecdotal evidence (Hawke, 1999; Raina, 2000) suggests it is unlikely that this is a unique pattern among parent-led disability organizations. Even though it is over fifteen years since parenting a disabled child was framed as a feminist issue, with the goal of integrating the women's movement with the disability rights movement (Blackwell-Stratton, Breslin, Mayerson, and Bailey,1988), there has been no research to date that has applied a gendered lens to parent-led disability organizations.

## Purpose and Goals of the Study

This study examines the changing role of women in the Canadian Association for Community Living (CACL) by exploring its origins, evolution and development. CACL is a grass-roots movement that operates nationally as well as provincially (there are 12 provincial Associations in the federation). Activists may be found at all levels although those whose work had an impact on the national organization are the particular focus of this study. It explores who were the founders, who filled the leadership positions, who did the leg work, who chaired committees, who has been represented, how this representation has been decided, and who has influenced the organizational agenda. Which functions/roles did and do women play? What patterns emerged? Who were the leaders over time? How many were women? When women were involved did it make a difference? What impact, if any, did women have on the femaleness of the organization and to what extent they were able to influence and shape its agenda historically? These will be the guiding questions of this study.

Historically, women's participation in their communities has addressed issues as diverse as temperance, child care, institutionalized neglect, local violence, the environment, settlement of new immigrants, poverty, nuclear testing, food, working conditions, racism, education and peace (Abramovitz, 1999; Reinharz, 1984; Wine & Ristock, 1991; Canadian Women's Studies, 1993; Bond & Kelly, 1984; MacIvor, 2001; Ruddick, 1995; Sangster, 2001; Naples, 1998b; Orleck, 1995). While their activities and influence have frequently led to the formation of social movements and organizations which have influenced Canadian society, women's contributions often were "hidden from history." Very few mothers' struggles in particular have been documented in the outpouring of literature recently that has tried to address this. There is virtually no scholarly work on the significant struggles for social justice and equality waged by activist mothers of disabled children.

An historical account of the origins of the parents' movement in the late 1940s traces the similarity of the key initiatives that launched parent organizations in England, the U.S.A. and Canada (Dybwad, 1990). Typically, an ad was placed in a newspaper by one mother wishing to meet other mothers of disabled children. Women were thought to be quiescent at this time, but a new site of their activism was emerging in the “space” that women inhabited - their kitchens and their households (Abramovitz, 1999). Small groups of women of retarded children began organizing across Canada (and elsewhere), beginning their careers as activists by resisting the only option open to them, to “put their son or daughter in an institution.”

These mothers protested in their neighbourhoods and schools, they lobbied governments, they went to court and they eventually founded an organization in 1958 that grew over the following four decades to include 40,000 members in 400 local chapters across Canada. Initially called the Canadian Association for Retarded Children, this grass roots movement changed its name in1968 to the Canadian Association for the Mentally Retarded and once again, in 1985 to the Canadian Association for Community Living (CACL). Each of these name changes reflected the organization’s growing mandate. Initially it focused on the needs of retarded children. The name change in 1968 reflected the expanded mandate to encompass the needs of retarded adults. In 1985, the name Community Living was adopted to fit with its broader community and social change agenda.

If the success of this movement is measured in terms of achievement of its goals, then it has not succeeded (CACL, 1987). Many policies of the Canadian state still discriminate generally against people with a disability. But success needs to be measured in terms of other benefits that have accrued. Significantly, the organization succeeded in politicizing women and adding their voice and perspectives to the growing debate about disability. Through it, many women came to speak for themselves, to confront authorities, to “tell their story”. Standing alone and separate, one from the other, faced with the power of medical and education authorities, these women might have remained marginalized and intimidated. But, through their commitment to their children, they found other mothers, and together they became challengers rather than passive subjects. Not only did they become experts in education, medicine, transportation, recreation, access and technology, they became effective community organizers. Across the country they organized into parent groups and exerted their influence on the public policy process to increase and restructure benefits for their own and other families.

## Significance of the Study

This study is important and timely for a number of reasons. In the first place, the particular women involved were not feminists; they did what they did out of a sense of “gendered obligation” (Abramovitz, 1999). In making an everyday decision to have a child they did something apparently very ordinary; however, a diagnosis of “disability” turned what appeared ordinary into something significantly different and much more complex. The research explores what “getting active” meant to these women, even if they did not see themselves as “activists”. When I asked one mother who was not part of this study if she considered herself an activist, she said, “I hope you mean that as a compliment.” Kaplan (1997) reported a similar distinction in her study in which mothers described the grassroots work they did as just doing what needs to be done, and not about “politics”. Ruddick (1995, p. 224) suggests this “politics of resistance” arises when women who take responsibility for “caring labour” find themselves “confronted with policies or actions that interfere with their right or capacity to do their work”, thereby impeding their ability to perform the womanly duties they have accepted and that are expected of them. Yet they may also be seen as “activist mothers” to the extent that their activities and sphere of influence set an example for their children and others in their community (Naples, 1998b). Their “work” included demonstrating and explaining how discrimination, prejudice and exclusion limit opportunities for people with disabilities; in so doing, they engaged in a form of participation that is, in many ways, a model in a struggle for progressive social change. It is now a commonplace in the academic literature that women have traditionally been left out of our historical record. This study offers another way of writing them in, adding to the growing scholarship on women’s activism, acknowledging its contribution to our history (Sangster, 2001; Cook, McLean and O’Rourke, 2001; Wine & Ristock,1991).

Secondly, this work is important because becoming active and getting political are still not the cultural roles society expects women to fulfill. “One of the most consistent themes to emerge from feminist analyses of women’s political praxis is the significance of constructions of community for women’s politicization and social action” (Naples, 1998a, p.331). Certainly facilitating parent-to-parent support programs (or, to be more accurate, mother-to-mother support) has been a fundamental organizing principle in the Canadian Association. The study explores the significance of this mutual support strategy in light of Naples’ assertion that central to all research on women’s community activism has been the significance of women’s social networks and their constructions of community for their political work. It is important to know how the possibilities for women’s activism are organized, especially during a period such as the current one of conservative backlash and declining morale on the part of those directly affected by reductions in programs and benefits. An important line of inquiry includes how the organization enables (and sometimes limits) activists’ skills and insights, the extent to which activists are able to shape the organizational agenda for action, and ways in which gendered differences in organizing styles are registered (Bond & Kelly, 1984). Additionally, it explores how mothers learned to distil their own gendered socialization so that when “polite” attempts to secure services for their children failed, given limited resources and their own as yet undeveloped capacities, they developed new and stronger tactics (Saini, 2001). They took risks and strategies, including those of direct confrontation of authorities, for which they withstood criticism and unpopularity often accorded to social activists. The study, in this context, investigates the extent to which their experience as activist mothers not only exposed their family life to criticism but also violated the cultural norms prescribed for women of their generation (Orleck, 1995).

Third, this study is important by virtue of its examining the largely unexplored terrain of the connection between how women translate the consciousness they develop through daily interactions with their communities and the state into a force for affecting political action. Just to care adequately for their children, they have confronted formidable social forces and a cultural ethos of ableism and discrimination in the context of political powerlessness. Catalysts for women’s politicization and resistance strategies can be located in actions or inactions of government or agencies of the state, official or informal policies and discriminatory practices of school personnel, health care providers, and social service staff. Yet activist mothers have become a vital force shaping advances in disability policy and providing lifelines of information to other parents (Wickham-Searl, 1992). This highlights the contradictory nature of the state as an oppressive set of institutions and yet as a terrain of political struggle. This is a key theme in research on women's community activism which will inform this study (Abramovitz, 1999; 2000).

Fourth, the study contributes to the growing scholarship in disability studies. By focusing on the social and historical context of disability activism, it turns the focus of research away from how individual families react to having a child with a disability towards the social and historical factors that shape that reaction (Hirsch, 1998; Longmore, 2003). It points to the interconnection between the existence (or lack of) organizational resources and capacities and the way families interpret and understand the meaning of disability (Ferguson, 2001). And it puts the onus on policy, away from how families respond to disability towards how society responds to families. This is especially relevant today when families and their disabled family members are not able to make new advances; gains are being rolled back or, at best, defensively held onto; policy changes that have been on the agenda for years are at an impasse. The activism of these mothers can illuminate how the restricting experiences that other mothers and their children continue to face are socially and politically constructed, and how they might be changed by social and political means.

Fifth, this study contributes to our theory of knowledge. As social work educators it is important to complicate and challenge the notion of knowledge and what knowledge is assumed to be. Critical intellectual inquiry recognizes that certain voices get silenced in academia as they do within the wider society where we practice. We see knowledge as a contested space where dominant groups in society enforce a dominant position by being producers of knowledge, often by making subordinate groups the objects of their knowledge (Hartman, 1992; Hill-Collins, 2000; Smith, 1987). Activist mothers learned the power of speaking from experience and, as such, they offered a challenge to bureaucratic and medical forms of knowledge. Their activist work included "arguing their child in from the margins" (Read, 2000, p.120). This study explores how mothers, faced with constantly having to present an alternative view of their child to the world, became more confident and outgoing in what they knew and the authorities did not. It considers how they came to identify with other vulnerable groups asserting similar claims. It examines how they came to recognize that knowledge is power and how the power imbalance in forms of knowledge keeps them and their families in a subordinate position.

Finally, this study attempts to illuminate and deepen our understanding of how ordinary homemakers have become activists though the experience of having a disabled child, how they overcame the obstacles associated with the denigration of mothers' care-giving work in society and the stigma which attached to them as mothers of disabled children; how they developed leadership skills in the context of working as part of a community and how they came to recognize that individual efforts alone are not enough to effect systemic change. The odds they were up against were considerable: popular opinion, traditional values, cultural practices and social policy. As they struggled to overcome these, there is no question that mothers' experience within the organization in which they acted transformed their lives in profound ways.

## Overview of the Study

A qualitative process of inquiry and an historical approach provide the methodological framework for the analysis. In this study it is a significant matter that mothers are naming and relating the experience themselves. The approach is informed by feminist scholarship and its recognition of gender as a category of social experience.

The research design utilized an historical investigation of 40 years of organizational records and archival documents of the Canadian Association (1958-98) as well as extensive interviews with three key informants who served as “expert witnesses” representing other mothers in the organization. Each of these three women became active as young mothers shortly after their disabled child was born and are now nearly eighty years of age. Through archival research and extensive interviews I investigated the major campaigns led by these three nationally recognized activist mothers, the campaign to close institutions and the campaign to secure human rights. I analyzed the path that led them from private circumstances to public leadership, and looked at what prompted them to move from the personal to the political.

The study is organized into eight chapters. Chapter One presents a review of the literature. Chapter Two provides the research design and methodological framework for the study. Chapter Three sets the historical context and examines the first ten years of the Association, from1958 to 1968, in which women’s gendered roles are analyzed along three dimensions of organizational life: volunteering, governance and fundraising. Chapter Four introduces the activist mothers through their biography. Each woman’s account is organized through a series of life course events and external influences to understand the antecedents to and the motivations for their activism. The chapter presents their activist activities at local and national levels and concludes with an examination of their activist skills and styles. Chapter Five and Chapter Six critically investigate their activism and success in leading two major campaigns, closing institutions and securing human rights, through the organization in which they "lived." These chapters explore how activist mothers negotiated an organizational environment rooted in a gendered division of labour which recognized women's support roles but not necessarily their leadership. Chapter Seven provides an analysis of narrative accounts of activist mothering in the Canadian Association and reflects on how the experience of activist mothers of disabled children might contribute to knowledge on women's grassroots leadership and struggles. Chapter Eight concludes by presenting key findings of this study and implications for disability studies, social work, social policy and women's activism.

The everyday world of activist mothers and their experience grounds the work; The three "expert witnesses" provide the "standpoint sample" used as the site of inquiry (Smith, 1987) for investigating the relationship between the experience and knowledge of activist mothers and the broader practices of administration, institutional and gender relations with the organization they founded. This inquiry is about the lives of women who risked challenging accepted traditions as social activists in order to provoke change. They contribute to the "mounting pile of historical studies of women's activism on the left – and on the right – that continue to question the myth of women's passivity" (Rowbotham, 1997, p. 3).

The term “social activism” denotes a struggle to toward greater equality. These participants experienced inequity as mothers through the experience of disability, and they contested the existing order to decrease inequities that result from the stigmatization of people with disabilities.

They did not start out to change the world; they started out trying to secure better services for their children. They became “accidental activists” when they reached a turning point, a disjunctive moment, a transformational node that expanded their consciousness beyond themselves and their own situation to include a wider web of associations with others. They acted initially, motivated by their identity as mothers in the private sphere of the family. But as they came to view the forms of injustice that encompassed children with disabilities and their families more broadly, they learned to mother as activists in a more public arena. Even then the label of “activist” did not always sit comfortably.

In their foreword to Guida West’s (1981) history of the national welfare rights movement in the United States, Piven and Cloward wrote about the significance of grass-roots movements:

> They are important because they can transform the lives of people who join them and because they can transform the society that gives rise to them. In other words, movements from below help make history (p.vii).

While this study will not be able to examine this subject exhaustively, it is conducted in the hope that it might begin to shed some light and point the way for future, more extensive research.

# Chapter One

# Literature Review

The literature review on activist mothers of disabled children will be divided into five sections as follows: 1)Therapeutic Approaches to Mothering; 2) Theoretical Frameworks of Family Support and Family-Centered Services; 3) Care-giving and the Gendered Nature of Caring; 4) Feminist Analyses of Women's Activism and 5) Research on Gender as a Feature of Organizational Life.

The first section will provide research relative to therapeutic approaches to mothering disabled children that focus on personal and psychological variables to the exclusion of social and cultural factors. The second section will define and provide a brief overview of the theoretical underpinnings of the concepts of "family support" and "parent-professional partnerships" as they relate to gender. The third will address the literature on care-giving and cultural stereotypes of women as "natural care-givers". The fourth section will explore literature sources that theorize and document democratic struggles by mothers in grassroots movements to help provide a framework for investigating activities of activist mothers of disabled children. The fifth section will review the literature on gender as a feature of organizational life.

## Therapeutic Approaches to Mothering

Much of the research on mothers of disabled children takes a therapeutic approach. It tends to highlight individual faults and deficits by focusing on personal and psychological variables. In so doing, it excludes a consideration of broader social and cultural factors and the ways in which families might be supported (Read, 1991). In this literature disability is seen as a personal tragedy, a view which logically concludes that personal rather than social solutions are required (Bowman & Virtue, 1993).

One recurrent theme is “mother blaming” and the characterization of “bad mothers” (Ladd-Taylor & Umansky,1998; McAnaney, 1990; Panitch, 1991; Roeher, 1993; Miller, 1994; Swift, 1995; Bowman &Virtue, 1993; Traustadottir, 1988; Olkin & Pledger, 2003; Gill, Kewman & Brannon, 2003). These sources document the many ways of becoming a “bad mother” where disability is concerned. They report ways that mothers are assigned fault for producing the disabilities in the first place or for failing to have a healthy child. They also enumerate many dimensions of attributing blame: pre-natal (for eating poorly, smoking, drinking alcohol, refusing an amniocentesis); emotional (for maternal deprivation, as depicted by the term “refrigerator mothers”, used in 20th century psychological literature to refer to mothers of autistic children); psychological (for being overprotective or overly concerned); biological (for waiting too long to have children); selfishness (for placing their child in an institution, even though there were no resources in the community); aggression (standing up to authorities to defend their child’s right, for example to go to school) or making “poor choices” (living in conditions that make one a “bad mother” - poverty, social assistance, out of wedlock). All these reasons are adduced to justify a less compelling right to aid and services. Hillyer (1993) even finds traces of evidence of mother-blaming among disability advocates of the independent living movement, putting them in the same corner as paternalistic professionals. She suggests that mothers of disabled children are held more accountable than other mothers to an externally defined concept of mothering because of their increased contact with social agencies. This is even more the case when a woman is a single mother (Gottlieb, 1997).

An important genre are the many first person accounts written by mothers to document their own family's personal story. These significant sources provide vivid testimonials to their experience and adjustment (Buck, 1950; 1965; Evans, 1953; Roberts, 1968; Ferr, 1978; Mancini; 1977; Stigen, 1976; Bondo, 1980; Dickerson, 1978; Wilks, 1974; Klein, 1975; Moise, 1980; Jablow, 1982; Marsh, Bowman and Boggis, 1995). When Dale Evans and Pearl Buck wrote about life with their disabled child in the early 1950s, these were rare personal disclosures at the time which encouraged other mothers to speak out too.[2] Importantly, these accounts lent authority to the ongoing struggle to claim the "problem" of disability as a "public issue", and not hide it away as a personal "private trouble" (Mills, 1959).

Later, autobiographical accounts provided more sophisticated information and strategies related to how mothers needed to become health experts, educators, advocates, negotiators and organizers as they sought a community-based solution (Hillyer, 1993; Featherstone, 1980; Schaefer, 1982; Edelson, 2000; Bowman &Virtue, 1993; Miller, 1994). Frequently, they also described their need for support and assistance and their elevated levels of stress (Turnbull & Turnbull, 1985; 1986; 1990; Mittler & Mittler, 1995; Meyer, 1995; Todd & Shearn, 1996; Stehlik, 2000).

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[2] Notably, CACL invited Dale Evans to be the keynote speaker at one of its earliest conferences in Vancouver in1962, no doubt expecting she would give families hope and ideas.

Many authors emphasize the stages and processes of adjustment to the realities of having a disabled child, and while they identify ways in which mothers play a positive role in their child’s life, often that is a subsidiary theme (Miller, 1994; Featherstone, 1980; Hillyer, 1993; Case, 2000). Miller articulates four stages of “adaptation” which include surviving, searching, settling in and separating. Jones (1989) locates the difficulties families confront in society’s values and attitudes, the additional responsibilities that come with having a disabled child and the need for additional resources. Lewis, Kagan, Heaton and Cranshaw (1999) note the additional pressures that come with multiple roles played by single mothers.

Ferguson, in recent research on families (2001), conceptually maps four decades of professional literature related to parental adjustment. That he made no reference to gender may have been based on what he found. Moving chronologically from the 1960s forward he identified four categories: i) the psychodynamic approach: the neurotic parent; (ii) the behavioural approach: the dysfunctional parent; (iii) the psychosocial approach: the suffering parent; and (iv) the socio-political approach: the powerless parent. He noted that even though dominant social worldviews of any era contribute to the development of new policies, those policies rooted in the past do not simply disappear, and so remnants of them all tend to co-exist even as important shifts in thinking are taking place. To take one example, Olshansky’s (1962) concept of chronic sorrow permeated professional thinking for decades and while this legitimated whatever sad feelings mothers might experience, it gave little hope for future happiness. This theme still appears decades later when the social and contextual approach to disability is widely embraced. Hillyer (1993), as an example, combines first-hand experience and academic knowledge to describe her personal chronic sorrow and grief and, by extension, that felt by mothers of children with severe disabilities everywhere.

## Theoretical Frameworks of Family Support and Family-Centred Services

During the last decade, social work theory as applied to families with disabled children has undergone a number of significant shifts. These have resulted in several parallel shifts in social work policy and practice. One noted development is reflected in the gradual movement away from the traditional medical orientation of chronic “illness” models toward a theoretical framework in which individual and familial strengths are accorded greater emphasis than perceived deficits (Dunst, Trivette and Deal, 1994; Singer, Powers and Olson, 1996; Itzhaky & Schwartz, 2000).

A related shift from an individual or child-specific focus to an environmental context has resulted in children with disabilities beginning to be understood in relation to their families and support systems, as well as in the broader social, political and economic contexts (Turnbull &Turnbull, 1986; 1990).

The transition from child-centred to family-centred service delivery provides an important alternative framework for working with families caring for disabled children. However, despite the transition to more family-centred and family empowerment models of practice, a closer examination of the theoretical literature on family support reveals the lack of any critical examination of the role of gender within these families (Turnbull & Turnbull, 1990; Turnbull, Patterson, Behr, Murphy, Marquis and Blue-Banning, 1993; Case, 2000; Lipsky, 1987; Seligman & Darling, 1997; Farber, 1986; O’Connor, 1995;

Sherman, 1988; Singer & Irvin, 1989). This research has informed policies and practices directed towards families of children with disabilities, yet it has been based on a view of the "family" as a single unit, and often the smallest unit of analysis. The shift in focus from the individual child to the broader environment does not appear to incorporate sufficient awareness of gender, thereby ignoring the difference in activities and experiences of individual family members.

Studies investigating the partnership relationship between parents and professionals report a focus in research and practice on cooperative approaches in which parents are involved in their child's education and care. But even recent studies still report that parents experience dissatisfaction as they encounter professionals who dominate through their various areas of expertise (Dunst et al., 1994; Gartner, Lipsky and Turnbull, 1991; Nemzoff, 1992; Turnbull & Turnbull, 1990; Turnbull et al., 1993; Seligman & Darling, 1993; Case, 2000; Dale, 1996). Brynelson (1984; 1990) argues that the relationship between parents and professionals, rooted in a power differential, is imbalanced from the start and often results in parents feeling insecure, overly dependent on professionals and resentful at being expected to adopt a teaching role with their children. Stehlick's (2000) study of parents caring for children with intellectual disabilities in Western Australia over five decades (from 1945 to 1992) located "sites of struggle" and tension between private knowledge and public knowledge. She identifies that from the moment of diagnosis, and throughout life milestones, parents reported a subordinate power relationship with the state and its privileged "expert" determination of services. Case (2000) similarly identifies professional control of the relationship based on knowledge, expertise, and power which thwarted parents' ability to advocate. But none of these studies take gender into account.

Traustadottir's work (1988) provided an early consideration of gender. She noted that when researchers studied families they usually interviewed mothers, but when they came to write up their findings, they typically referred to parents' views, thus rendering mothers' experiences invisible. She investigated the expectations of service providers working with mothers of disabled children and discovered a series of cultural stereotypes based on the notion of the selfless giving mother devoted to her child's welfare, which she concluded put tremendous pressure on mothers to conform to professionals' idea of who they should be. She found that if a mother, for example, expressed resentment at having to assume most of caring for the child (i.e. doing the work), professionals inferred she did not "care about" the child. Mothers who did not live up to a service provider's expectations, risked being denied services or having her child taken away. Traustadottir reported that service providers had different expectations of fathers. Fathers were expected to provide an adequate income and support the mother's dedication. Those, who in addition were involved with their child, were deemed "exceptionally wonderful". Fathers who were not involved were excused: "that is what the father is like; we cannot force the fathers".

McConachie (1994) suggests that in the early 1980s "parents as partners" was the popular slogan in child disability services but was never realized, partly because "parents" in fact, meant "mothers" who were the focus for service providers. She reports, with Brynelson (1990), that the strategy to educate mothers how to teach, feed or manage child behaviour and to assume a multiplicity of roles in addition to parenting, made the home a site of intervention and placed family integration at risk. Dale (1996), working with families in London, England, likewise notes this failure, and suggests that an assumption of partnership is more an illusion that does not reflect real-life encounters.

Historically, the relationship was defined in terms of professionals as “experts” who “transplanted” their skills to parents who would then become co-educators. Both approaches afforded professionals a range of powers based on access to resources, position and expertise, leaving parents with only the more informal personal power, or physical power to level the playing field. Gartner et al. (1991) suggest efforts to involve parents failed because they were based on a deficit model in which the disability becomes the focus of attention to the exclusion of the environmental and social context, and where professional blame parents, frequently mothers, for the ills of the child. Bowman and Virtue (1993) interviewed ten mothers and considered the public policy implications. They noted the extent to which women’s care-giving responsibility is disguised by bureaucratic jargon and how homogenising terms like “community care” and “carers” obfuscate the issue of gender in such relationships. Hillyer (1993, p.87) also noted the practice of rendering mothers invisible and suggested that although the situation seems “ripe for feminist analysis” such has not yet been attempted.

## Care-giving and the Gendered Nature of Caring

A significant body of research on care-giving is based on the assumption that mothers have the primary responsibility toward family and motherhood. Studies reflecting the cultural stereotype of mothers as the natural care-givers are numerous and do not treat this as a problematic issue. Significantly, this literature explicates the invisibility of so much of the caring work done by women and the mental, emotional and physical costs they bear in looking after a disabled family member. This invisibility relates to perceiving mothers' efforts as an expression of "love", not work, and the expression of a womanly, feminine character that renders the work itself, including the planning, orchestrating, coordinating and managing, as literally invisible. Ironically, the more skilfully and successfully the work is done, the more invisible it is (Traustadottir, 2000; Wickham-Searl, 1992; 1994).

Even when research focuses specifically upon mothers, many studies continue to perpetuate traditional beliefs by assuming that "parenting" is synonymous with the "mother" and by subscribing to traditional values and cultural stereotypes related to the "gendered" nature of caring. Traustadottir (1991) found that parents evaluated the impact of disability on the family not in terms of the actual nature of the child's impairment but on the restrictions or limitations it imposed on the family in functioning as a family unit. Significantly, the majority of parents did not seem to define it as limiting to have a child with a disability insofar as it only limited the mother's life; those restrictions were taken to be a "normal" part of a traditional mothering role. Ruddick (1995) conceives of mothering itself as a kind of caring labour, one that involves "work" and a set of practices, challenging the myth that mothers are "naturally" loving. By construing mothering as work, and not identity, she suggests the maternal thinking that goes into child rearing has the elements of a "distinct discipline". However, her universalizing tendency towards "ordinary" mothers and "normal" child development ignores the particular experience of mothering a child with differences.

Research on women’s informal caring tends to emphasize the deleterious impact of having a child with a disability on the parent and parent-child relationship. Even when this research acknowledges how, for some mothers, this may be a source of deep satisfaction and pride, it also emphasizes the extent to which such labours of love come with the suppression of other capacities and desires. Lewis et al. (1999) studied 40 families with at least one disabled child and found that mothers’ caring roles are still largely constructed as excluding employment possibilities.

More recent literature on care-giving embraces greater complexity. It addresses various dimensions of becoming a care-giver, including who the care-givers are, what activities are involved in informal and formal caring, how care-giving influences the life of the primary care-giver, the stresses and rewards, multiple responsibilities, class barriers faced by between care-givers as well as feminist theorizations of caring (Baines, Evans and Neysmith, 1993; Hicks, 1988; Ungerson,1987; Grant, Rancharan, McGrath, Nolan and Keady,1998; Traustadottir, 1991; Jones, 1989; Hillyer, 1993; Finch & Groves, 1983; Lewis et al. 1999; Stehlik, 2000; Cranswick, 1997; Panitch, 1991; Roeher, 1993;2000; Fisher & Tronto, 1990).

A number of researchers recognize care-giving as an important site for further feminist discussion of dependence and difference (Hillyer, 1993; Kittay, 1999; Fisher and Tronto, 1990; Keith 1992; Morris, 1991). Fisher & Tronto (1990) attempt to reconceptualize a theory of caring, noting the contradictions between the naturalistic dimension of caring that flows from individual motivations and sense of duty and the extent to which the practice of caring oppresses and exploits women. Keith (1992) writing as a disabled woman, laments the missing voices of disabled people in those debates.

A few important articles that attempt to reconceptualize disability and dependency, (Keith, 1992; Morris, 1991; Fisher & Tronto, 1990). Keith (1992), like Fisher and Tronto (1990), are mindful of the potential for changeable status between care-givers and receivers and seek to theorize a more reciprocal relationship. Kittay (1999), who is herself a philosopher and theorist on women's equality as well as a mother of a disabled daughter examined "dependency work" and concludes that while the care of dependents (children, people with disabilities and elderly people) is not exclusively the province of women, to call this work of caring "parenting" rather than "mothering", is a "gross distortion that serves women poorly" (p. xiv). In her own work she adopts the feminist practice of calling the care of a child, "mothering", and acknowledges that fathers, too, can be excellent "mothers".

Several authors attempt to explicate the terrain of mothers' activity in terms of careers that started by trying to get their own children's needs met and then carried into disability work more broadly (Traustadottir, 2000; Wickham-Searl, 1992; 1994; Darling, 1988; Kittay, 1999). In their research, however, "disability work" does not extend to mothers' involvement in political or activist work. Traustadottir (2000) examines the processes that recruit women for care work and the network of social and economic relations through which caring is socially organized and constructed. While she accepts that women's socialization for care work relates to the formation of gender identity, she de-emphasizes caring as part of woman's nature and locates it in social interaction. She categorizes the activities through which mothers extend their caring beyond their child to embrace advocacy and lobbying, and concludes they are more like those of a professional career than traditional mothering work. Wickham-Searl (1992; 1994) studied mothers who, diverted from their original careers because of the demands of care-giving, sought professional credentials to build upon the expertise they acquired in the line of duty. Disillusioned with the “experts” they confronted, they came to believe that acquiring a professional status themselves would strengthen their negotiating position on behalf of their own and other disabled children. Darling (1988) identified a series of stages or career moves as situational “turning points” when parents became engaged with advocacy or activism. Kittay (1999) defines the multiple levels at which parents have to work, including socializing the child for acceptance of the world while socializing the world so that it will accept the child. A self-proclaimed activist in many social justice struggles, she reflects (albeit inconclusively) on her reluctance to join in struggle with other parents of disabled children.

A recent study (Read, 2000) of 12 mothers in England analyzes the “mediating” role of mothers who act as buffers between various professional gatekeepers and institutions, and their children. Read suggests that the children indisputably changed mothers’ views of the world and of themselves, and the mediation role equipped mothers to act in a more informed and skilful way. But the analysis did not report any recognition of a need for collective action to challenge forms of exclusion that would continue to obstruct their children’s lives. These forms of exclusion take place in daily interactions with community day care programs, schools and recreation centres - all supports that are designed to augment a family’s care-giving capacity, exclusion from which is absorbed by mothers (Irwin, 1992; Roeher, 1993). There is a gap to be filled in the research that will enhance greater understanding about how other mothers with disabled children are prompted to assume an activist role to challenge the structures that exclude their children, and how this develops their capacities and desires.

## Feminist Analyses of Women's Activism

Key themes in the existing literature related to women's activism address questions of i) personal growth, ii) what prompts mothers to become activists, iii) the spaces women occupy and from which they organize, iv) networking, v) leadership vi) how women view their activist roles, vii) the relationship between women's activism and gender expectations, and viii) how women's activist work is supported by organizations.

### Personal Growth

Social movement literature may be drawn on for its research and narratives detailing personal growth and change as a consequence of social movement experiences and activism and the extent to which it frequently causes an upheaval in how women activists define themselves (Herda-Rapp, 2000; Reinharz, 1984; Kasnitz, 2001; Abramovitz, 1999; Orleck, 1995).  Several authors (Brown & Ferguson, 1995; Farenthold, 1988; Morris, 1984) suggest that women are the predominant actors across social movements.

Herda-Rapp (2000) reviews the literature on women's activism in the toxic waste movement and points to a number of important shifts as a result of women's participation including the formation of new relationships and friendships; enhanced political awareness, greater self-confidence and assertiveness; higher rates of separation and divorce; empowerment leading to a critique of patriarchy and gender roles. Her own research extends this analysis and examines how the effects of activism (the degree of that change and whether it is subtle or dramatic) are mediated by past experience, the openness of opportunities within social movement organizations, and gender identity. Orleck's (1995) collective biography of four Jewish immigrant women radicals identifies how in choosing to devote themselves to activism, they became "outcasts" from conventional life, forcing them to create alternative families and emotional support networks.

## What Prompts Mothers to Become Activists

A series of studies investigates why women who assert their identities as wives and mothers according to their cultural traditions become activists in social movement struggles (Reinharz, 1984; Herda-Rapp, 2000; Kaplan, 1997; Abramovitz, 1999; Naples, 1998a; 1998b; Orleck, 1995).

Reinharz (1984) documented working class women's activism and found the reasons fairly traditional housewives became engaged in neighbourhood activism related to concrete problems that affected them and their families, which she linked as "welfare-of-the-family–in–the-home-in–the–neighbourhood"(p.26). Herda-Rapp (2000) found that it was women who became the predominant actors in toxic waste struggles because the health of their children, families and neighbourhoods is threatened. Kaplan (1997) studied women in grassroots movements (i.e. outside the control of the state, church, union or political party) to understand how leaders, accepting their roles as wives and mothers in their culture and historical period, become activists to ensure food, clothing, housing and health care for their families. In so doing, they acted in accordance with “female consciousness,” a term she locates as a cultural trait, not a biological one (1997, p.185). Kaplan uses “female consciousness” to describe activism targeted to family and community needs by low-income women who accepted their socially defined wife and mother roles (as distinct from feminist consciousness and its focus on women’s equality).

Relatedly, Abramovitz (1999), conceptualizes social welfare activism as the “interplay of consciousness, objective conditions, and the wider social context”, and suggests such women are acting out of a sense of “gendered obligation” (p.223). Naples, who describes this form of activism as “activist mothering”, focuses on women’s work in the community to chronicle how women “build political houses” for the collectivity, rather than for their individual benefit. Drawing upon biographical narratives and everyday practices of community workers in New York City and Philadelphia, she defines “activist mothering” in terms of “political activism as a central component of mothering and community care-taking of those who are not part of one’s defined household or family” (1998b, p.111).

Ruddick (1995, p. 222) considers how maternal practice at times becomes a women’s “politics of resistance” which share three characteristics: the participants are women; they explicitly invoke their culture’s symbols of femininity; and their purpose is to protest certain practices or policies of their governors. Invoking their maternal duty to protect their child’s health and education, they may, for example, call on governments to stop nuclear testing, produce sufficient and affordable food, ban conscription, stop interfering with local schools. In her book, she draws on the example of the Madres of the disappeared in Chile and Argentina who bring pillowcases, pictures and toys to public plazas and "translate the symbols of mothering into political speech" (1995, p. 229).

Orleck (1995) found in her study of working class women's activism, that the organizers did not believe "home" existed in isolation from "the marketplace, the unions and the government" (p.7).

## The Spaces Women Occupy and from which they Organize

To theorize a framework for women's activism Abramovitz (1999) focuses on the history of black and white low-income women in the United States during the 20th century. To "bring women to view", she illuminates the "spaces" inhabited by women and gendered modes of activism. These include the welfare state (where they have acted to secure housing, adequate incomes and affordable food); the workplace (where they have challenged segregated occupations, inadequate working conditions and wages); and the community (where women have mobilized for economic security and racial justice). The centrality of gendered spaces, women's kitchens and domestic households, are noted as key sites of women's work. She argues that any investigation of women's organizing, leadership and activism must look at individual acts of resistance, including the "hidden politics of life"; collective social protest with its common action and pooled energies; as well as the more highly organized social movements at national and local levels including the bridging work of the "unheralded female foot soldiers"(pp. 221-223).

Naples (1998b) notes that in tracing their path to activism, some women expressed an appreciation for their mothers who contested negative stereotypes of marginalized groups in the media or social policy discourse because they transmitted important lessons on to their children or younger members of the community. She suggests, citing bell hooks, that handing down this knowledge from generation to generation, becomes a mothering practise that locates the home as “a site of resistance”. Similarly, Powers (1996) points to an important association in her research between parent advocacy and the disability rights movement. She traces the skills, commitment and perseverance acquired by many disability activists back to their early experiences in families who fought to create opportunities for their children to attend regular schools and become active members in their communities.

Abramovitz (1999) examines the tensions that arise from the impact of the social isolation of women’s care-giving, the ghettoization of disability policies and programs, and the growing gap between the legislative and constitutional assurances of equality and the harsh reality of people’s lives. These illuminate the contradictory role of the state which contributes to women’s activism. Fisher and Tronto (1990) suggest that feminists, “committed to making justice, equality and trust” part of all life activities, might find status in the household as a site for caring work. However, they argue, individual households are not well located to challenge the social, political and economic factors that shape the way caring is conducted. Instead, such factors may prompt women to go outside their own boundaries to improve structures and secure needed resources affecting caring activities such as by mounting a welfare rights campaign (pp.50-51). Blackwell-Stratton, Breslin, Mayerson and Bailey (1988) call for feminists to include mothers of disabled children in the women’s movement because their lives radically extend traditionally perceived boundaries of motherhood and point to a shared political agenda for child care and education.

### Networking

A number of studies report the importance of informal and relational groups for women’s activism (Reinharz, 1984; Naples, 1998a; MacIvor, 2001; Orleck, 1995; Kaplan, 1997). Reinharz (1984) found that women’s efforts to build responsive community settings rely heavily on networking for action and challenging the status quo. Naples (1998a) notes that one of most consistent themes to emerge from feminist analyses of political praxis is the significance of constructions of community for women’s politicization and social action.  MacIvor (2001) examined why women participate in unconventional rather than conventional political activity and identifies that they are more comfortable in less formal and hierarchical groups, that ad hoc activities are more easily combined with child care, and that male dominance of political institutions has led to an inhospitable environment where women have been regarded with suspicion if they try to leave their gendered roles. Orleck (1995) notes the importance of friendships as key in framing activists’ vision of social change, and suggests that the 1911 cry for “bread and roses”, in many ways foreshadowed the 1960s slogan, “the personal is political.” The feminist literature notes that the networks are built on the connections made during daily activities and places that women frequent as they carry out their gendered activities in parks, schools, child care centres, and markets. These spaces women occupy due to the gender division of labour in the home and community serve as “nodal points” (Kaplan, 1997), key places where political demands and social needs converge (Smith, 1987; Naples, 1998b; Abramovitz, 1999).

Krauss (1998) notes that as individuals move from subjective grievances to challenge dominant ideologies they develop an oppositional or critical consciousness. She attributes this to the everyday practice of mothering, in which informal networks emerge for comparing notes and experiences and for developing a shared body of personal empirical knowledge. Krauss interviewed women who at first claimed to be uncomfortable in the public realm but who later came to recognize that their skills as homemakers “translated well into this new thing called organizing” (Gibb, cited in Krauss, p. 141). Through informal support networks, the women in her study participated in a process of reflection and acquired a more politicized ideology of motherhood, reinterpreting it as a resource base from which to initiate resistance.

The “sociability work” of grassroots activists to create and shape social solidarity is noted by Feldman, Stall and Wright (1998). They investigated the practice of grassroots activists who built social cohesiveness in their communities by providing essential community services. These communal structures (a convenience store, a laundromat) offered “social spaces” outside of the family where women could work for others and for themselves, build relationships, acquire “participatory competence” and recruit new members. The authors claim the political significance of human connectedness in social networks lies in its mediating role; falling between the public and private sphere, it provides the base for a new politics.

Kaplan (1997) reports that because of their loose organizational forms and informal leadership styles women’s protest activities have been overlooked. Loosely knit ties and networks are often seen as “tendencies” on their way to becoming organizations rather than “strong webs connecting politically vital local groups”; but, Kaplan cautions, hierarchical structures underestimate the strength and “continuities” in certain forms of women’s organizing (pp. 181-182).

### Leadership

A number of authors open new spaces for exploring women’s activism by applying a feminist analysis to women’s leadership in social movements (Astin & Leland, 1991); women in workplace and community movements (Bookman & Morgen, 1988); and women in grassroots movements (Sacks, 1988; Bernal, 2002). Astin and Leland (1991) move beyond traditional approaches based on leadership “traits” and “positions” to investigate women’s leadership style. Their study explores the dimensions of leadership, including style, strategy, influence, power and interpersonal relations, which bring women into view and they conceptualize a model of the leader as facilitator who enables others to act collectively towards a common goal. Bookman and Morgen (1988) broaden the definition of political terrain to include working-class women. They suggest that when women extend their familial concerns to collective political action they do so not as generic mothers but as women from historically constituted race and class groups. Several case studies explore changes in women’s consciousness as a result of participating in political struggle. They show that while working class women may reject the label “feminist” they may still develop ideas and political concerns that fall within the repertoire of feminism. These women can also come to understand and reject patriarchal domination as they organize around issues that are not solely “women’s issues.”

Sacks (1988) studied gender and grassroots leadership in a hospital union organizing drive, viewing “leaders” and “organizers” as two separate tasks. But she found that when “leaders” are defined as those who exert formal power and serve as “spokespersons” it obscures the key role women play in network formation. She calls the women leaders who exert their power more informally, “center” people and she explores the notion of “network centers” to bring into view the “centerwomen” who play a vital, though often hidden role, in network formation and consciousness-shaping. She concludes that looking at grassroots leadership through women’s eyes means redefining the categories so that centers and speakers become “functions or dimensions of leadership, and hence separate issues from who carries them out” (p. 93).

Bernal (2002) recognizes five dimensions of grassroots leadership: networking, organizing, developing consciousness, holding an elected or appointed office and acting as an official or unofficial spokesperson. Based on her study of working class women in the Chicana movement, she argues that a traditional leadership paradigm does not acknowledge those who work behind-the-scenes to organize, develop consciousness, and network; as a result, their leadership remains invisible to historians. She offers a cooperative leadership paradigm to address the absence of Chicanas as participants in history and contemporary life and to demonstrate that when women provide leadership, their leadership may be different from more conventional forms but it is “meaningful and essential” (p.228).

## How Women View their Activist Role

How women view their activist roles is a key question addressed in this literature. Women's narratives in Kaplan's study (1997) illuminate a reciprocal relationship between how their knowledge and abilities as mothers and homemakers informed their activist work, and how their politicization led them to adjust their claims as mothers to a broader form of justice related to social need. Kaplan (1997) found some leaders who did not begin by seeing the issues as being "political" at all, but rather as being about people's lives; they start by simply having conversations and in so doing foster "social citizenship" as women come together to compare notes, confront authorities, and to stand up for what they believe – all touchstones for democracy.

Naples (1998b), building on previous work, explores the extent to which activist women are driven by a commitment to "practical transformations in everyday life through collective action" and "commonsense notions of human need rather than codified laws" (1998b, Chapter 1). She uses "activist mothering" broadly and defines "good mothering" as that which encompasses all actions, including social activism, that addresses the needs of their children and community and that relates to self conscious struggles against racism, sexism, and poverty. Many of her interviewees reported (pp.124-125) a firm distinction between their activities ("just doing what needs to be done") and actual "politics" (which they took to be electoral). Yet, Naples argues, in learning to mother as activists against injustice and oppression they "challenged the false separation of productive work in the labour force, reproductive work in the family and politics", a distinction Abramovitz (1999; 2000) also recognizes in her analysis of gendered participation at points of production, consumption and social reproduction. In the case studies, Naples (1998b) explores how community work shaped women’s approach to mothering and, in turn, how their approaches to mothering influenced their political strategies. Many were initially motivated by their identity as mothers, but once active, they defied the narrower notion of work performed in the private sphere of the family thereby challenging the dominant definition of motherhood itself.

## Women’s Activism and Gendered Roles

Abramovitz (1999) and Orleck (1995) argue that women defy gender expectations of passivity and dependence when they become active politically because their activism does not fit comfortably with traditional roles of wife and mother. By violating cultural norms, they often sacrifice respect, risk living unprotected lives, and expose themselves to charges that they are failures as women. Orleck’s history of the housewives’ movement of the 1930s illuminates how working-class women, focused on consumer and tenant concerns, refused to choose between political activism and family. She notes (1995, p.10) that many of the issues that moved the mothers to action - rising food prices, poor housing, inadequate child care and birth control – were considered “private sphere” matters. Refusing to leave their politics at the front door, they organized on their street corners, kitchens, and local food markets and challenged fundamental notions of what it is to behave as a “good” wife and mother (Sangster, 2001).

Reinharz (1984) investigated women’s competence as community builders and found that many women acquired the skills to address increasingly complex issues especially when further supported by national organizations that were attuned to reinforcing women's image of themselves as active and competent. However, even as some women readily proclaimed a challenge to cultural stereotypes of women as passive and dependent, others resisted the attention, regarding their own achievements as nothing extraordinary, "just natural". One political leader profiled in Orleck's study (1995, p.10) was reportedly irritated by accolades at the end of her life, insisting "I did my share, that's all." Herda-Rapp (2000) also notes that in some instances women did not want to deliver the speeches and fell into behind-the-scenes patterns. As a result gender went unproblematized, and despite their participation as activists, few gender-equity demands were placed on spouses, activist organizations, or social institutions.

## How Women's Activist Work is Supported by Organizations

There are four studies that are particularly relevant in addressing how women's activist work may be supported by organizations. In a case study of advocacy in two women's organizations, Bond and Kelly (1984) researched how organizational variables affect the efficacy of women in roles of influence to clarify how personal styles and organizational characteristics interact. The authors located themselves in the women's movement and its commitment to women's support groups. They identified three relevant functions of social support and used these as the basis to assess the extent to which the respective organizational structure played a role in (1) enhancing women's persistence in advocacy work; (2) yielding access to multiple resources needed for advocacy; and (3) reinforcing commitment to advocacy within the organization. Their findings reveal that, in one case, ideological support (i.e. support for beliefs about the goals of the organization and a shared world view) stood out as the critical type of support associated with effective advocacy. In the second case, the extent to which the organization afforded women opportunities for personal social integration and access to resources were identified as the most critical types of support associated with effective advocacy. These findings suggest how organizational advocacy work is nourished, supported, and replenished.

Also relevant is Kasnitz's (2001) research on the relationship between peer support and leadership development in a nationwide study of the independent living movement in the United States. She identified three types of leadership styles and skills: the "motivator", the "spokesperson" and the "organiser", and developed an analytic framework based on a life course event history model drawing upon personal and contextual factors. The essential domains included: a predisposition to leadership; significant life events resulting in exposure to injustice; the onset of disability; disability stigma and discrimination; an "AHA!" experience; acquiring a disability identity; peer contact and opportunity for further peer contact leading to 'roles' in the formal or informal disability network. Although her focus was on disabled people themselves, and not parents, her inquiry is significant because it recognizes important processes that create leadership in disability organizations.

The various insights that may be gleaned from the activist mothering literature sources that theorize and document democratic struggles by other mothers in other movements help to provide a framework for investigating the activities of activist mothers of disabled children. Unfortunately, the same cannot be said for most of the literature in organizational sociology as opposed to the literature on social movements.

## Gender as a Feature of Organizational Life

A small but important body of literature focuses on the significance of gender as a feature of organizational life. The extent to which organizations permeate people's lives compels a close examination of them for the way they contribute to understandings of gender and how they produce and reproduce social relations. This literature is relevant for identifying the cultural and structural dynamics of the organization in which mothers of disabled children became active.

Mills and Tancred (1992) report that until the mid-1970s, organizational theory was dominated by a "male-stream" paradigm, and this held even when radical approaches appeared to challenge the oppressive nature of organizations under capitalism. Little is written on organizational analysis from a feminist perspective (Billing & Alvesson, 1994). The result has been to normalize the idea that women are peripheral to the public sphere.

Over the last two decades there have been a number of feminist challenges to organizational theory (Ferguson, 1984; Hearn, Sheppard, Tancred-Shariff & Burrell, 1992; Hearn & Parkin, 1992; Mills & Tancred, 1992; Gherardi, 1995). A developing feminist organizational analysis, which takes as its focus the impact of organizational arrangements upon women, has provided a competing view to the  notion of universal truth. Its quest is to discover how gendered persons are constructed and maintained in organizational settings, and to reveal the suppressed gender subtext and meanings concealed in the processes in which organizations actively participate (Gherardi,1995). Fundamentally, this analysis has challenged the notion of "gender neutrality" as a “falsehood”; providing research to prove that the dominant theories are indeed gendered and serve to perpetuate male domination and gender based social inequality (Ferguson, 1984; Hearn et al., 1989; Mills & Tancred, 1992; Hearn & Parkin, 1992).

One of the major contributions of feminist scholarship has been to take gender seriously and recover it from its invisible status within the presumed neutrality of science. Sheppard (1992) observes that revealing the genderedness of the taken-for-granted world exposes organizations to be far from “genderless” but rather, reflective of, and contributing to, the prevailing societal gender structure. The question of gender in relation to organization structure and power has typically been considered in terms of employment and the barriers to women’s participation at a range of levels, and with regards to sexual harassment (Sheppard, 1992). Mills and Simmons (1995) locate discriminatory organizational practices in the failure to promote women to top positions which insinuates that leadership qualities are a masculine trait; pay inequities which contribute to the notion that womanhood is less than manhood; and organizational arrangements which create numerous contexts in which men occupy the only positions of power and authority.

Mills and Simmons (1995) trace the development of feminist organizational analysis starting from those studies which accept managerial assumptions and seek to include more women in management (Mikalachki, Mikalachi and Burke,1992; Davidson & Burke, 1994; Billing & Alvesson, 1994; Tanton, 1994); to more interpretive perspectives which concentrate on women’s understandings of reality (Gherardi, 1995; Hearn et al.,1989; Mills & Tancred, 1992 ), to more radical perspectives which seek to transform the character of organizational arrangements to end the domination of women by men (Ferguson, 1984; Kanter, 1977; 1980).

Importantly, the departure was led by Rosabeth Moss Kanter's study, *Men and Women of the Corporation* (1977), in which she investigated the structural causes of inequality within organizations, and described how disparities of power and numbers, along with other factors, contribute to an opportunity structure that communicates to women and men their relative worth in the organization. Her research enriched the field of organizational sociology with important new concepts: the "masculine ethic" of rationality and reason associated with managers, the relegation of women to "office housework" and the "skewed" representation of men and women at higher levels. (Kanter, 1977,1980; Tancred-Sheriff & Campbell, 1992).

Burrell and Morgan's (1979) survey of organizational theory and preliminary analysis of gender and organizations is well referenced (Hearn & Parkin, 1992, p. 49; Billing & Alvesson, 1994; Gherardi, 1995). Analytically, Burrell and Morgan (1979) identified four theoretical approaches to studies on gender as a feature of organizational life: those which neglected gender entirely or relegated it to no more than a variable; those which investigated organizational situations through men's rather than women's accounts; those which accepted class divisions as having greater significant than sexual divisions, and those which explored alternative forms of organizing but not the sexual division of labour.

Acker (1990) argues that as gender division and hierarchy exist as a subtext in the structure of all organizations, what is necessary to understand inequality is a systematic theory of gender and organization. She theorizes gender as occurring in five interlocking organizational processes: (1) the construction of division along gender lines (men's work/women's work; paid/volunteer; status and hierarchy); (2) the use of symbols and images that explain, express, reinforce or sometimes oppose those divisions (masculine/feminine forms of fundraising); (3) patterns of interaction (dominance/ submission; interruptions, emotion); (4) gendered components of individual identity (work, language clothing); and (5) the symbolic indicators of structures (job ranking and evaluation). Taylor (1999) draws on sociological theories of gender and social movement approaches to theorize gender and social movements. This dual analysis, she claims, provides a more intricate reading of the "contradictory impulses" in order to make explicit the role of social movements in affirming (by inscribe gender differences and maintaining gender stratification) and in challenging (by exposing contradictory cultural codes pertaining to gender) the social order.

Over the last decade a number of researchers have utilized a cultural framework to study gender and organization (Morgan, 1997; Billing & lvesson; 1994; Maddock & Parkin, 1994; Gherardi, 1995; Sheppard, 1992). Morgan (1997) shows how prevailing social and political attitudes, far from being obvious and overt, combine with organizational arrangements to create organizational cultures and practices of discrimination. He uses language to illustrate how gender bias favours one sex over another and draws upon terms which convey characteristics associated with organizations, and with men: terms like "being rational", "analytic", "strategic", "decision-oriented", "tough" and "aggressive". Language, political symbols, military and sports are singled out for their strong macho element which reinforces masculine identity. Relatedly, Billing and Alvesson (1994) identify how "gender symbolism" affects the work climate in personnel policies, formal communication patterns and styles of decision-making.

Gherardi (1995) prefers an interpretive definition of organizational culture for the meaning imbedded in such non-material things as what people think and what people say when they meet. She insists that organizations are strongly gendered and that organizational processes are ways of organizing and producing gender relations. These processes include: the gender patterning of jobs, wages, hierarchies, power and subordination; the creation of symbols, images and forms of consciousness which explicate, justify or oppose gender divisions; the interactions among individuals in the multiplicity of forms that enact dominance and subordination, create alliances and exclusions; and the interior mental work of individuals as they consciously construct their understandings of the organizations structure of work and opportunity.

Maddock and Parkin (1994) acknowledge that while gender cultures may be difficult to quantify they are far from vague and imprecise; every woman they interviewed recognized and understood gender culture as restrictions on their behaviour and expression and the extent to which they have to manage gender as well as do their jobs. They argue the dynamic of gender relations persists even when equality is espoused and in the case of “gender blindness” where difference is ignored, prove with Mills and Tancred (1992), it creates psychological walls for women and wastes potential for organizations.

The implications for women’s lives when they enter the male culture of the organization were explored by some authors (Sheppard, 1992; Kanter, 1977; Morgan, 1997). For women on the move (up) or “immigrants”, (Sheppard, 1992, p.144), organizational learning means “male” learning. She gives an account of the various ways women manage their status in relation to the prevailing power structure. They “blend in” by conforming to the expectations and comfort levels of colleagues; they take their “rightful place” but remain on guard; they take care in presenting themselves to be seen as “credible”; they adopt uniformity in dress and behaviour to appear more powerful and enhance organizational mobility; and they adopt a desexualized office norm in exchange for “sexiness” of success. Kanter (1977) exposes the precariousness of managing boundaries in light of the visibility that results from women’s under-representation. Similarly, Morgan (1997) notes the implications for women who wish to negotiate the corporate world and the risk they take by being assertive and playing a “male” role, opening themselves to criticism for breaking the female stereotype.

An inhospitable environment, Ferguson (1984) argues, has political consequences. Male dominance in organizational power contributes to women learning to be subordinate which seeds a climate for sexual harassment. Sheppard (1992) notes that in such a climate, women may be judged incapable of taking on positions of leadership, responsibility, and authority.

Some researchers highlight the continuing widespread neglect of research on the intersections of class, gender, and race/ethnicity despite these elements being “essential features” of organizational analysis. Billing and Alvesson (1994) note gender is significant as a discriminatory factor to different degrees in different organizations. Mills and Simmons (1995) consider how disparities of power and opportunity affect women, persons of colour, aboriginal people and the working class. Cox and Nkomo (1990) review research that addressed issues of race in organizations since the passage of the

Civil Rights Act of 1964. They found the total to be very small and that researchers tended to focus on evidence of overt discrimination in organizations rather than viewing race as a complex variable which is deeply ingrained in the social fabric of our society. Bell (1990) investigated how race and gender affect the careers of black women managers in organizations. She reported inflexible organizational structures, lack of accommodation for people of colour or women, token status as described by Kanter (1977; 1980), in addition to personal stress associated with compartmentalizing the dimensions of living a bicultural life.

There are only a few studies in organizational sociology that make recommendations for social change. Ferguson (1984) clearly states her writing is in opposition to bureaucratic discourse and structures. She draws on the voices and experiences of women to illuminate patterns of dominance and subordinance in bureaucracy. She sets her hopes with anti-hierarchical feminists to heal the breach between private and public life. With Smith (1989) she envisions a non-bureaucratic collective life that takes account of the care-taking and nurturing experience embedded in women’s role so women do not have to put to one side the “other realm” in which they live in order to succeed (1984, p. 29).

Morgan (1995) identifies new female corporate leaders who cultivate matriarchal (over patriarchal) values to reverse the traditional imbalance, and who create flat, networked ”webs of inclusion” to replace hierarchical structures; in this design the process of doing things as well as achieving outcomes matters, as does an openness to creativity and diversity. Maddock and Parkin (1994) call for men and women to challenge gender cultures to create more democratic organizations. Mills and Tancred

(1992) acknowledge that the domination of people is grounded as much in the materialist basis of life as in control over ideas thoughts and feelings. Raising people's consciousness about the discriminatory reality they are involved in is important but it must go along with recognizing the overall need for social change.

An interesting finding for this study in particular is that reported by Tancred-Sheriff and Campbell (1992) who suggest that the predominant setting for women who study organizations consists of service organizations. Such settings, they suggest, reinforce the accepted image and the proper concerns of women as nurturers and servers, an extension of the "mothering role", and fitting with the ideological and structural position of women in general. The conflict between this "mothering role" and the "activist mothering" concept identified in the social movement literature lies at the front line of the terrain of struggle in organizations like the Canadian Association for Community Living.

## Summary

The literature identifies several themes that help us understand mother's activism. One theme explores how activist mothers negotiate the boundary between their active public life and their personal private life (Mills, 1959; Orleck, 1995; Naples, 2998b; Kaplan, 1997; Stehlick, 2000). A second theme points to the significance of informal networks to women's grassroots organization (Reinhartz, 1984; Astin & Leland, 1991; Sacks, 1988; Bernal, 2002; Bookman & Morgen, 1988). A third looks at how "accidental activists" came to their activism through a sense of "gendered obligation," fulfilling what they believed society expected of them as mothers (Abramovitz, 1999). A fourth theme deals with the traditional notions of “good mothering” (Ladd-Taylor & Umansky, 1998; Sangster, 2001) and how this applies to activist mothers who resisted conventional thinking by promoting a more inclusive view of motherhood, one not narrowly based on the ideal of the “normal” child. Finally, to bring women into view, gender is used as a category of analysis to investigate how mothers’ activism violated the cultural norms for women of their generation and exposed the sexist divisions in the organization they founded (Abramovitz, 1999; 2000; Naples, 1998a; 1998b; Orleck, 1995; Kaplan, 1997; Herda-Rapp, 2000; Taylor, 1999; Acker, 1990; Sheppard, 1992; Ferguson, 1984). These themes in the literature will inform this study.

There is much evidence in the literature to suggest a genre of work written by mothers of children with disabilities themselves giving personal accounts of their own experience parenting a child with a disability. There is also evidence that they have been have been widely studied by researchers in the context of therapeutic interventions and gendered care-giving roles. The literature also shows that mothers have found new careers that started by trying to get their own needs met and then carried into disability work more broadly. There is however, no research that examines what it means to women who proclaim a gendered role as wife and mother to find fulfillment of that role by taking disability to a larger community and political forum. This study extends Nancy Naples’ concept of “activist mothering” to mothers of disabled children to explore the role they have played in making their claim for social justice and equality. In so doing, this study locates itself by beginning to fill that gap in our knowledge

# Chapter Two

# Research Design and Methodology

## An Overview of the Chapter

This chapter examines the methodology used to conduct this inquiry into "activist mothering" (Naples, 1998b). The study locates the unit of analysis in activist mothers, and investigates how and why women with disabled children came to recognize the importance of becoming advocates for change beyond their own families. Mothers, primarily, founded the Canadian Association for Community Living to place their issues on a broader platform but until now, that organization has not  recognized and profiled women's contribution and nor has it been thought of in gendered terms.

In this study I draw on Nancy Naple's definition of "activist mothering" as "political activism as a central component of mothering and community caretaking of those who are not part of one's household or family" (1998b, p.11). The everyday world of activist mothers and their experience ground the work (Smith, 1987). This approach is informed by feminist scholarship and its recognition of gender as a category of social experience. It is a significant matter that mothers named and related the experience themselves. The Association's structure, culture and practices provide a framework upon which to analyze the gendered nature of the organizational environment in which activist mothers carried out their work. Three "expert witnesses" provide the site of inquiry for investigating the relationship between the experience and knowledge of activist mothers and the broader practices of administration, institutional and gender relations with the organizations they founded. They instigated two major campaigns in the 1970s and 1980s. These were the campaign to close institutions and the campaign to secure human rights. These campaigns inform two key chapters which explore how women who proclaimed their roles as wives and mothers took their caretaking responsibility to the broader community through these campaigns, and how the organization contoured their lives in response to their activism.

The research design I have selected to study activist mothering in the Canadian Association for Community Living is based on a qualitative process of inquiry and an historical approach. This chapter begins with a rationale for my decision to use a qualitative research method. Next, I outline reasons for my use of an historical approach. I describe the data sources, data collection, and method of analysis. I examine some of the limitations of the study including the challenges of gathering oral history, what is sacrificed in breadth by the depth of detail about a single organizational site, and the need for further, more extensive research.

## Rationale for a Qualitative Process of Inquiry and an Historical Approach

I selected a qualitative process of inquiry and an historical approach to study activist mothering in the Canadian Association for Community Living. The study shares with other qualitative inquiries the goal of understanding the participants (the activist mothers) from their own point of view. I have chosen a qualitative process of inquiry because ontologically, it recognizes multiple truths over a single truth and allows for a multiplicity of views emanating from the participants’ own reference point in framing the problem (Lincoln & Guba, 2000). Significantly, it enabled me as a researcher to relate to these mothers personally, face-to-face in a natural setting, amidst their family photos, files, documents, and memorabilia.

I made an assumption in pursuing this approach that, while there is growing body of work on women’s activism, not enough is yet known about the particular relationship between the experience of disability and women’s activism. The topic did not lend itself to objective knowing, a single reality or operationalization of variables as a positivist approach might recommend. Rather, what seemed critical for building knowledge in this new area was a discovery-driven approach that promised description and explanation. Phenomenology is the theoretical tradition that helped frame this research question because it attempts to understand the meaning of events and interactions of ordinary people in particular situations (Bogdan & Biklen, 1983), and because its guiding question allowed me to focus on the structure and essence of experience of this phenomenon for these people (Patton, 2000). A qualitative approach A qualitative approach offered the best opportunity to explore the complexity embedded in questions of meaning and interpretation (Reissman, 1993).

There were three primary reasons for choosing a qualitative approach. I was interested in its discovery driven method and its capacity to elicit a depth of response through stories, narratives and anecdotes. Qualitative research can accommodate the experience of more than one woman’s experience and its flexibility allows for research questions to be generated even as the data comes in and the process evolves. In contrast, a research approach rooted in a positivist tradition with a predetermined, researcher-selected set of measurable variables would presume more knowledge than currently exists about this subject (Denzin & Lincoln, 2000). Qualitative inquiry was selected because it permits an investigative intimacy with research informants. It also recognizes the significance of context and its influence on human behaviour; and has the capacity to look at relationships activist mothers have with each other within a system or a culture over time (Janesick, 2000).

Second, in qualitative inquiry values are not only included but provide a "major point of departure" (Lincoln & Guba, 2002). Accordingly, my subjective relationship, prior knowledge, and experience enabled me to perceive reality as a social construction and to actively participate in constructing data (Glesnie & Peshkin, 1992). This contrasts with positivist assumptions that an objective reality exists and can be known by a detached and impartial researcher (Glesne & Peshkin, 1992).

Finally, I chose to do a qualitative study because it afforded me the opportunity to pursue a compelling life long interest that has social significance. There are important aspects of social activism that cannot be measured but they can be explored using a qualitative design.

My personal interest in history influenced my choice to take an historical approach to this study, but it is also methodologically justified. Selznick (1957) notes the importance of understanding organizational history. Because organizations tend to evolve over time, making fundamental decisions along the way, an examination of these commitments sheds light on whether the way in which it has operated has been effective in achieving its goals. Mintzberg and Walter’s (1982) study of organizations over time shows differences in strategies and policies ranging from those that were intended, those that emerge without planning, those that are realized and those that are not. The changing role of women was explored through an inquiry into the Canadian Association for Community Living’s origins, evolution and development. A number of investigative questions guided the research: Has the organization changed over time? Who were the founders? The leaders? The foot-soldiers? Who influences the organizational agenda? When women were involved, did it make a difference? What impact, if any, did women have on the femaleness of the organization? To what extent were they able to influence and shape its agenda historically? And, what was the relationship between the women’s experience and the historical record of their achievement? Patton (1990) notes the importance of history as a source of data, and suggests that historical research, including the history of an organization, can be a critical part of learning from the field. Past records of events provides a solid basis on which to conduct an analysis of activist mothering and the role of gender in the evolution of a parent-led disability organization.

## Data Sources

The study drew on two main sources of data: 1) oral history interviews with three activist mothers as key informants, and 2) organizational records and archival documents of the Canadian Association for Community Living.

In August, 2004, I enrolled at the University of California, Berkeley, for an Advanced Oral History Summer Institute offered by the Regional Oral History office. Readings, lectures and small group discussions proved highly relevant to this study of activist mothers, in particular the nature of oral history itself (Portelli, 2004), research methodology for conducting and analyzing oral interviews (Sangster, 2004; Anderson & Jack, 2004), and the role of oral history in culture and disability (Hirsch, 2004).

I was given generous access to the organizational records and sources I needed to conduct my study by the Executive Director of the Canadian Association. In addition he provided me with an office and photocopier to support my research. I was known in both a voluntary and professional capacity which aided me in entering the site. Being known, also assisted me with the interviews. The three activist mothers I invited to be the key informants in the study readily agreed to participate.

## Data Collection: Key Informants

### Interviews

I interviewed three key informants, now approaching eighty years of age, who became active as young mothers when their child was diagnosed as having mental retardation. These children are now adults in their 40s although one mother’s son died in 2004. This small number of purposefully chosen activist mothers was identified based on the expectation that they could provide information rich interviews from which key themes would emerge.

### Selecting the Participants

The women included in the inquiry met three criteria: seniority, reputation and geographic diversity. In the first place, each of them had became involved in local Associations for the Mentally Retarded in the 1960s when their children were young and had over time amassed years of experience and seniority. Second, they were known as leaders who were strongly affiliated with one of the Association's major social change campaigns: closing large institutional facilities for the mentally retarded and defining disability as a human rights issue. They were highly visible and had national reputations based on their accomplishments. The third criterion related to geographic locations. The three women come from different provinces in Canada. One participant lives in Vancouver, British Columbia on the west coast, the second informant lives in rural Ontario and the third is a Quebecois woman who lives in a suburb of Montreal. They brought different local and provincial struggles, perspectives and issues to strengthen the research. These three activists served as "expert witnesses" in this study, representing the participation of other mothers in the organization. In telling their stories, they bore witness to, provided commentary on, and illuminated the role played by women in the Canadian Association for Community Living.

### Structuring the Interviews

I used a semi-structured, open-ended interview schedule to carry out a “guided conversation” (Lofland & Lofland, 1984, p.84) in order to generate an oral history of key events in each woman’s life (see Appendix E). One aim of this study was to capture the subjective experience of a group of historical actors. Like all forms of evidence, oral history has its limitations. But as historian Paul Longmore has noted, oral history enables researchers to “cross-question their sources, probing memories and ‘unpacking’ their deeper layer of meaning” (Longmore, 2003, p.88). In this study organizational documents and records of meetings were used to corroborate and investigate the oral accounts of the activist mothers. While their recollections of specific details of particular events were often imprecise, their descriptions of activities, mood, and meaning were richly informative.

Three areas of investigation guided the interviews: the development of a biography of the activist woman’s personal history; an exploration of her organizational participation and analysis, and her perception of organizational challenges and vision for the future. The in-depth interviews generated a focused life-history of key events in each woman’s life related to her experience as a mother of a disabled child. The oral historical approach offered a framework to explore their development of their political consciousness and activism. Drawing on Dorothy Smith’s (1987) classic feminist text, *The Everyday World as Problematic*, I began from women’s experience as a point of entry to a broader investigation, with a view to analyse how local concerns generate ideas about broader issues.

Each interview began with a “moment”, the first moment each mother learned about her child’s disability and then moved outwards, casting a very wide net to facilitate more expansive thinking. To uncover what the activist work looked like and how it happened, questions moved through a reconstruction of early experiences related to family response, other significant relationships, external influences, discriminatory experiences,  encounters with health, social service and education professionals, useful or obstructive policies and practices, their sense of success and disappointment, and personal and political visions for the future. These basic topics ensured a consistent approach and a vehicle to enable their stories to speak to each other, across narratives.

### Conducting the Interviews

During my initial telephone contact with the participants I explained the nature of my research, the interview process and the approximate time commitments that this entailed (see Appendix A). Before commencing the interviews, the research participants were given a Letter summarizing the study and briefly describing the expectations of the participants during the research process (see Appendix B). They were asked to sign a Consent Agreement to participate in the interview. The letter of consent outlined the rights and responsibilities of the research participants. The research participants were informed they would receive copies of all transcripts and that they were free to withdraw from the study at any time (see Appendix C). They were also asked to sign a Letter of Consent to have the interview audiotaped (see Appendix D).

Research participants took part in two interviews and one focus group, each lasting approximately one and one–half hours. Two interviews were conducted with participants individually at a time and place agreeable to them. The third interview was a focus group held in Toronto in conjunction with a Distinguished Public Lecture they were invited to give to students in the Disability Studies Program at Ryerson University in July, 2005.

In the first interview with each research participant, I tried to strengthen rapport and communicate how important it was to hear them talk about their life. In that initial interview the research participants were asked to share autobiographical accounts of their early experiences related to becoming a mother of a child with a disability. They viewed this as “telling their story”. I listened, probed and offered my understanding to them for confirmation or correction (Mykhalovskiy, quoted in DeVault (2002, p.10), trying to generate insight but not force findings, as I sought to understand the meaning they made of their lives.  Upon listening to the first tape I realized there were times I may have missed rich aspects of the participant’s perspective and mood by participating too actively in the conversation, mostly when I interrupted and tried to pin down actual details (dates, events, names).

During the second interview, participants were invited to share information about their understanding, memory, and insights that related to promoting social justice/ inclusion/ disability equality. This interview placed the research participants’ thoughts, feelings, and actions into an historical context. They usually provided a chronology of life events that included family, social, and cultural influences. The direction of the conversation emerged according to the memories of events that had been formative for them. The continuous unfolding and developmental nature of their narrative in the second interview, emerged more readily and richly. They had had time to think about the questions I was asking and their past and had clearly pried some thoughts and memories loose in the interim. Their voices captured concrete experiences, memories and reflections on the social significance of their social activism. By this interview the three participants were able to begin to speculate on possible connections between their earlier experiences and later experiences.

During the final session, when all three participants met as a group they shared ideas, beliefs, and memories about their own and one another's activist work, and considered factors that enabled and constrained them. They challenged one another, spoke of their differences, and shared how they viewed one another's contributions. They reflected on their legacies and envisioned a future role for the organization.

The set of audio-taped interviews for each participant was transcribed verbatim.[3] This was done in order to return to the data frequently, attend to details which did not at first appear relevant but might later provide clues to deeper understanding (Bogdan & Biklen, 1983), and cross-check against historical records. To immerse myself in the data, I listened to the audio-tape (to hear their voices) and read the transcript (to see their words) simultaneously. Based on the interview transcripts and additional material they provided, I gathered all the comments

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[3] In 2004, I was awarded a $2,200 research grant from the Faculty of Community Services at Ryerson University to support the costs of transcribing the interviews.

participants made about central topics of conversation. I reviewed and summarized transcripts and through reading, thinking, discussion with colleagues, moving back and forth between collected speech and the organization’s archival and institutional records, I conducted the analysis. In addition to facilitating analysis, direct quotes from the transcripts provided a way for the research participants to “speak” in the final account of the research.

The women I interviewed are highly visible public figures and they had no interest in being anonymous. They are identified in the research by their first and last names. They offered me resources from their personal files which included correspondence, newsletters, and photographs and memorabilia that enabled me to draw upon their experiences, stories, and personal accounts of particular moments of struggle. They gave their time generously and willingly shared their experiences. While they were not reluctant to be interviewed, they did seem to need reassurance about why I felt their life and experiences were important and a worthy focus of research.

## Data Collection: Historical Documents

To illuminate the changing role of women in the Association, I conducted an historical analysis of the Canadian Association for Community Living. I examined 40 chronologically arranged, large binders that contained minutes of executive meetings, minutes of board meetings, and minutes of Annual General Meetings between 1958 and 1998.  In this study, historical and organizational records were the primary sources used to investigate: 1) the institutional processes (documents, activities, goals); 2) the social environment (where and how gender fits); 3) how administrative and professional practices are carried out; and 4) how they shape the experiences of the key informants (and by association, other activist mothers). These were examined at the national head office in a locked store room which holds the archives. The binders also contained a range of documents that were distributed at meetings and attached as Appendices. These included social policies targeted at federal and provincial levels (including those related to the provision of social benefits, institutional care and deinstitutionalization, home care, education regulations, access to schools for "exceptional" children, and restrictive or exclusionary policies, laws and professional practices) and briefs related to court cases and legal challenges. The Resource Room at the national office also held a complete set of the Association's Journal, *Mental Retardation,* published between 1964 and 1982 when it was replaced with *entourage,* published between 1988 and 1995. Occasional monographs and short historical accounts produced to mark important organizational anniversaries provided useful additional sources. Policy briefs, records of lobbying strategies and meetings, newspaper and other media coverage and public education initiatives provided additional sources of data.

The documents served a dual purpose: they provided a basic source of information about organizational decisions and background, activities and processes; they also provided important ideas that I was able to pursue in the interviews (Patton, 1990).

## Data Analysis

To conduct the analysis I listened in particular for the relationship between the activities the participants engaged in while carrying out their mothering work and the institutional structures and external authorities that shaped and ordered that work. Rather than simply describing the work activist mothers performed in looking after their disabled children, the research explores how this work was shaped not by their personalities or individual preferences alone, but within a set of institutional relations The ways in which mothers talked about their personal experiences in various situations were examined against how those social issues they fought for are captured, depicted, recorded, and given authority in the organizational records. The interviews explored these transitions, exposed any apparent tensions and contradictions in their lives which the transitions entailed, and investigated the extent to which shifts in organizational practices and goals were recognized and understood by activist mothers and what they did with this knowledge. The period during which they acted captures the variability of their individual experience and reveals a history of the organization's evolution over time.

To trace the path of activist mothers' transitions to leadership I utilize Devva Kasnitz's (2001) conceptual framework of life course event history. This offers an analytic process to elucidate the occurrence and sequencing of significant events and changes. The analytic domains most relevant for this study include: the onset of disability, family background, a predisposition to community work and leadership, significant life events resulting in an exposure to injustice, exposure to disability stigma and discrimination, a turning point, peer contact and networking, and new roles in disability advocacy. These are explored in relation to the narrative biographical accounts to explore how disability prompts women's activism. The narratives also provide a source for analyzing individual activists' styles and skills in dialogue with recent feminist accounts of women's leadership in social movements.

In examining organizational records, I paid particular attention to historic links, trends, antecedents and debates as they related to the key issues that provided the framework for the study (the work of the activist mothers as they took up their campaigns of closing institutions and securing human rights) as well as unanticipated events and issues. I attended to the struggles themselves, the articulated strategies and anticipated repercussions of taking a particular path, the fall-out from whichever decision was made, strategic realignments, and legacies. Significantly I paid particular attention to the embedded assumptions about gender and the battle for women's leadership within the organization as a whole. The voices of the "expert witnesses" provided a lens through which to explore women's social position in the organization, the gendered division of labour and dominant perceptions of the value of women's work.

Finally, I investigated how activist mothers made sense of their past, the dual pressures they felt to be a "good mother", how they succumbed and resisted conventional expectations to fulfill gendered roles, and how they want to be remembered.

## Problems and Limitations of the Study

The examination and analysis of historical records and organizational documents of the Canadian Association for Community Living allowed for an investigation of the relationship between the experience and knowledge of activist mothers and the broader practices of administration, institutional, and gender relations with the organization they founded. This was important because the activist mothers' own narratives did not always progress in a linear or chronological fashion. Although each began at the beginning, when they first learned of their child's disability, they often shifted to the middle, moving inward and outward, arranging the plot and sequence in terms of their relationship to that history, ordering the narrative according to what they viewed as significant and prior. Furthermore, details that provided useful signposts in their stories, for example dates of events or proper names and titles, were not always important to them, and any attempts to pin down the facts only succeeded occasionally; more often than not an interruption tended to break their train of thought, leading to a shift in focus and the introduction of new topics. It became clear they were more interested in making sense of the past and conveying the meaning of events they considered significant than describing them with precision and accuracy. Many of these details were obtainable through other means, such as organizational archival documents and records, minutes of meetings, newsletters, and legal and scholarly references, which made the oral history aspects of this study viable. The oral history was absolutely necessary, but it was not in itself sufficient.

While the design offers depth of detail about a small number of "expert witnesses", it sacrifices the breadth that might come from measuring the responses of many informants. Additionally, the purposive sampling of three older, white women, (although they represent the geographic range and national duality of Canada) eliminates a broader perspective that might be sought from younger mothers, from mothers coming from ethnically and racially mixed backgrounds and even from fathers caring for disabled children. In addition, I expect it would be possible to locate other mother-activists in comparable parent-led disability organizations that have played a similarly critical role in creating services based on their child's diagnosis and needs (e.g. Cerebral Palsy Association, Muscular Dystrophy Association, Easter Seals, or March of Dimes). If the study were to include a cross-disability focus there would be certain advantages associated with its' generalizability to a larger population. However, I suspect there would be fundamental ideological differences, even over the very definition of disability itself. Perhaps, in a larger study it would be interesting to tackle a broader spectrum, or in future research when the results of this work can be built upon, but given the constraints of what limited knowledge we now have, the advantages of my research are based on its depth of focus and single organizational site.

## Summary

This chapter on Research Design and Methodology outlined the rationale for using a qualitative inquiry and historical approach to study activist mothering in the Canadian Association for Community Living. It located the sources of data in oral history interviews with three “expert witnesses” in relation to archival material and organizational records and points to the key campaigns through which their activist work was demonstrated. The strengths and limitations of the study were examined.

The study now turns to a Chapter Three which focuses on the history of the Association and the organizational context in which the activist mothers emerged. It traces the first ten years, from 1958 to 1968, through three organizational practices: volunteering, governance and fundraising.  How the fledgling organization inscribed gender difference through these practices, what impact these organizational practices had on women’s social position in the Association, and how embedded assumptions about gender provided a contour to women’s activist lives, is threaded through the next chapter and carries forward.

# Chapter Three

# The Historical Context

## Introduction

Of all areas of human services, perhaps none was so neglected in public awareness, social provision and academic research until recent decades as that related to children with intellectual disabilities, known at that time as "mental retardation" or "feeble-mindedness." Widespread ignorance and neglect about the disability produced in families overwhelming feelings of shame, guilt, something to hide, even from one's relatives (Dybwad, 1990). A growing awareness of human rights after World War II, fuelled by the United Nations Universal Declaration on Human Rights in 1948, prompted parents to question their children's exclusion from school and other community-based activities and to get together to do something about it.

The rapid expansion of welfare spending in the post war years stimulated an explosion of voluntary sector activities. The rise of the voluntary sector was an important development in North America for its capacity to expand individual life chances, redress social inequities, and minimize the domination of some groups based on race, class, and gender (Wolch, 1990). In Canada, a new voluntary Association formed to extend human rights and freedoms to the emergent social concern about "disability."

> Spontaneously across Canada in the 1940s small group of parents with mentally retarded children began meeting together for mutual support. These

> groups challenged society's traditional attitudes about mental retardation. They founded local associations to promote the development of community programs for their sons and daughters as an alternative to institutional care. They started schools in church basements. They proved that retarded children could learn...
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> A decade later, the local associations had developed provincial organizations to coordinate information and knowledge, and to bring their common concerns before provincial legislators, service agencies and the public.
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> In turn, the provincial associations recognized the need for a national identity and in 1958, the Canadian Association for the Retarded Children was founded (Minutes, 1981, Binder 24).[4]

This standard account by the Canadian Association credits "parents" collectively with reaching out to one another for common action and mutual support, but in fact it was mothers who led the way. In the aftermath of war, just after Rosie the Riveter had laid down her tools, it was generally assumed that women were content to return home and resume their roles as housewives (Rowbotham, 1997). But a new site of their activism was emerging in the "space" that women inhabited, their

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[4] This history was developed for a larger presentation by senior staff and executive officers on the "Canadian Association for the Mentally Retarded (CAMR) Structure and Relationships" for the CAMR Board, January, 1981.

kitchens and their households (Abramovitz, 1999). Small groups of mothers of retarded children began organizing across Canada (and elsewhere), beginning their careers as activists by resisting the only option open to them, to put their son or daughter in an institution.

The purpose of this chapter is to present the history of the first decade in the life of the Canadian Association for Retarded Children (1958-68) by examining how the Association came to be, how it was governed, how it remained financially solvent, and how the seeds of activism were sown. Jo Dickey, Paulette Berthiaume and Audrey Cole, the activist mothers in this study, were then young mothers. Paulette's and Jo's sons were both born in 1955; Audrey's son was born in 1963. Each mother joined their local Association for Retarded Children. Jo Dickey joined Vancouver's North Shore Association in British Columbia in 1957 when her son Drew was two; Paulette Berthiaume joined the Montreal Association in Quebec in 1959 when her son Louis was four; and Audrey Cole joined the Ottawa and District Association in Ontario in 1967 when her son Ian was three and half years old.

The organizational foundations laid in the 1960s set the stage for the activist mothers' work over the following decades. Two important campaigns emerged in the 1960s: the campaign to close institutions and the campaign for human rights. These flourished in later years and defined the work of the Canadian Association. These campaigns, which will be discussed in later chapters, will help define what "activist mothering" meant as epitomized by three women's activism over three decades.

Three organizational practices characterized the first decade: volunteering, governance, and fundraising. Together these practices provided a vehicle for investigating how a gendered stratification was established in the early days and for analyzing how assumptions about gender provided a contour to women’s activist lives (Smith, 1987). Acker’s (1990) theory of gendered organizations and Taylor’s (1999) analysis of gender processes in social movement provide the conceptual framework for examining these practices. Acker theorizes gender as occurring in five interlocking organizational processes: the construction of division along gender lines (men’s work/women’s work; paid/volunteer; status and hierarchy); the use of symbols and images that explain, express, reinforce or sometimes oppose those divisions (masculine/feminine forms of fundraising); patterns of interaction (dominance/ submission; interruptions, emotion); gendered components of individual identity (work, language clothing); and the symbolic indicators of structures (job ranking and evaluation). Taylor studies the “contradictory impulses” to explicate the complex role of social movements in affirming (by inscribing gender differences) and in challenging (by exposing contradictory cultural codes) related to gender. The particular practices of volunteering, governing, and fundraising will be taken up in turn but it is to the laying of the organization’s foundations that the chapter now turns

## Laying the Foundations

In February, 1958, a National Association founded to help children with intellectual disabilities held its first Executive Committee meeting at the Lord Elgin Hotel in Ottawa. The order of business included items typical for any new organization. There was the question of locating the national headquarters; Toronto was selected although Ottawa and Montreal were strong contenders. There was also the matter of staffing the organization; a selection committee was authorized to recruit an executive director at a salary that could not exceed $7,000 a year. A committee structure was proposed and key chairpersons identified. To attract new members, a token registration fee was set for the first annual conference of $3.00 for the full 3-day package. Finally, to promote public awareness about the new organization and to demonstrate to provincial and local Associations the benefits of belonging to national body, the Association leadership proclaimed a “Canadian Retarded Children’s Week” in November, 1958. This was the publicity event of the year. Radio stations throughout the country were supplied with spot recordings to promote the week by well-known celebrities such as Milton Berle, Dale Evans, Joanne Woodward, Gene Kelly, and Perry Como.

This national organization could not have been founded without the courage and stamina of grassroots groups that built the foundation at the local level for many years (Foster, 1959; Taylor, 1967; Beck, 1998; Cole, Panitch, Tutt and Kyle, 2003; NIMR,1981; Anglin & Braaten, 1978; Dybwad, 1990).These types of organizations were one expression of the general expansion of civic and community organizations during the post war years. Many other parent-led health organizations and medical charities dedicated to specific disabling conditions also grew rapidly during this time. This period saw the founding of the March of Dimes and organizations for conditions such as Cerebral Palsy and Muscular Dystrophy. But as Castles (2004) suggests, none was comparable to the Canadian Association for Retarded Children in its determination to maintain parental dominance at all levels. These parent activists were very concerned that professionals were not committed enough to treating their children’s problems as social rather than individual ones. They were not confident that professionals would secure changes in public attitudes and improve community social services (Castles, 2004; NIMR, 1981; Cole, 1998b).

Despite the “official” references to parents, it was primarily young mothers who founded and joined these groups, seeking mutual support and starting schools in church basements and family homes when their children were approaching school age (Castles, 2004; McConachie,1994; Gartner et al.,1991; Traustadottir,1988; Hillyer, 1993). The sporadic accounts of the origins of these groups, presents a picture of mothers organizing from coast to coast (Taylor, 1967; Beck, 1998; Crawford, 1983; Anglin & Braaten, 1978; Cole et al., 2003).

Groups in British Columbia and Ontario were especially important. In 1947 in British Columbia, mothers first came together to form the Kootenay Society for Handicapped Children of British Columbia, and founded the first school for intellectually disabled children in Canada. A few years later, at the other end of the country,

> … three mothers, whose children had a disability, organized a provincial association in Prince Edward Island. Before then, there had been little, if no, change in services for persons with intellectual and other disabilities since the turn of the century. These mothers proved to be a force to be reckoned with. By mid-1955, the provincial branch was a legal entity and up and running. A

> well-trained teacher had been engaged and the first Day Training Classes were happily meeting in the classrooms of some elementary schools. They had enlisted the support of the Local and Provincial Commands of the Canadian Legion who continued to give financial and political support. (Beck, 1998).

Meanwhile, the Association for the Help of Retarded Children (Quebec) Inc, was started by the mother of a disabled child, Mrs. Hanna Wollock, who

> hired a salon in the Mount Royal Hotel, in Montreal, on January 7, 1950….and spoke to a handful of parents ….seventy-five in all, who had shown up at the meeting. …A Steering Committee of the parents present was formed, and this marked the beginning of [a series of] meetings which were held at the Montreal High School…The group realized that publicity was necessary…and the decision was made to hold public meetings. The first of these was held at Victoria Hall in Montreal where fifty to sixty people listened to Dr Gerard Barbeau, Director of the Institute-Medico Pedagogique at Rivière-des-Prairies (a government school for the educable retarded). The Charter for the Association was drawn up on November 16, 1951 and the Constitution submitted shortly thereafter (Taylor, 1967).[5]

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[5] In September, 1952, members of the Quebec Association opened its first school in the basement of St Mathews Anglican Church, Hampstead, the forerunner of the Snowdon School. This marked the third class founded by the associations for retarded children in Canada, after those founded by the Kootenay Society for Handicapped Children of British Columbia, in 1947, and the Parents Council of Toronto, in 1959.

The founding of the first such organization in Ontario began with an unsigned letter that appeared in the *Toronto Daily Star* on September 29, 1948. It was later revealed that the author of the letter was Victoria Glover who was bringing up her eight-year old orphaned grandson. She wrote:

> Sir: May I say a few words on behalf of our backward children, and their bewildered mothers. There is no school for such children, no place where they can get a little training to be of some use in the world…I am sure their mothers would gladly pay for their transportation to and from school. After all, they are paying taxes for more fortunate children’s schooling. I think it is time something was done for parents who from a sense of faith and hope in a merciful providence want to keep them at home living a normal life. These are real parents, only asking a little aid and encouragement to shoulder their own heavy burden. God bless them, and may the Ontario government help them and their children who might still be made something of, living a normal life and with the perfect love, understanding and guidance of such parents. (Anglin & Braaten, 1978, p.6).

A few months after this letter was published, seventy people met at Carlton Street United Church on November 4, 1948 and founded the Parents’ Council for Retarded Children.  Today it is called the Toronto Association for Community Living. According to the official history of the Ontario Association (Anglin & Braaten,1978), Wesley Stitt, the father of a young intellectually disabled son, contacted Mrs. Glover and then sent a letter to the *Toronto Daily Star* asking anyone interested in a meeting to contact him. Years later this was challenged by a member of the Stitt family who insisted it was Mrs. Stitt who took the initiative.[6]

Just as mothers took the lead in forming local chapters, and by the 1950s provincial Associations across the country, so they would take the lead in forming the national body. One was Lillian Hunt, who as President of the Ontario Association for Retarded Children invited all of the provincial groups to meet in Toronto in April, 1955 to consider forming a national organization. At a follow-up meeting a year and a half later at the Royal York Hotel in Toronto, the provincial representatives ratified a national constitution. The “Canadian Association for Retarded Children” formally came into being on January 31, 1958 with the particular goal of promoting the welfare of mentally retarded children and soliciting funds to this end.

The Executive Committee met two weeks later in Ottawa to prepare for the first Conference and Annual General meeting. The first President was Laurie Hall, a father from Montreal who, appalled at the lack of community services for his son, had joined a local group a decade earlier. At the first Conference held in Calgary in September 1958, noting that the delegates came from all ten Provincial Associations and represented 12,000 individual members in 116 local Associations, he called this a show of unity that could “awaken a sleeping giant” (Cole,1998). This new national

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[6] Donna Britten, Past President of the Toronto Association reported that the couple’s son had told her:"it was not my father, it was my mother, and she was also the one who sent the letter inviting parents to a meeting”. Donna Britten rose from her chair to make this remark to participants attending a session called “Mothers and Memories” at the 50th Anniversary Conference of the Ontario Association for Community Living held in Toronto, November 27, 2003.

organization that emerged out of widespread discontent with social and educational arrangements that excluded children with intellectual disabilities would soon have significant impact on agencies, professionals, school authorities, and government representatives across Canada.

This impact was further strengthened by events taking place in the United States. The first parent group, the Cuyahoga County (Ohio) Council for the Retarded Child formed in 1933. In 1936, the Washington Association for Retarded Children organized followed a few years later by the Welfare League for Retarded Children in New York. By 1950 there were 88 such groups. In September, 1950, parents came together in Minneapolis to form a national organization called the "Parents and Friends of Mentally Retarded Children" which became known as the National Association for Retarded Citizens (Scheerenberger, 1983). In 1957, Dr. Gunnar Dybwad was appointed its Executive Director. His wife, Dr. Rosemary Dybwad, assisted her husband by taking the job of international correspondence. There was not a staff member to perform these duties. This role became her "professional (unpaid) concern over the next three decades" and provided her with a unique international location from which to document the origins of the parent movement while she served as Secretary of the International Leagues of Societies for the Mentally Handicapped (Dybwad, 1990). The Dybwad's, who have been described as "the most important leadership figures in the field of mental retardation in the modern era," (Minutes, 1987, Binder 30) had a strong affiliation with the Canadian movement. [7]

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[7] President Gordon Porter in his 1987 Annual Report to the 30th AGM informed the Board that this tribute was paid to Doctors Gunnar and Rosemary Dybwad when they

Rosemary Dybwad's particular contribution came from skills we now call "networking." She launched a series of international newsletters and depended on a core of volunteers to translate incoming and outgoing communications. In 1961, Josephine Salloum, the Canadian Association's representative to a meeting of UNICEF, returned to inform the Board that she had met the Dybwad's and that Rosemary had put her in contact with no less than nineteen national parents groups around the world for information and exchange.

Betty Anglin, a founding mother now in her mid-80s, edited the Association's national journal *Mental Retardation* between 1968 and 1976. She remembers when she was personally mentored by Rosemary: "We were all mothers. We were all workers.  We could all write, and we pushed for things. We would go to conferences and she would introduce us"(Ontario Association Conference Presentation, 2003). Years ago she reminisced about this networking in a letter she wrote for a memorial celebration held in 1992 to mark Rosemary Dybwad's life and work:

> Rosemary touched people……especially mothers who received hope and the tools to endure well. ….I have treasured the feeling that I am one of Rosemary's women, along with Lotte, Ingeborg, Ethel, Delores, Althea, and all those women in Omaha, and  Brazil….Memories will surface for the rest of my days. One comes [to mind] immediately: sitting at the rear of a darkened conference room Rosemary leaned over and said, "I miss your magazine."  "Was it really good?" says I. "You know it was," she said

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were honoured at the 25th Anniversary of the Kennedy Awards which he himself had attended as a representative of the Canadian Association.

> sternly….and then I knew. (Anglin, personal correspondence, December 12, 1992).

However exceptional leaders such as Rosemary Dybwad were, ordinary parents, especially mothers, were the backbone of national Associations such as the Canadian Association. Once they encountered mental retardation in their own families and recognized the enormous stigma attached to it, they became radicalized through a deepened awareness of their own stigmatized position as the alleged creators of this “defective” condition. The term “defective” was applied to a general class of people regarded as idiots, imbeciles, feeble-minded, dumb, deaf, blind, epileptic, insane, and delinquent. The term “mental defective” was used to distinguish people with mental retardation from the general class (Roeher, 1996). As mothers, they were held accountable for the failure of their child to measure up to a normative standard of behaviour and independence. They were faulted by professionals as “bad mothers” for producing children that “went wrong” and for their “grassroots unwillingness to concede the diagnosis” (Ladd-Taylor & Umansky, 1998, p.109). The most notable anti-mother laws of the early twentieth century were those permitting the compulsory sterilization of the “feebleminded”. The perception of people with intellectual disabilities as a “menace” and unfit to bear children gained hold as a result of the eugenics movement. In 1927, the United States Supreme Court upheld the principle of compulsory eugenic sterilization in Buck v. Bell. The following year the province of Alberta introduced the first eugenics sterilization law in Canada, followed by British Columbia in 1933; neither were repealed until the early 1970s which resulted in many Canadian women and girls with intellectual disabilities being sterilized without their consent. This was the cultural milieu in which mother’s insistence on their own and their family’s “respectability” (Castles, 2004; Hillyer, 1993) shaped the organization’s rhetoric and reform agenda. In radically reframing mental retardation as a social problem worthy of sympathy, interest and understanding in the society-at-large and in offering a vision of a better future they created an advocacy movement with a “belief system of extraordinary power”(Freeman, 1999, p.22).

## Volunteering

Mothers joined local groups not only to further their goals and objectives but for the opportunity to share concerns and interest with like-minded people (Brockley, 2005; Jones, 2004; NIMR, 1978). Traditionally, their point of entry was a dual process of membership and service. First they became involved in the direct operations of the organization, later graduating to a more administrative voluntary role (Naylor, 1973; Wolfensberger, 1973; Dybwad, 1990). Each level of volunteering presented particular challenges.

At the operational level they helped at the office, put out organizational letters and bulletins, stuffed envelopes, and assisted in community fundraising campaigns to pay for materials, space and teachers. They provided transportation to recreational activities, and worked with “trainees” in sheltered workshops. In many cases they visited other mothers with newly diagnosed children and invited them to join the Association. Often they started and then took their own child to quasi-educational child development programs, typically in a church basement with untrained teachers that operated a few hours a day on a few days a week. The mutual support that came from immediate contact with other mothers of disabled children was crucially important. Here lay the origins of the important social networks that supported and sustained activist mothers in their work. Betty Anglin remembered what it was like in the mid-50s when her son was born: “There was just no help. We weren’t getting it from the medical people. But you have to get the facts and face up to them. Parents met and we learned together” (Anglin, 2003, Ontario Association Conference Presentation). As the Associations grew and shifted from an informal family-operated organization to a more formal one with somewhat bureaucratic structure these volunteers experienced tensions that came with the expansion of services, the employment of full-time staff, the identification of new sources of funding, and struggles to maintain identity and domain (Kramer, 1987; Wolfensberger, 1973).

At the administrative level they served on various types of committees, task forces and boards of directors, and participated in planning and evaluating the broad framework upon which specific program and service activities were based. They began to realize it was not possible to be part of a voluntary organization that was unrelated to government policy and action. Here volunteers experienced the growing power of professionals, the double-edged nature of receiving public funds, and they confronted the thorny question of whether Associations could provide effective advocacy and speak out for families with intellectually disabled children while receiving government funding to provide services (Wolfensberger, 1973).

No matter in what capacity mothers served, women's role became a metaphor for a broader cultural and ideological debate about social values. Just when the local and provincial Associations were flourishing they became surrounded by the stormy debates in the 1960s that raged about voluntarism and the role of women. On one side of these debates were feminists and their organizations; in their view volunteer work downgraded women's abilities, increased their dependence on men and jeopardized their chances for "equal pay for equal work" (Rowbotham, 1992; 1997; Rosenberg, 1992; Rebick, 2005; Baines et al., 1993). Voluntary sector organizations were seen to perpetuate the image of women as "servants" or "social homemakers" (Amott & Matthaei, 1996), and in so doing, support sexist traditions. Traditional divisions of work and power that ghettoized and confined women's activities signified there was little room for women at the top (Bakal, 1979; Kaminer, 1984; Kanter, 1977).

On the other side of the argument were organizations, traditionally led by socially prominent and wealthy women, who believed that far from keeping women subordinated, volunteer work allowed women to achieve positions of responsibility denied them elsewhere. In addition, they strongly endorsed the need for "professional volunteers" as guardians of the moral well-being of society (Bakal, 1979, p.79; Jeansonne, 1996). By 1971, the second wave of feminism had gone so far in opposing "traditional values" that the National Organization of Women in the United States passed a resolution proposing that women should only volunteer to effect social change, not to deliver social services that it deemed little more than demeaning unpaid housework.

> Rather than have a woman teach a child to read on a one-to-one basis, we would like to see a woman devote her efforts to changing the system that failed to teach the child to read. As long as women don't continue to challenge that national priorities be reordered, they are propping up a system that would fail without them. These women are rushing in with band-aids for a system that is in need of massive reorganization. (Quoted in Bakal, 1979, p.80).

The "new woman" could be an activist, she could work without pay to change an inequitable system, but she should not be a volunteer in the traditional sense (Kaminer,1984; Traustadottir, 2000). Lobbying for funds to establish a public welfare system was permissible, but working for free with needy individuals was not. Such service-oriented volunteerism only served as a safety valve for women's energies, giving the illusion of participation with no real power (Loeser,1974; MacIvor, 2001). She could, however, be involved in self-help organizing that linked women in the family to wider neighborhood networks and concerns as an extension of the domestic role (Rowbotham, 1997; Rebick, 2005).

It is difficult to distinguish between service work and advocacy when those closest to you and the members of your community are the people at risk. For grassroots mothers who started the Associations, it was often necessary to work in both directions; applying the Band-Aids and creating the services, and at the same time working for broader social change (Abramovitz, 1999; Zakanyi, 2001; Naples,1998b; Kaplan, 1997; Herda-Rapp, 2000). For Paulette Berthiaume, Audrey Cole and Jo Dickey, the women in this study, volunteering gave them their political life at the civic and associational level and introduced them to the broader political process as activists and community leaders (Berthiaume, 2001; Cole, 1974; Dickey, 1978). But they encountered a number of contradictory messages along the way. They were caught between cultural admonitions that warned them against being overly-concerned and smothering mothers, while making them feel guilty for not staying at home. They were willing to get involved through their local Association into public life but found themselves exposed to criticism for stepping outside women's traditional domestic role (Rowbotham, 1997). They were wedged into the dynamics between boards of directors and volunteers and experienced a gendered division of labor where they were cast not as leaders but as cheerful "workhorses" (Rebick, 2005) and "unheralded female foot-soldiers" (Abramovitz, 1999).

These "contradictory impulses" corroborate Taylor's research on how gender differences are inscribed in social movement organizations. How the Association differentiated between paid or volunteer status and leadership or support workers confirms one of the interlocking organizational processes identified by Acker (1990) in which the division of labour is constructed along gender lines. From the beginning, mothers of disabled children created informal networks for mutual support and information. Excluded from sites of power and influence as a result of gender differentiation within the Association, they learned to exercise their leadership at the community and grassroots levels (Reinharz, 1984; Astin & Leland; Taylor, 1999; Abramovitz, 1999; 2000). In time these networks became a strong power base for activist mothers.

In 1965, Executive Director Allan Roeher, in his Annual Report spoke highly of the “loyal and industrious corps of volunteers who gave service on a regular basis at the national office, performing such tasks as addressing envelopes, collating, stapling, and assembling materials.” Immediately following his report, it was moved and seconded that

> a sincere vote of thanks, on behalf of the Board and the entire membership of the Canadian Association for Retarded Children be extended to this volunteer group of ladies who regularly, willingly and cheerfully work at such a variety of useful tasks for our organization and to the ultimate benefit of the retarded and through their families throughout Canada. (Minutes, 1965, Binder 8).[8]

The organization made good use of its volunteers but reflective of the time, it placed women in a marginal status. This was true even in an organization founded by mothers. The new feminists’ proscriptions meant little if they were heard at all.

## Governing the Organization

The following general picture captures the organizational environment of the Canadian Association in the 1960s. The Association was founded as a grassroots organization, with constitutional authority for the democratic election of provincial and national governing bodies vested at the local community level. In this respect the

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[8] The motion was carried, “unanimously – with ovation.”

national body is unique among major national health agencies in Canada. But it is also vulnerable to the many divisive factors implicit in federated democratic organizations. Each of the local Associations is autonomous. Each plots its own course and defines and pursues its goals in keeping with local needs. Each is responsible for obtaining the funds required to carry out its activities. They share few commonalities in terms of size, program mix, fund-raising and advocacy/service role.

The boards of directors of the provincial Associations are elected by local Associations, on a regional basis. Among other duties, these volunteer boards set provincial goals and policies, issue charters to new locals and are responsible for the management of provincial operations, including fund-raising. Their leadership role varies from province to province as does their involvement in supporting and guiding the work of their locals. By and large they define their success by the positive responses of the provincial government to the needs of the children and adults with intellectual disabilities.  The Canadian Association, created by the provincial Associations, is governed by a member board that is representative of provincial groups. The board is responsible for setting policy, directing the operation of national office services and speaks for the organization in Canada as a whole.

The Canadian Association is similar to most other voluntary agencies that perform a number of important social roles and are often celebrated as an important democratizing force. They are pluralistic agencies serving minority or underserved populations with citizen participation at their centre (Kramer, 1987; Powers, 1996; Shapiro, 1993). Such agencies have the capacity to pioneer new programs and frequently deliver services that government may be unable or unwilling to assume.

They also act as advocates, critics, and watchdogs, pressuring government to extend, improve or establish needed services for minority groups (Minkoff, 1995). However, questions have been raised about how democratic such voluntary organizations actually are (Kramer, 1987; Powers, 1996).  Their Boards are typically large, with twenty-five to forty members. But whatever the size, there is a tendency for policy-making to become concentrated in the hands of a few self-perpetuating board members. Shaiko (2001) suggests that high-status community members, often the white men from the corporate and professional community, are disproportionately represented on the boards of significant non-profit organizations, particularly hospitals and universities and large arts organizations. But nonprofits considered “less vital”, including social service organizations, maintain boards that more often consist of women and men with few corporate ties (Chernesky, 1998; Middleton, 1987). Although the non-profit sector tends to be characterized as independent, flexible, innovative, and experimental, boards tend to select like-minded members, preferring those who fit in and hold values and attitudes compatible to the organization’s work as incumbent board members. Informal networks act as a screening device to judge potential candidates and their abilities to offer, for example, managerial skills, policy expertise, constituency representation, financial input, political connections, and celebrity status (Shaiko, 2001; Middleton, 1987; Chernesky, 1998).

Some boards develop a hierarchy of committees with high-status members on the influential executive, fund raising, and nominations committees, and low status members on the less prestigious program and personnel committees. The executive committee, even when controlled by by-laws, tends to become a powerful body, an "inner core" when its members are officers and committee chairpersons who are the most active board members. The nominations committee performs the gate-keeping role, determining which new members are recruited and oriented. This similarity among board members reinforces relationships, social connections, status and respect, earning non-profit boards the accusation of "playing it safe", or being, "conflict adverse", and tilting towards the status quo. While collegiality increases the efficiency of large boards, it also minimizes the ability of those not in the inner core to participate. A governing board infiltrated by male bias diminishes opportunities for the selection of female directors (Morgan, 1997; Gherardi, 1995). Moreover, if a glass ceiling exists at the governance level and the barriers to breaking through it are organizationally based, then women are more likely to occupy the lower rungs on the ladder (Ferguson, 1984; Shaiko, 2001; Chernesky, 1998).

These dynamics found their expression at the national level and characterized the organizational terrain that had to be negotiated. Yet beneath the level of the national and provincial boards much else was going on. Almost immediately after its founding, organizational tensions arose between the volunteers and the national board revealing sharp differences about what women meant by "getting active."

To many women it meant a mothering role of service of a traditional kind. They organized bake sales and bingo nights to raise funds, hosted children's parties and taught preschool classes when there was no money to hire a teacher. Paulette Berthiuame collated and stapled newsletters for her local Montreal Association in order to meet other mothers; "getting active" to Paulette meant "being on the ground". To others "getting active" meant playing a pivotal role in shaping the organization agenda for action, taking risks and making advances in policy, providing lifelines of information to other parents, and illuminating how the restricting experience mothers and their children faced were socially constructed and might be challenged by social and political means. Audrey Cole lobbied the Board of her local Ottawa Association, to “do something for kids like Ian”; “getting active” to Audrey meant advocating for “the bigger picture.”

Women served in positions of responsibility at many levels of the organization from the start. They were executive officers, committee chairpersons, board members and task force members. However tracing the trajectory of their organizational careers and the types of assignments they were offered reveals a pattern of persistent gender inequality.

There is no question that women were underrepresented in leadership roles. It took ten years from the time the organization was founded in 1958 until a woman was elected President. Women moved in and out of top positions on the Executive Committee but always in a disproportionate ratio to men, and frequently as the only woman. For example, in 1958 Adele McGrath, a mother from Ontario was elected Vice-President and served in that capacity for three one-year terms. But she never received the presidential nomination. Her departure in 1961 left a gender gap since no other women were nominated or elected to the executive committee that year. In 1963, Louise Stuart, from Quebec, became Vice-President and held that office four consecutive terms under male Presidents. During her tenure in office she devoted hours of volunteer labor to prove her leadership capacity. She coordinated the National Conference twice; represented Canada in legislative negotiations with

American congresspersons; and in 1965 organized a Gala fundraising dinner at the Royal York Hotel with Rose Kennedy as the guest of honour. It took almost a full decade for Stuart to be elected the organization's first woman President.

Women were significantly underrepresented at the Board level. One or two women were included in every provincial delegation to annual general meetings (according to the by-laws smaller provinces had 3 voting delegates, the largest, Ontario had 8 delegates). They were also appointed to chair national committees but they were consistently outnumbered by men on the National Board. Women filled only one third of the fifteen positions on the National Board between 1958 and 1960. In 1961 only one woman was elected to the Board, and in 1962 only two. The same year women headed nine national committees; but the top positions continued to be filled by men.

When it came to committee appointments, women were tracked into "women's work." During the early years Board minutes reveal a gendered pattern in which women were asked to chair those committees concerned with domestic issues: education, home care, recreation, and community liaison. Who chaired the committees mattered. The internal debate over "who should chair the Research and Clinical Services committee?" provides an early example. Josephine Arrowsmith, appointed the first chair in 1959, was credited with having "done a good deal to make the CARC research minded" during her term, but when she stepped down the following year a dispute erupted over her replacement. There were those who preferred to appoint a doctor, for example, a "respected pediatrician". Others recommended the chair be "sociological" rather than "medical" given the nature of the problem faced by parents and the community. Women called for the submission of a “broader list” from which a chair could be chosen (Minutes, 1960, Binder 3). This debate between the value of bio-medical knowledge and socio-political expertise was replayed over the years as new understandings and perspectives on disability shifted the field of research from the body to broader society (Oliver, 1990; Linton, 1998).[9] This shift from medical to sociological proved receptive for valuing mothers’ knowledge about their children and created a space to challenge the hegemony of medical opinion. Three examples demonstrate the spaces women opened in making this shift.

In the first of these, Milla Rasmussen, who attended a 1962 Conference on Exceptional Children in Ohio, prepared a summary for the Board in which she highlighted only those sessions she thought would be “most helpful.” She reported on new developments in special education, curriculum development, teacher training and the “President’s Panel on Mental Retardation.” Notably, none of these were “medical” (Minutes, 1962, Binder, 5). In another instance, in 1964 the Association

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[9] By 1960 the committee was renamed the Scientific Research and Advisory Board (SRAB). Dr Allan Roeher, then the Provincial Coordinator of Rehabilitation in Saskatchewan, joined the SRAB in 1960. He proposed the committee raise $100,000 to launch a research program, the Canadian Fund for the Mentally Retarded, and with Board approval hired a director based at the central office but who traveled across Canada to survey the needs for further research and training. The committee members agreed that hiring a university faculty member as a research director was “an excellent start”; and that it need not be “a medical graduate”. This powerful committee was the forerunner to the internationally recognized National Institute on Mental Retardation (NIMR) founded in 1967 as a nerve centre for the collection, distillation, and dissemination of the latest information and developments in all aspects of mental retardation. Thus began what would become Allan Roeher’s twenty year relationship with the national organization. He served as Executive Vice President of the Canadian Association 1962-70, Director of NIMR 1970-76, Special Consultant to the Canadian Association 1976-79. He died in 1983 in a plane crash. In 1986 the Institute was renamed in his honor, as The G. Allan Roeher Institute.

marked the 100th anniversary of the “listing of the syndrome by Dr. Langdon-Down” by agreeing to find an alternative to “mongoloid, mongolism and mongol baby,” terms that mothers found “repulsive” (Minutes, 1964, Binder 7). In a third, activist mothers in the 1960s rejected the narrow definition of “prevention” as it applied to medical research into specific diseases. Instead, they lobbied to find a definition more suited to the social determinants of disability; that way interventions would look towards the “prevention” of such social factors as malnutrition, prejudice, warehousing and environmental dangers (Moise, 1976).

Women often filled the most labor intensive roles of the Association. They were always assigned to coordinate the National Conference, a “mammoth task”, widely recognized as “the organization’s most time consuming and demanding volunteer job”. Staff in particular, “dreaded the thought of this last major volunteer role ever being added to the office workload”. (Roeher, quoted in Minutes, 1968, Binder 11). Adele McGrath chaired the first National Conference and was asked to do it again the following year. The Association “hoped” that she would agree, but “not from a sense of duty, against her own judgement”(Minutes, 1958, Binder 1). Mrs. McGrath replied that “this is the kind of work she enjoys doing and if it is the wish of the Board she would not mind undertaking it.” However, she added that, “the 30 hours a week she was spending as a volunteer was leaving her feeling strained and in need of more support” (Minutes, 1958, Binder 1). In 1961, however, the Nominating Committee did not include her in the slate for Executive and Board positions. She was nominated from the floor first for Vice-President and then for the Board, and lost both times. Only men were elected to the executive and only one woman to the

Board. Whatever Adele McGrath’s disappointment, she continued to serve and even take on a new portfolio, Chair of the International Affairs Committee. Women chaired both standing committees and special committees. However, just which committees they were asked to chair, provides a vantage point to assess how assumptions about gender were embedded in the Association’s early institutional practices and bureaucratic processes.

### Standing Committees

There was a hierarchy of committees in which high-status male members were asked to chair the more influential committees such as research, policy, organizational procedures, resolutions, legislation, and nominations. Women, on the other hand, were put in charge of the less prestigious standing committees on religious education, education, home care, community liaison, recreation, education and the annual conference.

From their written reports it is clear that the women who chaired committees in the young Association had a strong vision and often embraced controversial issues. For instance, Louise Stuart, chairing the Committee on Religious Education, urged the organization not to ignore “the spiritual life of the mentally retarded”(Minutes, 1962, Binder 5). In a very spirited 1962 committee report she stated: “Providing services such as education and habilitation are important, but no matter how skilled George becomes on the printing press in a sheltered workshop or industry; no matter how proficient Mary becomes as a mother’s helper it is their spiritual depth that will comfort and sustain them in times of stress sorrow, rejection or emotional upset" (Minutes, 1962, Binder 5). Stuart also introduced an official prayer for the Association but families would not adopt it, insisting this was a matter for home, not community. At the same time, the Education Committee headed by Milla Rasmussen, undertook two major tasks: (a) an examination of federal/provincial arrangements as they related to (the lack of) services for native retarded children; and (b) a determination of the feasibility of educational programs in hospital schools (institutions) being placed under the jurisdiction of departments of education rather than departments of health. This exploratory work on such complex matters contributed to "education" remaining a major concern throughout the life of the Association.

Under the leadership of Therese Lavoie, the Home Care Committee pioneered an alternative to institutional placements. For a long time her vision to establish opportunities for intellectually disabled persons to be cared for in their own home through big brothers/big sisters, foster care and babysitting arrangements took a back seat to the "institutions" committee. Home care became a dominant theme in the Centennial Crusade Fundraising Project in 1964 and increasingly central to the mission of the Association in the years to come. Meanwhile, June Braaten, chair of the Recreation Committee, encouraged municipal and volunteer recreation agencies to run programs for disabled children. In 1961 year she approached the Canadian Association of Girl Guides to change their membership criteria by replacing the narrow membership clause that read "open to girls with an IQ of 50" with the less stigmatizing "open to girls who are able to understand, participate and benefit from the Girl Guides Program"(Anglin & Braaten, 1978; Minutes, 1961, Binder 4). Through these and countless other efforts to enable disabled children to participate in sports and recreation, Braaten developed a model for Fitness and Amateur Sport in Canada that gained international prominence (Minutes, 1968, Binder 11).

As chair of Community Liaison, Dorothy Reid called for a broad based disability coalition. Her 1962 committee report recommended that the various disability organizations join forces to form a "better bargaining agent for change":

> The day arrived long ago for the serious thought and constructive effort that should have been made towards the function of a Canadian Council composed of representatives of all National organizations working to provide training, education, rehabilitation for all children and adults who deviate from the normal no matter what the deviation is (Minutes, 1962, Binder 5).

Reid was ahead of her time. Her call for a broad based disability coalition was not heard again until the International Year of Disabled Persons in 1981 (Obstacles Report, 1981).

The women who organized the annual conference in the early period had a bold vision. Hoping to provide visibility for their concerns, Adele McGrath invited both Dale Evans and Pearl Buck to be keynote speakers at the 1961 conference in Vancouver. Both mothers had written books about their intellectually disabled children. The following year, Louise Stuart suggested that, "it would be timely to have one of the Kennedy family – they are all good speakers and would have great drawing power"(Minutes, 1962, Binder 5). In 1963 in collaboration with Allan Roeher, Stuart invited a prominent scientist to address the 6th Annual General Meeting to encourage the membership to think of the bigger picture. Roeher and Stuart believed that "an advanced effort" was needed "to emphasize new progress in the field and to realize that the themes of a few years ago are sometimes invalid, or inadequate" (Minutes, 1963, Binder 6).

### Special Committees

In addition to the standing committees, women also chaired special committees and took on particular assignments. In 1962, Una Johnstone from Manitoba, organized a Special Programs European Tour to "prominent centers, schools, sheltered workshops in European countries which are far advanced in the education and welfare of retarded children; to gain insight into what we can do better by way of facilities for retarded children in Canada" (Minutes, 1962, Binder 5). The tour visited Stockholm, Copenhagen, Hamburg, Amsterdam, London, Nottingham, Edinburgh, and Aberdeen. Given the cost, $596.25, it is likely that only the affluent members of the Association were able to join the tour.[10]

Women clearly assumed leadership roles when the doors opened to them and were generally active as organization members, moving and seconding motions, adopting reports, often as a tag-team. But they also worked behind-the-scenes on significant projects for which they only occasionally received recognition. In 1963,

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[10] The cost of $596.25 included the flight, tour, meals, sightseeing, and transportation through Europe by motor coach.

Laurie Hall, a Past-President praised a group of women activists in the Association for their successful effort to have the Federal and Provincial Governments hold a national conference on mental retardation. This Conference, held in1964, was officially appreciated by Board members who described it as “a major achievement in the life history of the Canadian Association for Retarded Children which has probably done more than any single previous event to advance the total cause of mental retardation in Canada”(Minutes, 1965, Binder 8).

Despite the praise and success of the work by women leaders, internal pressure existed to create a “Women’s Auxiliary.” As early as 1959, at the second national conference in Prince Edward Island, the Association included a session on “Women’s Auxiliaries and Volunteer Groups.” Clifford Bowey, Chair of the first Institutions Committee publicly thanked attendees and presenters for building, “good community relations” in their work with the training schools (as the institutions for the mentally retarded were euphemistically called at the time). Board members again expressed the “desirability of a session on Women’s Auxiliaries” for the 1967 conference. Some of the women’s auxiliaries worked inside the institutions and their insistence for recognition was part of a larger struggle between “community parents” and “institutional parents” about which more will be said in Chapter 5. Others, in Quebec and Toronto, were community based. In 1965 the Quebec Women’s Auxiliary sold saving bonds. In 1967 the Toronto Women’s Auxiliary raised $3500 for a student research bursary. But in general the women’s auxiliaries were marginalized in the organization that they had been central to founding. Unlike the “Kinettes”, the ladies auxiliary of the Kinsmen Club, the men’s service organization that donated a building to the Association in 1970, the women's auxiliary of the Canadian Association did not adopt a diminutive name for themselves.

The reference to women in the Association's minutes reflected the times but seems paternalistic today. In his 1968 Executive Director's Annual Report Alan Roeher stated: "The life blood of our organization is still the busy volunteer whose own time is limited but whose contribution, given a little help, is invaluable" (Minutes, 1968, Binder 11). Whether as appointed committee chairs or as movers and seconders of motions, the minutes identified women first in terms of their marital status, then by their husband's initials, and finally by their own first names --in brackets. For example, the newly appointed chair of the Community/Institution Liaison committee (1959) was listed as "Mrs J.G.M. MacDonald (Helen)." The chair of Special Projects (1961) was presented as "Mrs A.J.F. Salloum (Josephine)." This practice remained in effect until the 1980s.

The ways in which women's work and responsibilities were allocated and ranked in the early life of the Association confirm Acker's (1990) analysis of the interlocking processes that construct gender. She noted how the symbolic indicators of structure as well as symbolic indicators of individual identity contribute to gender stratification. The data in this study corroborates her analysis. Structural indicators were evident in the way women were underrepresented at the National Board; in how they were tracked into "women's work"; how they filled the most labour intensive roles and often worked behind-the-scenes; and how the committees they were asked to chair were typically the less prestigious ones. Symbolic indicators of individual identity were evident in the references to women in the minutes: first by their marital status, then by their husband's initials, and finally by their own first names in brackets. The next section will show how another of the interlocking processes, the use of symbols and images to reinforce the masculine/feminine division, were used by the Association in fundraising.

## Fundraising

Fundraising was a major preoccupation during the early years. The Association adopted two major campaigns to keep the organization financially solvent – the National Crusade for Canada's Mentally Retarded and the Flowers of Hope Campaign. This section illuminates how these operations drew on women's gendered identities.

In 1959, President Laurie Hall cautioned that "unless the Association can find a source of funds independent of its members" it would never be able to "undertake a program" of research and organizational activities (Minutes, 1959, Binder 2). Three years later the national operating budget was still under $100,000. Although the financial situation improved somewhat in 1964, Executive Director Alan Roeher reported that "the Canadian Association for Retarded Children has the weakest fund organization structure among major voluntary agencies in Canada (Minutes, 1963, Binder 6).[11]

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[11] The 1964 budget shows the Association raised $45,000 through assessments from its provincial affiliates; received an additional $180,000 for the John F Kennedy Memorial Fund, $100,000 from the Scottish Rite Research Foundation, $43,000 from the Foster Foundation, $25,000 from the federal government (up $10,00 from the previous year) and small additional donations (Minutes, 1964, Binder 7).

During the formative years the membership consisted almost entirely of parents and families. But over time as the Association gained momentum, it changed its activities from service provision to advocacy and the number of non-parent volunteers increased substantially. A 1976 survey conducted to inform a 5-year planning and fundraising initiative reported that non-parents comprised fifty percent of the Association.[12] The authors of this survey attributed the rise of non-parent membership to the credibility, viability, and public acceptance of the movement and its objectives. They reported that the interest of the public at large in the Association and its cause was impressive. However, on the basis of 100 questionnaires and personal interviews conducted to complete the survey, they came to a number of conclusions: that this broader membership did not reflect "above-average wealth"; that the membership was not a major source of private funds; and that Association volunteers were "first and foremost attuned to service delivery and only secondly to fund-raising" (Fund-Raising Study Report, p. 6, Binder 11). Unlike many national voluntary agencies, the Association could not list among its members leading representatives of the business and corporate community at either the general membership or governing board level (Minutes, 1977, Binder 20). One corporate executive, quoted in the study, said: "If the Association doesn't soon start enlisting some influential and experienced businessmen to its boards – particularly at the national and provincial levels, I fear for its future" (Fund-Raising Study report, p.18,

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[12] *Fund-Raising Study Report for CAMR*, prepared by Gordon L Goldie Co. Ltd., Toronto November, 1976.

Binder 11). That fear has hovered over the Association throughout its history. Not surprisingly, fundraising continues to be a major preoccupation.

Two styles of fundraising dominated the 1960s. As the names of the campaigns suggest, gender played a role in several ways. For one, the high-profile, well-publicized and generously resourced campaign, the National Crusade for Canada's Mentally Retarded, was symbolized by the "flying crusaders", typically "busy men" who flew into communities to recruit other leaders. In contrast, the Flowers of Hope campaign was a grassroots, direct mail and door-to-door campaign that depended on thousands of mothers across the country to write letters, make phone calls, stuff envelopes, deliver mail and march in their neighborhoods to collect donations.

Second, the ambitious campaign plan for what became known colloquially as the "Crusade" excluded women. It was devised and resourced by Harry "Red" Foster, a man with personal wealth, social connections, business savvy, and a brother with Down Syndrome (Foster, 1959). Foster appointed himself Honorary Chair, recruited senior corporate business leaders to serve on his Honorary Board of Governors and turned the campaign into a Centennial Project to commemorate Canada's 100th birthday in 1967 (Minutes, 1965, Binder 8). Future replications of this Crusade were equally ambitious but never as successful. This massive fundraising campaign between 1965 and 1967 succeeded in raising $15 million for a series of demonstration projects, many based at universities, to increase education and technical knowledge in the field of mental retardation. The most lasting of these was the National Institute on

Mental Retardation (NIMR) as the Association's research, information and technical arm.

When the proposal for the "Crusade" first came to the Executive Committee in 1964, it was challenged on the grounds that it left women out. Louise Stuart (then Vice-President) asked whether the Board of Honorary Governors was to be "entirely male." This was affirmed by Mr. Foster who explained that "ten or twenty prominent businessmen and industrialists in Canada would be invited to fill that role." Mrs. Hunt, Chair of the Information Committee, asked why it was "Businessmen only?" She suggested a need for greater diversity, "a range of professions" from which to draw. That idea was dismissed and a motion passed which authorized the Officers "to establish an advisory board comprised of some of the top businessmen in the country" (Minutes, 1964, Binder 7). Briefing notes for the solicitation stage of the campaign advocated getting "the right man to call on the right man"(Minutes, 1965, Binder 8).

Much of the seed-money for this Canadian Centenary Project consisted of donations to the Canadian memorial fund established to commemorate President Kennedy for having established the President's Committee on Mental Retardation which brought unprecedented profile to the issue of intellectual disability.[13] Supplemented by a $19,000 gift from the Foster Foundation, the Crusade was officially launched in September, 1965, at a Gala Dinner at the Royal York Hotel organized by Louise Stuart, one of the organization's women activists noted earlier. Rose Kennedy was the guest of honor at the Gala that was attended by Canada's

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[13] The President's Committee on Mental Retardation was established in 1962 and reported annually. The 1976 report, *Mental Retardation: Century of Decision*, was especially significant for its breadth and depth on the state of knowledge and accomplishments in the field over 25 years.

Governor General, the Prime Minister, the Premier of Ontario, the Mayor of Toronto and the “heads of many of the country’s major corporations”(Minutes, 1965, Binder 8). Not surprisingly, the event was covered by national television. The Symbol of the National Crusade, a sad looking little girl with long hair, appeared on the mast head of the *Crusader*, the Campaign’s weekly newsletter and was part of an extensive communication strategy designed to appeal to pity (Shapiro, 1993, pp.12-40).

As the organization grew, women continued to be sidelined. By the time the campaign ended, the members of the central Advisory Board were “the 70 top names in Canadian business and industry and commerce” with over 300 contacts nationally. In 1966, to take advantage of the “many excellent candidates” brought into the Association by the campaign, the Nominations committee recommended that the Canadian Association change its structure and by-laws by creating five more positions for Directors-at-Large to which these corporate leaders might be appointed. However, the motion was defeated at the AGM (Minutes, 1966, Binder 9). And while the lack of women in the mix did not cause the defeat, male bias continued to characterize the organization’s activities. The organization presented the Crusade’s National Chairman, Deputy Chairmen and all the Provincial Chairmen with personalized, initialed cufflinks manufactured in sheltered workshops. In his annual report to the 1965 AGM in Saskatchewan, Robert Jacques, the National President at the time, paid tribute to this group of men, “the flying crusaders for their flying visits to seek leadership for the campaigns in the various provinces”(Minutes, 1965, Binder 8). Louise Stuart did not receive a mention. The National Crusade corporate campaign was conducted by an old boys’ network.

In contrast the “Flowers of Hope”, the parallel campaign was much more a women’s affair. Mrs A. Buckwold, a mother from Saskatoon, became known provincially and nationally for having first conceived the idea in 1962 (Minutes, 1962, Binder 5).  In 1963, local Associations in Saskatchewan and Alberta tested the Flowers of Hope campaign and discovered its potential for fund-raising and public education. Allan Roeher assured the membership that this was “one of the most penetrating pieces on the market” in his 1963 Annual Report (Minutes, 1963, Binder 6). The Association offered its full support and notified all the provinces. During the 1960s well over 100 local associations across the country conducted Flowers of Hope campaigns.[14] National Association staff and volunteers coordinated the production of promotional materials. The campaign included several strategies. A direct mailing of flower seeds representing “hope” was sent to households around the time of Mothers’ Day. Dorothy West, Chair of the Ad Hoc Committee on Flowers of Hope described the seeds as “a conversation piece” (Minutes, 1967, Binder 10). The idea was that children would plant the seeds and watch them grow while families would associate mental retardation in their minds. The direct mailing also contained a blank cheque and a pre-paid return envelope for the anticipated donation.

Other components of the appeal included a campaign symbol of a “broken heart” designed to exploit this theme of tragedy and affliction; a rescheduling of “Retarded Children’s Week” to coincide with Mothers’ Day to increase the emotional appeal of the drive; the production of “Hopeful Heart Tags” that read: “If they could,

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[14] Statistics about Flowers of Hope activities are hard to find but the 1976 Fund-Raising Study suggested the 65% participation rate represented 100 campaigns, largely conducted in Alberta and Ontario.

they would ask for help and when they can, they will thank you!" and the broadcasting of special recordings to millions of homes.

Public education spots were carried by popular television shows of the time, including: Ben Casey, the Lucy Show, Ed Sullivan, Wayne and Shuster, Hockey Broadcasts, Big Four Football, Bonanza, Don Messer's Jubilee, Juliet, Walt Disney Presents, and The Saint. Highly visible spots were similarly found on the French network. Campaign manuals and promotional materials were designed to support local efforts, including place mats, window stickers, lapel pins for canvassers, text for church service bulletins and thank you cards. Publicity kits and fliers were produced encouraging local Associations to invite their mayors or notable personalities to plant seeds in honour of Mothers' Day and the Flowers of Hope campaign. The slogan for the May 1965 Retarded Children's Week campaign became: "A Flower of Hope Unit and a Knock on the Door for every Canadian Home."

The fundraising campaign in Quebec was particularly vigorous. In 1964, the Provincial Association distributed one million Flowers of Hope units to 50 municipalities and launched the Centennial Rose Campaign. The Lakeshore Association in Montreal sponsored a nationwide competition to select a rose for Canada's Centennial. Mothers sold rose bushes, established test gardens, organized voting and recruited judges. Three varieties were chosen and patented which meant that for every rose bush sold the Quebec Association received 10 cents and an additional 60 cents a bush from several Rotary Clubs who adopted "mental retardation" as their own Centennial project. In June 1966, "Air Canada chartered a flight to present the Centennial Rose to Her Majesty Queen Elizabeth" (Taylor, 1967 p.22 ).

Despite such massive efforts in the early years, the results of the Flowers of Hope campaign were disappointing. The Board's expectations had been raised by the success of other disability charity fundraising strategies, notably the Marching Mothers door-to-door campaign to eradicate polio (Hawke, 1999). The Board learned that although in the United States, the March of Dimes raised only $40,000 in 1938 by 1953 the charity had exceeded $5 million in that year alone (Bakal, 1979). The Easter Seal campaign for "crippled children" and the Christmas Seal campaign for Tuberculosis prompted the Association to consider Mothers' Day Stamps. However, this strategy was never adopted at the national level. The Board did raise the profile of the fund raising campaign by giving consideration to renaming many of the summer day camps for the retarded "Camp Flowers of Hope." The Calgary Association, seeking to boost their campaign, borrowed the idea of a poster child from Easter Seals, their "Timmy and Tammy", and arranged for a full page advertisement featuring a "retarded girl as Miss Hope" in May 1966. The marketing and selling of Christmas cards required a similar grassroots effort by mothers. The earliest cards were designed by disabled children themselves; later, influenced by UNICEF, the selected designs combined pictures with brief explanations. In 1970 Eileen Kleinsteuber, Chair of Christmas Cards Committee, reported the new cards showcased "our people" doing beautiful work in ceramics, leather, metal work and to show "that our organization is winning, that our people are amazing us with very beautiful products and worthwhile results" (Minutes, 1970, Binder 13).

Despite the countless volunteer hours undertaken by women to stabilize this program nationally, by the 1970s it faltered. Committee Chair Dorothy West attributed the failure to “a garden of hope without sufficient caretakers at the National level”(Minutes, 1970, Binder 13). However, a more self-reflective discussion at the Board on whether to continue the program revealed that the “pity” aspect of the promotion had contributed to the decline. In 1970, a Special Committee was appointed to evaluate the program and reported:

> archaic concepts of hopelessness, dependency ….be discarded and that the retarded emerge in our message as a person who has abilities and is capable of achievement….projecting people who physically appear retarded is particularly damaging to the dignity of the majority of disabled people. [It was] too high a price to pay to emphasize negative factors in order to raise funds or attract membership (Minutes, 1970, Binder 13).

The Committee strongly recommended that “hearts and flowers” and the concept of “hope” should be “discontinued in light of the advances and progress that have been made for and by the mentally retarded in recent years” (Minutes, 1970, Binder 13).

This history of fundraising campaigns in the early years of the Association demonstates how gender distinctions and hierarchy were expressed in ideology and cultural practices in the organizational context (Acker, 1990).Images of masculinity and femininity were reproduced by the Association through language, ideas, symbols and emotions in its message to mobilize and influence support (Taylor, 1999).

## Conclusion

This chapter has demonstrated that women were active as volunteers, leaders and fundraisers within the organization. But they also understood that to develop the organizational solidarity and ensure its growth they had to develop an effective national identity. The needed identity was gradually forged as women brought forward a range of issues that reflected their deep understanding of “mental retardation” in its broadest social and political sense. As mothers, they identified concrete problems that affected them and their families, in their neighborhood and in their community. Acting in accordance with “female conscious” (Kaplan, 1997) and “gendered obligation” (Abramovitz, 1999), they learned to mother as activists (Naples, 1998b). While mothers were not alone in voicing their concerns over problematic matters, by wrestling with the issues, taking positions and speaking out, they acquired the skills used to lead new campaigns. There were two important issues that prompted their attention and action in the early years.

The first and most pressing concern was the threat of nuclear war. In 1960 a group of women in Toronto founded the Voice of Women to promote peace and disarmament. Within months thousands of women joined, lending credence to the claim that the Voice of Women was “the seedbed for the second wave of feminism” in Canada (Rebick, 2005, p 3). In a famous campaign, members collected baby teeth from mothers across North America to demonstrate high levels of strontium- 90, a product of radiation. This was part of a strategy to persuade U.S. President Kennnedy to stop nuclear testing and to dissuade Canadian Prime Minister Pearson from bringing nuclear arms into Canada. Mothers of disabled children recognized that “an increase in background radiation due to nuclear fall-out will raise the percentage of children born with physical and mental handicaps” and in 1960, they introduced a Resolution to the Association’s 3rd Annual General to stop nuclear testing (Minutes, 1960, Binder 3).

The second issue was a problematic law: a restrictive American statute governing border crossing from Canada to the U.S. by children and adults with intellectual disabilities. This was a well-known and long-standing problem that especially irritated families because of the requirements that they notify authorities before undertaking any travel and that they post a non-refundable bond. Families described the humiliation they felt having to pay a fee so that their disabled child could cross into the U.S. or having to hide their child under a blanket in the back seat until they went though the border (Minutes, 1969. Binder 12). In 1965, as Vice-President of the Association, Louise Stuart put this law on the agenda because difficulties were being encountered by both Canadian and American families with a disabled member who tried to move across the national borders on either a permanent (immigration) or temporary (visiting) basis (Minutes, 1965, Binder 8). Both National Associations made some joint headway on immigration regulations, but it took three more years of advocacy and lobbying to solve the problem for temporary crossings.

As the first woman to serve as President, in 1968 when she stepped down from office Louise Stuart reflected on “the first mile”. She stated:

> A decade ago, what parent, searching out another parent with a similar problem and hoping to do something to help their retardate, such as a special classroom, could have possibly dreamt that in 1968 they would be sponsoring modern special schools, small group residences, sheltered workshops, and viewing television broadcasts dealing intelligently with the problem that they faced – or in 10 short years launching a $15 million series of highly sophisticated demonstration and research projects? We have gone the first mile, and I wish I could say that the second mile will be easier. I am afraid not…(Minutes, 1968, Binder 11).

This chapter provided an historical overview of the founding of the Association. Conceptually, it is guided by Acker's (1990) theory of gendered organizations and Taylor's (1999) analysis of gender processes in social movements. It focused on gender processes in three organizational contexts that characterized the first decade: volunteering, governance and fundraising. Those institutional practices provided a vantage point for investigating how embedded assumptions about gender influenced women's participation.

The next chapter turns to the activist mothers who took up the challenge of Louise Stuart's "second mile." Jo Dickey, Audrey Cole and Paulette Berthiaume encountered numerous stumbling blocks as they traveled that next mile, individually and collectively. Notable among these was the Association's "gender regime" (Connell, 1987, p. 120) whose divisive roots took hold in the first decade. Their biographies reveal how the disruption of their taken-for-granted life through a personal experience became a social experience, and how they developed an oppositional consciousness that enabled them to see their discontent as systemic. (Krauss, 1998). The following chapters will investigate further obstacles activist mothers faced and how they overcame the odds to wage their campaigns to close institutions and secure human rights. It will be seen that critical to their political success was the formation and development of social networks at the grassroots and community levels.

# Chapter Four

# The Activist Mothers

## Introduction

In October, 1985, the Canadian Association's 28th Conference and Annual General Meeting was held in Alberta, Canada. Leading women who attended that meeting came with a variety of issues they wanted addressed at that Conference. This was the first time Jo Dickey, Audrey Cole and Paulette Berthiaume met on the national scene. They held different positions and had different responsibilities, but they were unified in their determination to urge the membership to take progressive positions on social issues. Jo Dickey, Chairperson of the National Institute on Mental Retardation, was from British Columbia; she had a proposal to change the name of the Institute. She was showing solidarity with people who had been labeled "mentally retarded" themselves and who had campaigned to have this term removed from the Association's name. She also wanted to publicize her provincial government's response to deinstitutionalization; the province was moving residents out of one institution only to place them in another. She wanted the National Association to advocate strongly that residents were moved to appropriate community settings. Until this point the organization had only conducted a letter-writing campaign. Audrey Cole, from Ontario, was Co-Chair of the National Advocacy Committee and a candidate for Vice-President having been recommended by the Nominating Committee. She was commissioned to prepare a background paper on amniocentesis for a scheduled debate at the Annual General Meeting. She brought copies of her report, “Prenatal Diagnosis: Why?” and a draft resolution. She wanted to spark national action opposed to genetic testing. Paulette Berthiaume was a delegate from Quebec. She led a growing parent group that mobilized in response to the government inquiry into institutional abuse at Rivière-des-Prairies where her son lived. She wanted to alert the Board to the struggle for deinstitutionalization forming in Quebec that had implications for the other provinces. She also came with a specific request from the parents’ group for financial support.

The issues of deinstitutionalization and human rights would not have claimed national attention that October, 1985 unless they were already supported at the local and provincial levels. Having it on the national agenda by 1985 was a testament to mothers such as these who laboured in the trenches for years to build support in addition to their own credibility.

This chapter draws on the women’s narratives to highlight significant moments in their political lives; it reveals the meaning the work held for them and emphasizes how their commitment was shaped. From Jo’s first introduction to a local Association which offered a preschool program for Drew, she would lead a national campaign to close institutions by redirecting government funds away from bricks and mortar to funding individuals returning to their communities. From Audrey’s initial editorials in a parent newsletter for the Children’s Developmental Centre which Ian attended, she would write policy briefs, resolutions, and by-laws to push the National Association towards greater recognition of human rights. From Paulette’s beginnings as secretary to a small group of parents whose children lived in the same institution as

Louis, she would find her activist voice to expose abuses at government operated institutions in Quebec and bring that passion to her presidency at the national stage. Together, the biographical accounts in this chapter set a historical context told from below through which to locate the campaigns these activist mothers took up. The chapter is guided by the question: "What does leadership look like when women's voices are at the centre of analysis?" (Sacks, 1988, p.77). The next two chapters will focus on the campaigns themselves. But before turning to the details of the campaigns it is important to examine the particular circumstances that led Jo Dickey, Audrey Cole and Paulette Berthiaume to join the Association and work in it by drawing on extensive interviews conducted with them for this study.[15]

The merit of collecting biography is acknowledged by Astin and Leland (1991) and Taylor (1999). Astin and Leland see biography as "a means of understanding the antecedents of activism and passion, the driving force in leadership behaviour" (1991, p.160). Taylor recognizes the "emotion cultures" cultivated by women's interpersonal networks and the significance of legitimizing "attention to participants' feelings and personal biographies." She sees this as a means to challenge the division between the "public" and "private" spheres (1999 p.27).

This chapter now turns to the biographies of activist mothers. It begins with Jo Dickey, continues with Audrey Cole followed by Paulette Berthiaume. Each account is organized in two sections. Section One: Antecedents to Activism explores the

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[15] Unless otherwise indicated all quotations are based on interviews conducted between January 2004 and July 2005. With Jo Dickey on January 15, 2004 (Vancouver), February 28/29, 2005 (Toronto), April 15, 2005 (Toronto), and July 10 (2005); With Audrey Cole on March 15, 2004 (Smiths Falls, Ontario); November, 2004 (Toronto) and July 10, 2005 (Toronto); With Paulette Berthiaume on March 14, 2004 (Ottawa)and July 10, 2005 (Toronto) . A focus group interview was held with all three on July 10, 2005 (Toronto).

circumstances that contributed to mother's activism under three sub-sections: (i) the onset of disability; (ii) the experience of disability discrimination; and (iii) external influences. Section Two: Activist Activities investigates their activism at (i) the local level and (ii) the national level. A third section, Section Three: Styles and Skills of Activists analyzes their different methods and talents by drawing on the mothers' own narratives and literature sources that apply a feminist analysis to women's leadership in social movements (Astin & Leland, 1991; Sacks, 1988; Bernal, 2002; Bookman & Morgen,1988). These conceptualizations of women's leadership inform the analysis of three sets of activist styles and skills represented by the three women in this study. Jo Dickey mobilized the Association as a Catalyst, Audrey Cole troubled the Association as its Conscience and Paulette Berthiaume empowered the Association as a Capacity- builder. The chapter concludes with an analysis of mother's activism and gendered identities in the Canadian Association for Community Living.

## Jo Dickey

*I was invited to Australia in the mid 1990s to meet with families and talk about how we closed the institutions in British Columbia. When I arrived, the immigration officer said, "So you're Jo Dickey. Have you seen the morning paper?" And of course he knew I hadn't seen the morning paper, I'd been sitting on a plane all night. So he shoved it across the desk and it [the headline] read, "Activist from Canada arrives in Australia."*

*“Well,” he said, checking me over, “you don’t look like much of an activist to me.”*

## Antecedents to Activism

### Onset of Disability

Jo Dickey’s son, Drew, was born in 1955 in Vancouver. Although Jo saw he had difficulty breast-feeding, he was sent home from hospital as though nothing were the matter. Three public nurses came to the house on separate occasions and each left saying, “he was fine”. When her mother noticed his ear lobes were blue, she took him to a specialist who diagnosed a “hole in his heart.” Drew was then six weeks old. In 1955, pediatric heart surgery was not available. Instead, the doctor wrote a prescription, predicted Drew had six months to live, and sent him home. Drew would prove the prognosis wrong and live until 2004.

> We knew there was damage and …from then on it was hard. [But] it meant every day we were thrilled to have him. Never in my wildest dreams would I have expected he would reach 49 years old, never…

A neighbour, who also had a disabled child, told Jo about a preschool program run by the local North Shore Association for the Mentally Retarded. She enrolled Drew three mornings a week, started to attend meetings, and gradually got drawn into the work of the local Association. For Jo, the simple act of joining a group was an important first step to get beyond the sense of isolation. As MacIvor notes (2001), women are often more comfortable in informal groups and ad hoc activities that combine with child care than conventional political activity.

> In your naivety you just see what needs to be done. I could see families, mothers in particular, needed a place to talk to other mothers…There was a very nice pediatrician on the North Shore but I could never understand why she took objection to one mother talking to another. We might say the wrong thing and the wrong thing would be to give hope.

Stimulated by his family and the pre-school program, Drew gradually began to say a few words. However, when he was two and a half, Jo had a kidney transplant. Medical complications kept her in bed for 18 months, much of it in hospital. Visiting rules excluded children. Drew reacted to this separation from his mother, which came at a critical stage in his development, by ceasing to talk and withdrawing socially. At times Jo's husband was forced to rely on strangers to provide child care, "just anybody off the street." The financial implications were devastating for the family, their "budget and everything went down the tubes."

### Disability Discrimination

North Vancouver was a small community which meant that everybody knew what she was going through, but "nobody came" to offer support.

> When you first learn your child has a disability, immediately, immediately you are in a class of your own. You’re different, your child is different, people treat you different, expect more of you, blame you for things, and it’s not that they mean to, it’s just what happens…People ignore you in stores or they tell you your child is making too much noise. So you take your kid out and you never go back.

When someone from her religious congregation finally came it was not to offer help, but to ask for money and lecture her for not attending services. That was when she became “put off with the Church.” Alienated from the formality of a faith community, she came to recognize, “my church was Drew.” Jo threw her energies into the North Shore Association. She became the Chair in 1965 which led the Association to take some radical positions. “To my knowledge we were the first in Canada to appoint a person with an intellectual disability to the board – this was the mid-1960s and people were uncomfortable, but he gave us insight.” Before long she was attending provincial conventions and sitting on various committees of the British Columbia Association for the Mentally Retarded. Her committee work focused on residential services which then meant changing municipal by-laws to permit the building of group homes and confronting neighbourhood resistance, widely recognized as the Not In My Backyard (NIMBY) syndrome.

Meanwhile, Drew continued with his education, attending a segregated class for disabled children. Jo recalls that although he had “lost the spirit to talk,” he seemed happy enough until he underwent a psychological test.

> At 13 somebody decided to give him an IQ test which in my view should be banned…and then the school acted on it … so instead of moving him up with the kids he had been with, moved him in with children with no language. He became frustrated and I had to take him home.

His mother became the focus of his agitation, because, as she explained, “in his mind I was to blame for separating him from his friends, and I was the one who should have done something.” She applied for government funding, requesting $7600 to hire someone for a few hours a day, but was turned down. Drew became more threatening and aggressive, and Jo could no longer manage. Eventually, she and her husband Rob, sought help. The “help” they were offered consisted of placing him in Evandale, a mental institution.

Drew was admitted to Evandale where he stayed for three months, during which time Jo was not allowed to see him. Then, one night, without letting her know, he was moved to the Woodlands institution in New Westminster. Woodlands School in British Columbia was the largest congregate care facility for people with intellectual disabilities. The following morning she received a call:

> I drove to Woodlands. The Superintendent (who they called the Psychiatrist) said to me, your son is here. Yes, I said, and if it takes me the rest of my life I will get him out of here. It's the last place I want him. So of course I was tagged right there as a trouble-maker. There was a desk where you have to check in but I learned what ward he was on so I kept going. There was a heavy door, and when they opened it I put my foot in. They offered to bring him to see me but I said, No! I am going to see my son. So for about a month I went everyday and I sat with him. They hated it, they just hated it…if you've ever seen *Cuckoo's Nest* you know exactly what those places are like.

Getting him out was not the problem. The problem was that like parents in similar situations across the country, Jo Dickey had to decide between keeping her son at home without adequate support and provide 24-hour care herself, or leaving him at Woodlands, a traumatic environment where neglect or abuse would be a near certainty. Instead of granting her modest request for $7,600 a year to care for Drew at home, he ended up in a provincial facility that cost $70,000 a year. Jo became increasingly afraid that the environment was posing serious risks to the health and well-being of her son and others. With Drew in the institution, she became more deeply involved with the Provincial Association because, she said, "It was only way I thought I could close Woodlands." She remembers the many names she was called and learned to confront those who considered her hysterical, overbearing, and a "trouble-maker" – in short, a "bad" mother (Ladd-Taylor & Umansky, 1998). Propelled by her role as Drew's mother, she came to challenge the dominant definition of motherhood itself (Naples, 1998b). Although she lived in an era when maternal absence was believed to be devastating for a child's emotional development, being a "good" mother where disability was concerned meant handing your child over to institutional care. Jo was not prepared to be a "good mother" under those conditions.

## External Influences

Although Jo Dickey had never been active in any organization, her personal circumstances led her to political activism (Mills, 1959; Stehlick, 2000). She quickly showed evidence of the feistiness and social awareness that led her to be made Chair of the North Shore Association. As a young woman coming of age in Saskatchewan she made several attempts to find work she liked. Her father pressured her to enroll in a business course which she found "so boring" that she repeatedly skipped classes. When the school called to report her absences, she remembers, "it was the only time I saw my dad disappointed in me." She applied to join the Navy, (she was told to grow up and come back in a few years), and considered nursing (she was discouraged because she was told she was too small). She took a receptionist job in a hospital physiotherapy department. Despite having "never heard of physio before," she liked it and decided to apply to the degree program at McGill University. She recalls arriving in Montreal "75 pounds soaking wet," only to find her instructors and classmates were "all Amazons." As a result of her size she went though a "rough time personally" because faculty and students repeatedly tried to get her to quit. But they underestimated her tenacity: “I passed the exams much to their disgust.” The anger is still just below the surface as she recalls her late teens and early twenties and the message she heard: “Because you are small you don’t fit, and neither can you do anything. Size eliminates you.”

After graduating she moved to British Columbia and found a job in a children’s hospital. Later she worked in a veteran’s hospital in Vancouver where she met her husband, Rob. Working in different kinds of institutions as a practicing physiotherapist she concluded that life for people inside was “pretty poor.” She would say of these experiences, “I had seen enough to know what institutional settings did to a person.” This did not lead her to take them on, however, and she gave up working when her children were born. It was only when she faced the institutional dilemma personally, that she became a social activist through a sense of gendered obligation to fulfill what she believed society expected of her as a mother (Abramovitz, 1999).

## Activist Activities

### Activism at the Local Level

Once Drew was admitted to Woodlands School she began to advocate in earnest. She lobbied her Provincial Association to push for community-based residential options as an alternative to institutions, beginning a bitter and acrimonious struggle. The Association’s membership included many “institutional parents” who, concerned about their children’s care, pressured the Board to advance programs and services inside the institutions as well as strengthen relations between the training schools and the broader community outside. “Community parents,” on the other hand, insisted the Board endorse the trend to smaller, decentralized units, and demonstrate that commitment publicly. In this debate, Jo Dickey’s consistent and progressive position was hard to ignore. Though not explicitly investigated for this study, it may be assumed that gender was a “subtext” of organizational life at the provincial level as it was at National (Taylor, 1999). Nevertheless, whether because there was a vacuum of leadership or because of her hard work and tenacity, in 1973 Jo Dickey was elected Chair of the British Columbia Association for the Mentally Retarded for a two-year term and re-elected in 1975. Her expanded public role was fuelled in part by the fact she was still hurting, personally, from the Association’s rejection of creating a community-based home for someone “as aggressive as Drew.” Although elected with a clear agenda, she faced resistance from most members on her Provincial Board. Many felt superior for not having given up their children and resented any possibility that funds designated for community services might have to be shared as a result of deinstitutionalization. There was resistance at the local level too. She recalled, “I’ve never felt so abused in all my life as when we went around telling people we were going to close the institution.” But becoming active and getting political are not the cultural roles society expects women to fulfill (Sangster, 2004; Bernal, 2002; Kaplan 1997; Herda-Rapp, 2000).

She felt trapped, unable to move forward on the issue she considered most vital, until an opportunity presented itself. In January 1976, Gunnar Dybwad (who, as seen in Chapter Three, was a renowned expert in the field) toured Woodlands while a visiting professor at the University of British Columbia, saw the deplorable conditions there that became the subject of a public lecture. It was reported on the front page of *The Vancouver Sun*, under a headline that read, “Conditions at Woodlands so bad school should close” ( January 23, 1976). This exposé would prove a catalyst for action. As one official history of the Association put it:

> Upon reading the press coverage of Dybwad’s speech, one woman whose daughter was in Woodlands called the British Columbia Association for the Mentally Retarded to express her concern that “my child seems to be regressing instead of developing” in the institution. She asked that someone meet with her. Soon afterwards, a staff person and the chair of the Association who was herself the parent of a son living in Woodlands, visited the woman’s home. With two other mothers present, the parents began to speak about their children, the experiences of institutionalization and their fears. (Roeher, 1991, p. 156).

Jo Dickey was the Chair of the British Columbia Association who made that home visit. Until then it had been impossible to meet other parents because a confidentiality rule prevented staff from revealing the names and addresses of parents whose children resided in institutions. She remembers how excited she was anticipating meeting other Woodland mothers and thinking about what they might do together. “I’ll never forget, I got out of the car and said, maybe this is it and maybe this is it.”

Thus began the Woodlands Parent Group, a core group of mothers all of whom, initially, wanted the institution to close. As Jo says about one of the other mothers in the group:

> Jackie, and I don't remind her of this, broke down. She thought this was the end of the world, her world, she was so afraid of her son coming home. If it closed, what was she going to do? And that's what most families felt. The core included eight of us, people like Jackie. Some were very nervous and I didn't blame them, some of us were pigheaded and determined and it didn't take Jackie very long to turn around.

Then, the Woodlands Parent Group evolved a plan to broaden their base of support:

> We started getting names… it was a bit of a secret. We knew the institution had a newsletter which they sent out, so we asked if we could put a flyer inside saying very subtly we wanted to make some changes in Woodlands and if you were interested in joining us, make a check-mark and send it to such and such an address. It was safe enough for them to distribute…and we got back 325 answers. All of a sudden we had a constituency.

The informal network grew to a grassroots organization. The Woodlands Parent Group was now in a position to lobby for change. First they addressed changing the situation in which their sons and daughters were living but it did not take them long to realize that no matter how much money was poured into it, how many changes they demanded, nothing would make the place a home. Within a year they requested a meeting with the Minister of Human Resources who responded by offering to invest two million dollars to make it the best institution in the world. Jo Dickey remembers that meeting:

> Instead of applause there was dead silence. You know what we said, unrehearsed? We said, “we’re sorry, we thank you very much, but we don’t want it. We don’t want you spending money on a concept that cannot work.”

After they suggested he take his two million and go back to Victoria, he asked what they wanted instead. “We want to take them out to live in the community.” He asked who exactly they wanted to take out and they all shouted back, “Everybody! Everybody!” In thinking about these events later, Jo Dickey wrote, “When I think about it now, I just can’t believe we did that. I don’t know how we had the guts. It was just how determined we were that this was the wrong way for our kids to live (1978). She began to develop a critical consciousness that informed her action and direction. The ideology of motherhood, typically rendered invisible in the private sphere of women’s work, became a source of power in the public sphere (Krauss, 1998).

The Woodlands group now focused on developing a proposal for a community-based system of services as an alternative to institutions like Woodlands. Writing proposals was not Jo’s forte but recruiting talented people with expertise, was. By February 1977, their proposal was on the desk of the Minister of Human Resources. By the fall, the government endorsed the concept and announced their commitment to close all institutions in the Province over the next ten years.

### Activism at the National Level

Jo's activism provincially brought her to national attention. She attended her first National Conference as a voting delegate from British Columbia in 1970 and was soon invited to join a Task Force on Residences. In 1974 she attended a Policy and Planning Conference at Geneva Park, Ontario. She spoke out in support of a resolution that urged the Canadian Association to promote community alternatives to institutions actively and publicly. For reasons that will be examined in Chapter Five, this resolution was defeated. This dismayed Jo, who believed that any hint of caution at the national level would only weaken the position of local and provincial associations when they approached governments for support for community-based services. Another mother, Audrey Cole, strongly expressed the same view cementing a friendship based on mutual frustration at the Association's cautionary stance. Furious, Jo returned home and as President of the British Columbia Association wrote an angry letter to the National President, Rollie Lutes:

> At this time when the Canadian Association for the Mentally Retarded and provincial Associations are making the strongest possible representations to government for more and more support for community programming and the

> phasing out of the institutions, such an admission of ambivalence on basic policy puts into their hands a ready-made reason for refusal – to say nothing of its impact on our sincerity…To allow the inference of compromise and lack of confidence in our own beliefs must surely be the most damaging kind of admission our association could make.(Minutes, 1975, Binder 18).

Jo Dickey served as President of the Canadian Association for three years. The most significant act of her term was the “Montebello Retreat” she organized in 1980 to revitalize the Association. Closing institutions was on the top of her agenda but it was by no means the only issue. She included people with intellectual disabilities in the work of the local association, which she also included at National. As she stated, “I was really passionate about that. Here we had an organization in which the people most affected had no voice. I thought it was a travesty…I was absolutely convinced that if I had anything to contribute it was this.” In 1979 she created the “Consumers Advisory Committee” to establish their role and formalize their relationship with the Board. She also organized a petition campaign across the country that succeeded in convincing the Minister of Justice to include “mental and physical disability” in the equality clause in new Charter of Rights and Freedoms. She also prepared the Association for taking up the campaign against sterilization which, as will be seen in a following chapter, took off in 1981.

In the same year Jo became National President, she brought Drew home from Woodlands. “I went out to get him, I brought him to my house for dinner and I never took him back.” By then her group had secured provincial funding to establish the

Community Living Society with the responsibility “to assist handicapped persons in institutions to move to the community in order to lives as independently as possible”(Roeher, 1991, p.160). The government agreed to undertake a “pilot project” which would redirect the annual allocations used to maintain an individual resident in Woodlands from the institution into community supports. That meant that Drew was able to move into an apartment in Vancouver with three other residents and with support staff (Roeher, 1991, pp. 73-79).[16]

Jo’s activism continued after Drew left Woodlands and after her term as National President. Her passion to close institutions bought her to Montreal in 1982, at the invitation of Paulette Berthiaume and other families in Quebec eager to bring residents out of Rivière-des-Prairies but without the experience or know-how. Jo remembers that visit, and others that followed: “We were far enough along and could offer comparative comfort that it worked.” Paulette would travel from Quebec to British Columbia to see first hand how the Woodlands parents did it and though it would take her another decade, she like Jo, would not only get her son out but agitate to close institutions in Quebec in the process. The competencies she acquired as a result of Jo’s advice, help and encouragement, characterizes the role of social support in fostering women’s leadership (Bond & Kelly, 1984).

In March, 1986, Jo Dickey was granted the prestigious Thérèse Casgrain Award by Health and Welfare Canada[17] for her contribution to improving the social

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[16] The Community Living Society received $238,000 for core funding for the first year, and funding for the purchase of services up to $18,000 per year per individual.

5. The Thérèse Casgrain Award was established to commemorate the work of Thérèse Casgrain(1896-1981) and honour those who have demonstrated a lifelong

fabric of Canadian society. That same year the British Columbia government announced its firm intention to close Woodlands by 1991, although in reality it would take a further five years. In October, 1996, British Columbia became the first Canadian province to make the full transition to community living when Woodlands, the last of its large institutions for people with intellectual disabilities, was finally closed. Jo's ongoing commitment to parents led her to chair an "Assembly of Families" during the 1994 International Year of the Family. Although it was "parent" activists who were invited from each province and territory to revive the national network, it was mainly mothers who participated. Jo Dickey's accomplishments were recognized at a conference celebrating the 25th Anniversary of the Community Living Society in 2003. She remembers with delight, the story told about her at that event.

> The first time I ever saw Jo Dickey was when she was walking to the Day Room to visit her son. When she left I asked one of the institution administrators, "who is that woman?" "Oh, that's Jo Dickey. She thinks she's going to close Woodlands."

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commitment to volunteering. The award is presented annually to two Canadians, one man and one woman whose volunteer efforts have enabled fellow citizens to participate in the workplace and/or their communities, and who have demonstrated leadership, creativity, cooperation and hard work in advancing a social cause. Thérèse Casgrain was involved in provincial, national and international social justice organizations and was one of the pioneers of the women's rights movement in Canada. As founder and later President of the Quebec League of Women's Rights, she helped Quebec women gain the right to vote in 1940 and was instrumental in making women the beneficiaries of family allowance cheques. She was the leading post-war proponent of women's participation in government in Canada. In the 1960s, Thérèse Casgrain participated in the World Disarmament Conference, where she was the only female Canadian delegate. She was appointed to the Senate in 1970 and became a Companion of the Order of Canada in 1974.

Jo would never underestimate the significance of that achievement: “It’s a war, it’s just a war…What we did was truly revolutionary.”

## Audrey Cole

*Our struggle is long-standing. It will not only continue but will gain strength with every denial of a fundamental right to any person of any age with or without disabilities in this country… Outrage, as you know, can be a unifying force for the achievement of social justice* (Cole, in a letter to Ontario Education Minister John Snobelen, published in Directions, Ontario Association for Community Living Newsletter, Vol. XV No. 1, Spring 1997).

### Antecedents to Activism

#### Onset of Disability

Audrey Cole gave birth to her son, Ian, in Ottawa, Ontario, in 1963. She remembers how she had only a moment with him before nurses took him away. “I had a little glimpse of his face and had seen something in that brief look. They took Ian away to see a specialist who diagnosed his Down Syndrome. I was not included in any of this … it actually felt like a conspiracy”.

Yet she was not altogether surprised. The thought that her pregnancy might not be straightforward had previously crossed her mind when she noticed she was the oldest pregnant mother in her pre-natal class. It wasn't until Ian was finally brought back to her on the second day that she could see for herself.

> I cried for hours and hours and hugged Ian and told him he would be safe. I just kept stroking his club foot which was bent right into his crotch, and I told him I wouldn't let anyone treat him like others I knew had been treated… I knew there was something different about my way of thinking and I saw the first night as the beginning of setting forth on something that would be different… I was an activist right from the beginning.

By the time she got home from the hospital, her husband Fred, a librarian with Health and Welfare Canada, had stacks of books ready for her to read. When she went back for a check-up, her obstetrician told her she had given birth to a "Mongolian idiot" which "annoyed" her. But their family doctor gave them a "tremendous start." Unlike many other general practitioners at the time who recommended institutional placement to families in similar circumstances, he was encouraging, telling them, "Ian's a baby and that's all you need to know. Babies need lots of loving and caring and if you take care of that, other things will fall into place." Most importantly, he gave Audrey the address of the local Association.

### Disability Discrimination

Audrey joined the Ottawa and District Association for the Mentally Retarded in 1967 when Ian was three and a half years old. He attended the pre-school program it provided three mornings a week until he was six when he no longer qualified for funding. “That’s when we hit what I thought was a rights issue,” she said. When he reached seven years of age, in 1970, Ian was not allowed to go to public school because he did not meet the admission standards established by the Ottawa-Carleton Board of Education. They required a child to hold a cup and be toilet trained before they could be admitted. Audrey saw this as an intolerable discriminatory policy, but in the meantime she turned to her local Association in search of alternatives. She said, “For the first time in my life I stood up in an Association meeting and *demanded* they look at doing something for kids like Ian…I was shaking.” (In recent years she has reflected on that moment, and on her demand that the Association start a special program: “That was the worst thing I ever did, becoming an activist for segregation.”)

### External Influences

Audrey’s concern for human rights had been seeded in an earlier experience she had had as a young woman in Yorkshire, England. In the late 1940s she became engaged to a man who was half-Japanese, and she witnessed the discrimination he experienced looking for work in his field given anti-Japanese sentiment after World War II. Although the engagement soon ended, Audrey was deeply pained by the arbitrariness with which his rights were determined and taken away, and this would stay with her. With her brother, she immigrated to Canada in the early 1950s, and worked professionally as a technical illustrator. Through mutual friends, she met her husband Fred.

Neither Fred nor Audrey had been politically active but they were both politically aware and sympathetic to progressive causes.

> When Ian was born the civil rights movement was very active and of course I saw the connections, there were so many parallels...I am quite sure it wasn’t the birth of Ian that set me on the track I went on, it was the fact that I had been already alerted, primarily by somebody for whom I cared a lot, how wrong society can treat people for no reason – and that’s why I became so involved so quickly in rights issues [in the CAMR].

## Activist Activities

### Activism at the Local Level

By 1972, the Ontario government responded to the pressure coming from the Ottawa Association by amending the Day Nurseries Act to set up Developmental Centres for children Ian’s age. Audrey began to work closely with other mothers and fathers whose children attended the Children’s Developmental Centre because like Ian, they had been excluded from regular schools. It was at the community level she began to acquire the skills to address increasingly complex questions and to challenge cultural stereotypes of women as passive and dependent (Reinharz, 1984; Abramovitz, 1999; Orleck, 1995). Audrey remembers how she – and other mothers got started:

> You start as a volunteer because of your situation – your son’s situation or my son’s situation – and it brings you into learning and gaining experiences that you simply wouldn’t know about were it not for that.

In 1973 Audrey was elected to the Board of the Ottawa and District Association for the Mentally Retarded. She served on the Schools Committee, chaired the Family Services Committee and before the year was over she was made Vice-President. She questioned what she perceived to be an undemocratic process in the Association and remembers being severely censured by male leaders for asserting her opinion. As Maddock and Parkin (1994) note, while gender cultures may be difficult to quantify, they are far from vague and imprecise. Audrey experienced a constriction on her behaviour and language which she still remembers, more than 30 years later:

> I remember Bill Law, the President, saying to me, “Audrey, your problem is you are obsessed by law and order.” But I didn’t say anything. Later, when Bob Chevrier (a board member) said that my problem was that my principles were too inflexible, I challenged him by saying, “Well I thought that’s what principles were!”

Audrey recognized that by taking her work outside the private sphere of the family she was leaving herself open to criticism and exposing her family life to public scrutiny (Orleck, 1995). To defend herself, she amassed knowledge; that became her power base. In 1973 the Provincial Government circulated the Welch Report (1973), a "green paper" which proposed a radical shift towards community-based services and programs as a deinstitutionalization strategy. Audrey convened a study group to develop a response and then wrote the brief on behalf of the Ottawa Association.

> I didn't know I could write…I went on to write a newsletter (for the Child Development Centre) and once wrote an article about Ian being excluded from school which I submitted to the Ottawa Citizen. They paid me 35 dollars. I used the number of children being excluded as well as facts about the $2 million surplus the Board had that year to show how little it would cost to provide education for our kids.

Audrey's experience in the Association was transforming her personal life; she became more politically aware and self-confident (Herda-Rapp, 2000). For Audrey, the issue was not only the provision of services but more fundamental ethical and moral questions to do with basic human rights. She followed with great interest the debate in the Canadian Parliament in 1976 on Bill C-72 which became the federal Human Rights Act. She subscribed to *Hansard*, read it daily and became alarmed that "disability was never mentioned." One day she sat down at "Fred's old little portable Olivetti typewriter" and typed up a resolution that would have national significance.

> Early in 1976, in an attempt to influence the content of Canada's embryo Human Rights Act, I took it upon myself as a member of a local Association to draft a resolution calling for the inclusion of mental and physical disability as prohibited grounds of discrimination in Bill C-72 which was then under consideration by Parliament. Fellow members of the Canadian Association supported that resolution at regional, provincial and national levels and, as a consequence, made representations to the Government of Canada (Cole, 1982, conference presentation).[18]

The next year the Ontario Association followed up by submitting a brief which recommended the Ontario Human Rights Code be extended to provide protection against discrimination on the grounds of "intellectual disability." In 1979, the Ontario government responded by drafting a separate bill, An Act to Provide for the Rights of Handicapped Persons (Bill 188). Audrey remembers the controversial debate that took place within the Association at the time. Arguments hearkened back to 1954 and the famous American Supreme Court decision in *Brown vs. The Board of Education* that challenged the principle of "separate but equal" in racially segregated schooling.

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[18] Audrey Cole, paper (untitled) presented in 1982 at the Annual Conference of the Canadian Association of Human Rights Commissions, panel on "Section 15 of the Charter: Mental Disability," Montebello, Quebec, author's personal files.

> The Bill was initially supported by some members of the Executive Committee as well as by some members who did not understand "separate as unequal"… I heard Ivy [Ellingham, President] say it was "wonderful" in an interview on the radio. I called her and said "No, Ivy, we need to get it withdrawn." Internal pressure convinced the Executive it must oppose an Act which was in itself segregationist.

Pressure from a coalition of disability groups succeeded in having Bill 188 withdrawn and it was clear that Audrey's work over the previous three years had been instrumental in this. She "wrote a letter about discrimination" which was published in *The Globe and Mail*, Canada's national newspaper. It "caught the attention of staff" and she was invited by the Ontario Association to give her "first plenary speech" at their annual conference in 1977. That same year she was elected Chairperson of the Champlain Regional Council which automatically gave her a seat on the Provincial Board, a position she held until 1982.

Fred took early retirement in 1978, just as Audrey was getting more and more active provincially. As chair of the Standards Committee, she developed a set of standards of performance to evaluate local Associations and then traveled across the province to promote them. At about the same time she was recruited to lecture Fourth year medical students in the Department of Epidemiology and Community Medicine at the University of Ottawa. Although she had given up her job when Ian was born, she put her technical skills to work and became well known at the University and the

Associations for the illustrated, diagrammatic overheads that accompanied her lectures and speeches. Knowing her husband could manage at home and attend to Ian, she felt freer to travel, attend meetings, and tackle the work she felt needed doing. However, running the household still remained her responsibility, and with each new project she strategized how she would "break the news to Fred." She learned to manage the delicate balance of work, activism, and family life with care (Kaplan, 1998b; Orleck, 1995).

To Audrey the issues were always larger than the individual family. Able to stand apart from her own personal everyday experience, she acquired a critical, oppositional consciousness (Krauss, 1998). She attributed the discontent she and other families faced to structural, cultural and systemic causes and not their own personal deficits and recognized the need to take these concerns to the public arena. In her view, individual households were not well located to challenge the social, political and economic factors that shaped the way her son and others were treated (Fisher & Tronto, 1990). But her perspective was not widely shared in the Association. She often found herself a lone voice in advocating for the "bigger picture." As a consequence, she was not re-elected in 1982 and "went from having the highest number of votes to having the lowest number of votes in one year." She suspected it was because she just "rubbed too many people the wrong way," but it was not only that. Her position on the highly charged "Eve" sterilization case that emerged in 1981 (to be discussed in Chapter Six) went against the official position of the Board. Her refusal to be a "team player" would be held against her for years. It was comforting that she was in this position with her friends and fellow activists, Marjorie McPherson and Muriel Clarke, who were similarly defeated in that election year.[19] Audrey would say that meeting Marjorie and Muriel in the mid 1970s (when Ian was about 10) was a significant moment because, "until then I didn't find any women on my wave length." The bond she felt with them came from a sense of "unity from sharing a cause;" merely linking up with others was not, as Audrey put it, her "best role." She did not seek out women. She looked for people who "had the same values and sense of rights." The fact that these three activist women were defeated in the same year raises an important question about how the "gender regime" (Taylor, 1999) may have operated in the provincial Ontario Association. The creation of alliances and exclusions are one of the many ways organizational processes structure gender relations (Gherardi, 1995).

Audrey did not need to hold elected office to make a contribution. She built a reputation that was legendary for drafting new Association bylaws. She knew others considered it "a lot of dull stuff," but drafting bylaws allowed her to render practical what she called her "instinct for what's right." Undemocratic processes irked her, and she saw them everywhere. One that caught her attention was the practice which required delegates at conventions to vote on a slate of new officers prepared by the old ones rather than engage in open elections. As she said, "those bylaws were

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[19] Marjorie McPherson, as President of the Ontario Association between 1977 and 1978 encouraged the earliest discussions about the need to adopt more of an advocacy role and to turn service provision over to others. This followed the recommendations laid out in *The Future Role*, a 1976 study by David McKoy, which highlighted the conflict between trying to offer both advocacy and service provision. Muriel Clarke, Board member, mother and outspoken disability advocate, was one of the first in Ontario to secure from the Ministry of Community and Social Service individualized funding for her son rather than a designated program. One of her favourite quips was, "Rob will never get a degree but he's never going to push the button either."

appalling and needed to be changed.” However, when she attempted to change them, she was reprimanded. When she demanded accountability by calling for a recorded vote on controversial issues, she became unpopular. She was not included by the “in-crowd” who socialized together. But in her opinion, “you don’t sit on the board unless you’re prepared to take a stand or hold a position.” Yet she did not consider her work as being in any sense “political” (Kaplan, 1997; Naples, 1998b).

## Activism at the National Level

Audrey found her volunteer work at the provincial and national levels exciting and intellectually stimulating. She loved sitting with like-minded people to envision what a better future for Ian and others might look like. In devoting herself to activist work, she became disconnected from a more conventional life, but found in the Association emotional support networks and an expanded family (Orleck, 1995). In 1980, Jo Dickey, as part of her strategy as President to revitalize the Association’s membership appointed Audrey Chairperson of the Involvement Committee and later Vice-Chair of the Advocacy Committee. Word of her passion and competence for legal advocacy work spread, so that Audrey was often asked to participate in formulating the Association’s position on court cases and complex social issues. For three years (1982-85) she served as the Canadian Association’s representative on the National Associations Active in Criminal Justice. In 1991-92 she chaired a National Task Force on Alternatives to Guardianship.

Despite years of hard work and hundreds of assignments for which she was specifically recruited, unlike Jo Dickey and Paulette Berthiaume, Audrey never made it to the top in the Association. In fact, she never served on the National Executive. The closest she came was in 1985 when the Nominations Committee put her name forward as Vice President. Past President Marie Gallagher was its Chair, and she approached Audrey personally, urging her to let her name stand. Audrey knew that it would be a "break with tradition" since the position of Vice-President usually went to people who had "done their time on the Board." She agreed to let her name stand but assumed her chances were slim and she was right. The Ontario leadership made it clear from the start they would not support her nomination. National President, Andre Blanchet,[20] fearing he would lose his largest provincial base, tried to persuade her to withdraw. Audrey reflected on what losing meant to her:

> I think is highly inappropriate for presidents to be involved in discussing nominations with anybody – that's why presidents under [Roberts] Rules of Order are not allowed to be on nominations committees. That bothered me. And the fact that I had been the subject of discussions…that's what hurt. I understand how I became unpopular. I don't think I was wrong but I felt quite hurt to think that I became unpopular when I continued to fight for things that

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[20] Andre Blanchet was elected Vice President of the Canadian Association in 1982 and President in 1984. The 1982 Nomination Committee report stated he was: "a psychiatrist with 15 years of human service background", as the current "Director of Adult Services with Rivière-des-Prairies Hospital and also Chief of Psychiatric Services at Granby Hospital." He served on both the provincial Quebec Association and Canadian Association Boards.

> the Association said it believed…People were starting to understand the implications of some of the issues and of course they didn't like the implications. A lot of people are very paternalistic and some of the issues I got involved in brought that out... I don't think being paternalistic is the same as caring for what happens to your kid. I care as much as anybody what happens to Ian.
>
> I have always felt very strongly that I didn't want Ian's life to change just because we got something for Ian. What we had to do was change things so we got something for everybody and then Ian would benefit… I'm not a believer in making change one at a time - who can live that long?

In 1991, Audrey was nominated from the floor for President but was defeated. That same year she was asked to Chair a special Task Force on Alternatives to Guardianship, "I suspect it was a consolation prize…but that didn't stop me because it was what I wanted to do." This would prove to be one of her most satisfying projects.

In June 1997 the Province of Ontario bestowed its highest honour upon Audrey Cole when she was invested in the prestigious Order of Ontario for her "disability activism."

## Paulette Berthiaume

> *My husband used to call me his "night bird." For over 30 years I used to get up during the night and write on my typewriter all my worries, hopes…I am 79 years old and able to sleep well since Louis left the institution. It must be so for more families who [also] deserve to sleep well at night when they dream of their sons and daughters with disabilities. I am not finished yet.*

### Antecedents to Activism

#### Onset of Disability

Louis Berthiaume was born in 1955 at the Jewish General Hospital in Montreal. It had been a difficult delivery. Paulette remembers it "like it was yesterday." The attending pediatrician advised her: "When a bird makes a nest and the little birds come, if one is not right they throw it out of the nest and forget about it. Just forget about him and place him." Fifty years later, it still rankles Paulette that he could talk that way about a human being, and especially about her son. Doctors diagnosed "hydroencephaly", and when Louis was three months old Paulette was told he would never work or go to school, and that he would need supervision all his life.

> Even though you are told this, I didn't know what to do – there was nobody to relate to, I had no model, nothing. So I just changed physicians…But I knew

> right away I had to be there for Louis and defend him all his life. This was the way I lived…with my husband, my older son Marc, and always Louis, [whom] I would defend with everything I had.

Marc had many questions for her, such as the time he said: “Mom, the children want to know what kind of language Louis talks.” All she could say was, “he talks that way because of his throat, he cannot pronounce.” Although she tried to be reassuring, she felt her explanations were grossly inadequate. There was nothing wrong with the question, she felt, “it was me… there was still so much I did not understand.”

> I had this little booklet, *Mental Retardation.* It was sent to me by the Montreal Association and I used to read it like the Bible – it was the Bible to me…. I am francophone but in Quebec they started with an Anglophone Association. It was the only [community] Association I knew at the time and I used to go and help put letters in envelopes there.

But in the early years her focus was on life at home. She was consumed with caring for Louis, helping Marc understand why his younger brother took so much of her attention, and supporting her husband for whom the emotional and financial pressures were “very, very hard.” Even visits to her extended family were problematic: “I was always invited. There was an open door to dinners, Christmas, New Year’s….but when Louis started being unhappy I just excused myself and left. I never, never imposed my son, never would they reproach him…That was the way I lived." In this she gave voice to a private inner conflict as she tried to live up to being a "good" woman, "good" mother and "good" wife (Ladd-Taylor & Umansky, 1998; Sangster, 2001).

### Disability Discrimination

Paulette kept Louis at home until he was eight, but his persistent wakefulness meant interrupted sleep which took a toll on her own health. She needed surgery and since she had to be hospitalized, there was no choice but to "place him" – and in 1963, there was no place but the local institution, the Rivière-des-Prairies Hospital.

> There was nothing, nothing for Louis. Marc went to a private school, so why not Louis? I fought. I went right to the government, I fought all the way, but there was nothing, nothing there. ….The Montreal Association started a school but it was for "their" people not people like Louis; he was too handicapped to go there….It was just awful. And for years, when he was younger, every time I went in there I used to come out of the institution yelling on the street and crying….
>
> Obviously my son was in prison. Society wanted that, even my family wanted that, they said it was too much for me. My father said, "Paulette take care of your self." I don't blame them, they loved me. But my son was my son and to me, he was in prison.

She felt she had to choose between what she knew she needed to be a “good mother” and what her family said she needed to be a “good wife”. In their view, placing Louis was justified “for her own good” yet this contradicted everything Paulette herself knew about good mothering. She could not reconcile the double standard: separating mothers from their children was predominantly devalued except in the case of disability, where it was encouraged.

### External Influences

Growing up during the depression in Montreal she remembers the poverty in the 1930s. She and her five brothers and sisters ate well because her father always worked and her mother was a good cook, but some families in their neighbourhood were on welfare. She recalls going out with her younger brother late one night and taking a small wagon to the Jean Talon market after it closed to gather left-over fruits and vegetables which they distributed to those families. But at the time she did not understand why they did not go out and buy their food. She did understand when it came to defending her older brother. As a result of having polio he had one leg shorter than the other and when children taunted him for being “different,” she “didn’t stand for anything.” Just as she learned to protect her brother in the playground, later she would fight to protect her son in the institution.  Her father was her “confidant.”

> I was brought up with a father who used to work on the CPR Railway...He was an activist in his union, the Railway Brotherhood of America... if somebody needed help he was there…he didn’t have much schooling but he was very intelligent. He knew right and wrong and justice. My father always talked about justice and he always defended his men whether they were right or wrong. From my father I learned a lot. He used to tell us [about] cases at dinner time, how what we’re doing to women, to employees was wrong – and I used to say, “What did you do? What did you say?”So it was always in me.

She had intended to become a nurse after high school but at seventeen was too young to enroll. Instead of waiting the year, she found a job at Bell Telephone where she stayed for four and a half years until she met Marcel whom she married when she was 23 years old. Like most women of her generation she did not work after her children were born, but when Louis went into the institution she reconsidered. She was still thinking about nursing but at thirty-seven felt she was too old to start the course and so abandoned the idea. Instead, she found a job at the Bank of Montreal where she began as an intern and worked as a financial officer. She said, “It’s only after Louis was placed I said to Marcel, ‘I’m going back to work’. I couldn’t stay home, I couldn’t. I would be there every day missing him, I would go crazy! So that’s why I went back to work.”

## Activist Activities

### Activism at the Local Level

At the same time she returned to work she joined her first parents' group, an "inside" one, made up of parents of people in the institution. She served as its Secretary for years, trying to fix the system from within.  Tensions with the administration were there from the start, accelerating in later years as her group fought to establish a monitoring system to keep track of what was happening to residents. Accustomed to "polite" dealings with those in authority she nevertheless learned that to be a "good" mother meant acquiring new skills, even learning to be confrontational if that resulted in securing services for her son (Reinharz, 1984). She became a member of several boards: L'Association pour les deficients mentaux, Rive Sud--St Lambert, the Horizon Workshops and Action Integration in Brossard. After she joined the Quebec Association she served briefly on its board. Paulette recalls:

> We were three parents there – [the Chair] used to call us his three little daughters. Mes petites filles. We were three mothers. I always worked with mothers…We had the same concerns, we tried to develop services, we talked about justice, we thought our sons and daughters didn't have what they wanted.

Fathers attended too, but they were "more in the background."

> I still get calls saying “what do I do?” but it’s very seldom I have fathers, always mothers. Some fathers are like mothers – they’re right there, but mostly the men are there behind – like Marcel. He listened to me and sometimes he would say, “Paulette, I would do it this way.” They help but in other ways. We don’t see most of the fathers…I noticed if there is a scandal they’re all there…you never see them otherwise.

## Activism at the National Level

It was not until 1984 that Paulette became involved at the national level where she was invited by the President, a fellow Quebecois, to serve on the Advocacy Committee that Audrey Cole had served on earlier.

> “What are you going to do there?” I was asked. And I said, “I don’t know but I am going.” I would go Saturday mornings to Toronto to have that meeting and this is where I learned about the Association and where I learned about what was going on across Canada... I learned a lot from that little magazine, *Mental Retardation*, I always read every article.

It was only in this context that she became involved in the deinstitutionalization campaign. She said, “I never thought about it until Andre Blanchet said, ‘Paulette, we won’t fight the institution, we’ll take them out.’” She remembers meeting Jo Dickey: “She’s the one who gave us the push” and inviting her to Montreal:

> We were not talking about taking them out of the institution at the time because there was nothing [else]…we were talking about having a better life for them inside. But then they started [community] residences. And in 1984 I went to visit Jo Dickey when they took the people out of Tranquille. So we learned. We saw that they lived well, four of them and ...it was a marvelous thing. So then we changed.

This would prove timely in Quebec when allegations of abuse at Rivière-des-Prairies appeared in the media in 1985. Paulette, shocked by what was being exposed, organized a new parent group that the Canadian Association backed financially and morally and demanded a full-scale investigation into the Hospital. She supported other mothers individually and collectively to stand up for their rights, confront authorities and work towards social and policy changes, but described her role rather modestly: “I just pushed the pin! I just pushed and made sure everything was done properly…We had guts [but] we were afraid. Our sons and daughters were inside. We parents, we were a small group, we didn’t know how to fight this way…”

They learned quickly. Paulette built a network, creating the “social space” to develop “participatory competence” and fostering a sense of connectedness and solidarity (Feldman, Stall & Wright, 1998). The parents’ group, becoming impatient when the process stalled because of legal procedures, took matters into their own hands and conducted a “people’s trial.” They collected 200 affidavits from parents and friends which they summarized and distributed first to the authorities and then when they failed to respond, to the media. Although they started as a small informal network, their grassroots people’s campaign resulted in the first inquiry in Canada into events in an institution. Paulette took time from work to attend the inquiry, always sitting in the front row of the court room with half a dozen other mothers. One day, exasperated at hearing government lawyers repeatedly dismiss their disabled children as “nothing”, she staged a walk-out.

> I couldn’t stand it, I had to go. I was in the front row and I made [the Chair of the Inquiry] know how I felt about all this…I walked slowly to the middle aisle and I walked out. I thought the only thing they can do is put me in prison. But I couldn’t sit there it hurt me so much ...talking about our sons and daughters like that, they wouldn’t treat an animal that way…I walked and the next thing I knew, each mother walked very slowly and we all went out. And apparently, I was told, there was a silence there and everybody was looking at one another.

For Paulette, this was a “turning point.” In 1986, at the age of sixty, she took out her pension from the Bank of Montreal and enrolled in a Diploma in Rehabilitation “to learn more, to work on the street”. Upon graduating she became Rehabilitation Director of Residential Services in Laval and was soon recommended for a government appointed team to evaluate 88 adults living in the Saint Theophile institution. Despite her credentials, she usually refused to identify herself as a "professional" but insisted she was a "parent activist." But in this case she kept it "very shush" and for good reason. In 1988 a public hearing was launched by the Quebec Human Rights Commission into the misuse of funds, exploitation of patient labour and the poor quality of care at Pavillon Saint Theophile, and Paulette's insider status as a professional was instrumental in helping to evacuate all 88 residents in what became celebrated across the country as "The Kidnapping." This institution was closed two years later and in 1992 the Commission awarded the former residents, now living in the community, the largest settlement ever recorded in Canada for human rights violations, an unprecedented $1,400,000 in personal damages.

In a political climate conducive to recognizing human rights, Paulette succeeded in giving deinstitutionalization a larger profile; the events in Quebec in the mid 1980s caught peoples' attention and catapulted her to the national stage. She was elected to the Board of the Canadian Association in 1986, and was immediately appointed to several key committees: the Executive committee, the Management Committee, and the Task Force for Replacing Institutions. In 1991 she was elected Vice-President and launched a national leadership project to nurture and promote the "Leaders of Tomorrow," developing leadership potential in a younger generation of women. In 1993, at the 38th Annual General Meeting in Calgary, Paulette became President of the Canadian Association.

On April 1, 1994, Louis Berthiaume left Rivière-des-Prairies after 30 years of living in an institution; her private struggle and public campaign came together. This achievement became core to Paulette's message as President. Her term coincided with a significant expansion of international activities that the Association initiated in the early 1990s. For Paulette, the highlight of this activity was an International Seminar in Managua, Nicaragua in December 1993, which brought together representatives from 34 countries in South and Central America to talk about human rights and social justice. Meeting so many other people in an international context who felt the same way was “a marvelous experience.” (Berthiaume, 1995). While other presidents agreed to have their speeches written for them, Paulette remained independent. “How am I going to say someone else’s words…I need the feeling and then I could write.” In Managua, she turned to a French singer, Juliette Greco, for inspiration

> I remember, I started my speech with four lines of a song that begins ‘Chante, mon fils, chante’ [sing, my son, sing] about a young boy going to war and the song is about liberty. I listened to it over and over and it struck me, what it was saying – and what I wanted to say - was that we are all at war and we have to combat all those who are intolerant of our sons and daughters.

When asked to reflect on her national role, she had this to say: “I liked it - but I like to be right on the floor, to have my feet on the floor where everything is going on. We’re ground people.”

## Styles and Skills of Activism

New spaces for exploring women's leadership have been opened by feminist accounts of women in social movements (Astin & Leland; 1991); women in workplace and community movements (Bookman & Morgen, 1988); and women in grassroots movements (Sacks, 1988; Bernal, 2002). Bernal (2002) recognizes leadership skills in grassroots leaders who work behind-the-scenes to organize, develop consciousness, and network in addition to those whose work is visible as spokespersons and office holders. Sacks (1988), explores the notion of "network centers" to bring into view the "centerwomen" who play a key, though often hidden role, in network formation and consciousness shaping. Astin and Leland (1991) move beyond traditional approaches based on leadership "traits" and "positions" to investigate women's leadership style and propose a model based on the leader as a facilitator who enables others to act collectively towards a common goal (p.11). These conceptualizations of women's leadership inform the analysis of three sets of activist styles and skills represented by the three women in this study. In the following section I propose a typology for explicating and understanding their activist styles. These are identified as: catalyst, conscience and capacity-builder. The term "catalyst" is used to suggest a visionary who has the personal magnetism to persuade and mobilize others to embrace that vision. The term "conscience" is used to denote the qualities needed to raise the awareness of the members to complex and controversial issues and to understand discrimination at its more sophisticated and oblique forms. The term "capacity-builder" is used to identify the mobilizing role needed to organize and empower community people to confront authority and get what they want for their children. Jo Dickey mobilized the Association as a “Catalyst”, Audrey Cole troubled the Association as its “Conscience” and Paulette Berthiaume strengthened the Association as a “Capacity- builder.”

## Jo Dickey: The Catalyst

“Maybe I was a catalyst,” Jo Dickey volunteered in an interview for the study. She saw herself as someone who had a vision and who facilitated others to come to share it. Her vision was radical and clear: she was out to change lives. She did that in a number of ways. She helped the Woodland mothers acquire the confidence and encouragement to do things they never thought they could do. She built a constituency and knew when it was time to “go political.” She surrounded herself with talented people who used their talents and expertise to act collectively.

Jo was very visible in her activist work. She believed that families were the instruments of change and she promoted loose networks and strong bonds to strengthen their voice across the country. She mobilized her local, provincial and National Association to make “closing institutions” a priority, transforming communities and families into a political force. She worked formally through the Association with the Federal Government, and informally with parents in whatever community they lived to advance this issue.

Unlike Audrey, she hated to write. In her opinion, Audrey had many admirable skills which included the ability to write briefs and dissect a document. But to Jo, doing that kind of work was like being in a “torture chamber”. She did not do the behind-the-scenes work that nourished Paulette. What Jo possessed were outstanding interpersonal skills and as Provincial and National President she took advantage of her status and public role. Politically astute, she understood how to use the system and she sought opportunities to do so. Jo stated she would like to be remembered for “having a sense of what the future could look like” and for “being part of taking that place down.” But she added, “I think I’ll be remembered for an awful lot of other thing that maybe weren’t as cheerful.”

Jo’s activist style was formed by her passion to close Woodlands. She created a climate for change in the Association, and her vision provided the catalyst for action.

### Audrey Cole: The Conscience

“I did not come to my activism with any history of linking up,” said Audrey Cole. “That’s not my best role; I came to it intellectually.” Audrey was committed to a set of values and principles that she expected the Association to uphold. She was prepared to tackle issues that were complex and controversial. All the same she found it “demoralizing” to be “the only dissenting voice” when she considered the matter “fundamental.” She respected fair procedures and became an expert at Robert’s Rules of Order for conducting meetings. She never forgot the time she was reprimanded for raising the issue of “accountability” in the Association and was told her principles were “her” problem.

Audrey believed in the power of information. She built an extensive library of books, government documents, articles, and press clippings. She was not afraid of hard work and preferred to be named to working committees. As she said, “I don’t get a kick out of just looking at something.” She wrote briefs, letters to the editor, talks, lectures, resolutions and by-laws, and drafted responses to government legislation and legal decisions. She lectured at colleges and universities, mentored students and professionals.

She did not compromise easily. One of the areas she differed with Jo was on the primacy of the family. She acknowledged that parents are wrapped up in difficult personal situations but, she said, “unless you’re able to change the bigger picture the next generation is going to have exactly the same things to face.” In her view the horizon had to be “bigger than the family.” The Eve case had shown that families don’t always have a sense of what “an entitlement to equality” means.

She was committed to developing consciousness and enabling others to see inequities as she saw them, work that is often overlooked as part of the dynamic process of leadership (Bernal, 2002, p. 242). But as Audrey learned, helping others understand what they have not seen before can be difficult and unrewarding. She noted, “I was never one of the clique –they had some respect for me but I was kind of in a different space.” She was not interested in socializing for its own sake; there had to be “discussion and it had to be substantial.” She did her homework before meetings because if she was going to “stick her neck out” she had to be on solid ground. She became “impatient” when others did not and complained she was “sick of hearing the same stupid silly arguments.”

She was admired for the quality of her written communications and verbal presentations; this brought her credibility but a limited profile. She was never elected to the National Executive. She felt upset and disappointed at being marginalized, but she says, she never thought of quitting: “I’ve always believed in what this Association said it believed…I don’t think there’s any other Association that would be so right for me to be in.”

Audrey’s activist style was shaped by her perseverance and curiousity to uncover truths about discrimination and raise the consciousness of the Association.

### Paulette Berthiaume: The Capacity-builder.

Paulette Berthiaume liked to be “on the ground”. She said of herself and her fellow activist mothers, “We’re ground people. Doing the job, right on the ground, where the feet hit the floor, where everything is going on.” Her activist work involved organizing community people and encouraging them to expose poor conditions in the institutions in Quebec. Her leadership style was characterized by informal organization and non-hierarchical structures; her concept of procedure was cooperative, consensual, and egalitarian.

Paulette participated in many local struggles. She coordinated a “people’s campaign,” gathered affidavits, communicated with parents, arranged meetings, communicated with lawyers, pressured public officials, worked with the media and resisted threats and intimidation from her opponents. She claimed she was “not necessarily good” at those kinds of activity and only undertook them, “out of obligation” because, as she said, “I didn’t see I had any choice.” She was content to work in the background, in the institutions and outside, using her personal friendships and networks to bring attention to the issue of institutional abuse. Paulette viewed her activism as an extension of her domestic responsibility towards her son and persuaded other mothers to join her.

She acquired the skills to lead local parent organizations and confront powerful authorities on the job. She insisted that in the beginning they were “innocent” and “not organized…. not organized at all!” She was responsible for managing the groups, holding them together, and keeping them focused but she played down her role, saying, “I just pushed the pin.”

To Paulette, leadership included depending on other people around her. She remembers what her generation went through and she is “afraid for tomorrow”. She is particularly concerned about younger mothers: “Maybe it is because I come from an institution that I know what could happen.” She agrees her generation “opened many doors” but there were many more doors to open and to do that, she says, “they need to organize.” She is willing to help but not knowing the best approach, offers this: “Anytime they [younger mothers] need to get together on something, anytime they need to take to the street, maybe it is a thing we could do together.”

Paulette’s style and activism was well suited to capacity-building: she was most effective in extending networks and support systems, developing the potential of “leaders of tomorrow,” and empowering mothers to get what they wanted for their child.

## Conclusion

This chapter presented each mother's organizational biography starting with the antecedents to their activism.  These included the onset of disability, disability discrimination and external influences to show how important early experiences were in shaping their development and commitment. It then examined the forms of activist activity the mothers pursued at the local and national level. It explored the leadership styles and skills typified by the activist mothers as catalyst, conscience and capacity-builder. The chapter now concludes with analysis of their biographical accounts and what it meant to mother as an activist in the Canadian Association for Community Living.

The starting point for each mother was the diagnostic "moment" they first learned of their child's disability. They could recall this moment, as Paulette said, "like it was yesterday." Audrey still remembers being shocked her doctor's use of the term "mongolian idiot." When Paulette's doctor recommended she place Louis in an institution her husband and father concurred; they all claimed it was "for her own good."  Jo's experience was similar: "Everybody tried to sell it that way, I don't know how many times my doctor told me I should put Drew in an institution. I know he was thinking of me. He thought it was such a burden."

Each mother remembered a radicalizing "turning point" where they confronted a situation in which their child was being discriminated against on the basis of a disability. The turning point for Audrey was when Ian turned school age and no school would admit him; given the entitlement to universal education in

Canada for children of his age, that to her became a “rights” issue. The turning point for Jo was Drew’s admission to Woodlands; then and there she committed herself to getting him out and closing the institution. The turning point for Paulette was learning that her local Association had “no place for people like Louis” leaving her no alternative but to place him; she joined a parent group and tried to fix the system from within, for a while.

Their backgrounds were very different but each mother looked to their roots to trace the key external influences that shaped their values. All three women were sensitized to injustice by the social and economic climate in which they grew up, the depression and World War II. They noted the significance of personal relationships and family figures in alerting them to issues of human rights. Jo and Paulette both credited their fathers for endorsing their intellect, giving them a sense of independence and setting high expectations. Audrey witnessed the impact of anti-Japanese sentiment on someone who was close to her. Paulette grew up with a father who was a union organizer and a brother with polio whom she protected from other children. Both Paulette and Audrey came from working class backgrounds and went to work after finishing high school. Jo, on the other hand, earned a University degree and practiced as a physiotherapist before moving to a prosperous area of Vancouver. Of the three, she enjoyed greater privilege and displayed a stronger sense of what she expected the state to provide for her son.

They remember being “spotted” and encouraged by others. Audrey was drawn into provincial level work by staff who read her letter in the newspaper. Paulette was invited to join a national committee on the basis of her activism at the local institution. Jo was invited to join a local Association by another mother. They were invited to conferences and seminars where they met like-minded people, gained visibility and confidence in themselves and their ideas. They continued to read and learn and lay the foundations for the campaigns they advanced.

As they became active at the local and national levels they entered a period when women's lives and the meaning of gender were being transformed by the women's movement. They denied any experience of discrimination on the basis of gender, but they did not contextualize their experience in those terms. They did not identify with feminism and were not exposed to scholars and activists who articulated that consciousness. They did experience overt gender discrimination, but in subtle forms that sought to silence them and undermine their self esteem and confidence. Jo Dickey remembered what it felt like to be in the minority when she commented: “It's hard to walk into a room of men when you're 5'2” – it's not very comfortable.” Paulette Berthiaume remembered being intimidated by the “arrogance” of the male lawyers in the courtroom. Audrey Cole did her homework because she knew that, as a woman, she needed to excel to be heard. They felt minimized by language that referred to women as “girls” and “ladies” and by attitudes that dismissed them as “emotional” when they expressed strong feelings.

As women, they were outnumbered at senior levels in an organization that was not always hospitable to women with political aspirations. As mothers, they carried a disproportionate burden of responsibilities because of the gendered division of labour inside the home which constrained their opportunities for organizational involvement. As leaders, they had no role models other than the men around them which meant adapting to a male model of leadership. Not surprisingly none were willing to claim the mantle of "leader." Jo said she was merely the "one with the idea;" Paulette said she just "pushed the pin;" Audrey said she was only fighting for "things the Association said it believed."

There were strains and costs to being an activist. Their personal lives were contoured by meetings, phone calls, fatigue, and rejection. Jo Dickey was labeled a "trouble-maker", Paulette Berthiaume, a "cage-rattler" and Audrey Cole was humiliated for demanding accountability. Still, they were not timid about stating their ideas out loud even if that meant exposing themselves to the risk of attack. Audrey's human rights resolutions broke new ground. Paulette recalls that her parent group was "booed" for complaining about the institution, but having "guts," they stood their ground. Jo knows her "revolutionary" campaign to close institutions was legendary. They took on roles that were not deemed proper for women but they were replenished by relationships, networks and a shared ideology.

Their awareness and actions embodied contradictory ideas about their place in the world as women and as mothers of disabled children and they came up against the constraining notions of motherhood. Paulette's account in particular highlights a number of encounters as she moved out of her comfort zone and the cultural patterns for women of her generation; this was more pronounced in her case as a result of growing up French Canadian in a province heavily oriented to the Catholic Church. As a young girl, Paulette was socialized to be polite and to avoid confrontation. She recalls being told, "You don't speak unless you are told to speak." Becoming an activist meant not only learning to speak out, but in the case of the courtroom, learning to walk out as well. Her early training is “still strong,” she says, but now it is balanced by her experience: “I am still very respectful of people but don’t touch me and don’t touch my son!” As a young wife, she gave up her job when she started her family, because back then, “women didn’t usually work.” But she went back to work after Louis went into the institution as changes in her personal circumstances paralleled political, social and economic changes brought about by the women’s movement. As a woman at home she remembered showing her rage by “brushing the walls, crying, yelling, and washing until it was out of me.” As a woman in public life she learned how to manage her emotions differently. She continued to have passionate feelings and a sense of outrage but learned to speak calmly and conceal her feelings at Board meetings, not wanting to reinforce the stereotype of the emotional female. Paulette sensed, as did the others, they would not be listened to if they did not act like men. While emotionality might be valued in the private sphere of the family, it was scorned as “inappropriate to ‘objective’ discourse” in the public arena (Krauss, 1998).

The particular conditions of these women’s lives fostered different kinds of political consciousness and action. Their practical experience as mothers led them to make the connection between their personal lives and government inaction. However, they did not see their activism as being in any way “political”. They were propelled by their sons and came to their activism through a sense of gendered obligation (Abramovitz, 1999):

*Audrey Cole:* "I always used Ian as my base. I would ask myself, what would this [action / policy / decision] mean to Ian and nine times out of ten it would mean bloody all."

*Jo Dickey:* "I measured everything I did against what I wanted for Drew."

*Paulette Berthiaume*: "I knew right away I had to be there for Louis and defend him all my life."

It is difficult to say whether the women in this study would have would have found other causes to advance given the historical period in which they came of age, their personal and family backgrounds and their early exposure to injustice had the disability experience not provided a focus for their leadership activities. But there is no question that it was their ability to connect their own personal experience to a collective status with shared public issues that propelled them to assume leadership roles in the Canadian Association. They mothered as activists according to their individual styles and skills, as catalyst, conscience, and capacity-builder. They assumed these roles independently from societal expectations of how a competent woman should behave (Bond & Kelly, 1984). They applied those techniques to the campaigns to close the institutions and secure human rights to which the next chapters turn.

# Chapter Five

# The Campaign to Close Institutions

## Historical Overview

Interest in “mental defectives” emerged in the middle of the nineteenth century spreading from France and Switzerland to the rest of Western Europe and the United States and Canada. At this time, progressive spokespersons came forward on behalf of many neglected and oppressed groups, including slaves, prisoners, inmates of asylums, and people who were blind and deaf (Rothman, 1980; Roeher Institute, 1996). In 1839 lunacy policy was introduced in Canada which authorized the construction of an Asylum for the “insane.” This was based on the assumption that mental disease could be cured. Those considered mentally retarded, or in the language of the day “idiots,” were believed to be incurable and excluded. However the absence of alternate local welfare institutions meant that significant numbers continued to find their way into the asylum. Legislators devised a solution to provide more accommodation through a secondary system of asylums; they established a practice of housing the mentally retarded in cheaper, custodial institutions because there would be no return on “investments” (Simmons, 1982).

Samuel Gridley Howe and Eduard Seguin, two American pioneers in the education of mentally retarded children, established a system of residential care and training schools which took hold across North America by the mid 1870s (Wolfesnberger, 1975). In Canada, the first residential setting for people with mental retardation opened in Orillia, Ontario in 1859. Called the “Asylum for Idiots,” it was built during a phase of optimism when many residents appeared to improve with education and well-planned regimes. Despite early successes, a number of failures followed that compounded one another.

Optimism waned when “care” failed to achieve the anticipated complete and rapid “cure”, when growing numbers of residents were admitted with more severe disabilities and when communities refused to accept people back once they had been removed. As attitudes towards mental retardation deteriorated, themes of pity and charity characterized the provision of services. Increasingly, people were moved out of society to “protect” them from the stresses of daily life into enlarged congregate care facilities that could accommodate thousands of residents (Crichton & Jongbloed, 1998). When this tendency converged with the wave of scientific information fuelled by the eugenics movement in England, the perception of people with mental retardation as a social menace took root in Canada (Park & Radford, 1998). A wide range of social problems were attributed to mental deficiency. Supporters of eugenics were encouraged by scales for measuring intelligence published in 1905 by Alfred Binet and Theodore Simon in France. Exported to the United States and Canada, I.Q. tests were applied to identify more and more people as “feeble-minded.” Beginning in the 1920s, drastic measures were taken to control, confine, and eliminate persons deemed subnormal (NIMR, 1981; Roeher Institute, 1996). The growth of institutional care dominated the social response until the 1950s and 60s when individual community based services created and operated by local parent Associations began to appear. But the institutional dilemma hovered.

## Background

The campaign to close institutions was perhaps the most important in the Canadian Association for Community Living's history (Berton, 1960; Simmons,1982; Lord & Hearn,1987; Roeher Institute, 1995; Crichton & Jongbloed,1998; Dybwad,1990; Castles, 2004; Jones, 2004)). In waging this campaign, the mothers in this study confronted prevailing laws, social policy, professional practice, and cultural beliefs about disability, still none of them regarded their activist work as "political."

Traditionally, institutions (built and run by provincial governments in Canada) were large facilities which could accommodate anywhere from 500 to 3000 intellectually disabled children (Department of National Health and Welfare, 1964; Mooney, 1971;Welch, 1973; Radford & Park, 1999; Rothman,1980; Rothman & Rothman,1984; Canadian Council on Social Development,1985). Parents were typically told by medical experts to "put their child away and try to forget", and the demand for places outstripped the supply. Indeed, members of the legislature frequently took on the task of facilitating admissions for their constituents (Williston, 1971).

The campaign to close institutions originated with one group among the first wave of post-war mothers who resented the alternative of either giving up their child to 24-hour institutional care or keeping them at home with no community support. Their rebellion initially took the form of newspaper advertisements to find other parents with whom they might create activities for their children in their communities

(Anglin & Braaten, 1978; NIMR, 1981; Dybwad, 1990; Brockley, 2004). However placing the ad was itself considered provocative, and some newspapers refused advertising space for fear of libel suits associated with bringing a family's "shame and disgrace to public attention"(NIMR, 1981).[21]

An Institutions Committee was one of the first to be struck by the newly founded Canadian Association in 1958 (Roeher Institute, 1995; Cole, 1998a; Simmons, 1982). Vocal members at the first annual general meeting insisted that its chair be someone from the community, a "lay person with organizing ability" rather than a "facility Superintendent"(Minutes, 1958, Binder 1), and they succeeded in having Eileen Kleinsteuber[22], a mother from Ontario, appointed with a mandate to improve the facilities. Given that the committee's membership was primarily made up of those who were known as "institutional parents" whose children lived in large institutions that were also known as "hospital schools" or "training schools", it is understandable they were concerned with improving programs, services, and amenities in the institutions and strengthening relations with the community. They also expected the Association to recognize and appreciate the good works performed within the facilities by various volunteer women's auxiliaries and to profile their activities at the annual conferences. There was another group of members known as "community parents" who were more interested in alternatives to institutions and who

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[21] See the example cited in "The Role of Volunteer Associations in the Life of the Handicapped Child and His Family', a Public Lecture presented by Rosemary Dybwad, Vice President , International League of Societies for the Mentally Handicapped on January 22, 1976 at the University of British Columbia under the sponsorship of the Cecil H. and Ida Green Visiting Professor Fund.

[22] Eileen Kleinsteuber served as President of the Provincial Ontario Association from 1965 to 1967.

urged the Association to endorse smaller, more decentralized living arrangements. It is worth noting that at the time, even the advocates for community residential options made the case for them largely on the grounds that they alleviated institutional overcrowding rather than because they fostered enhanced quality of life. The next generation of activist mothers recognized the limits of this approach, but persuading the Association to articulate a consistent and progressive position on alternatives to institutions proved to be a bitter and acrimonious struggle.

The hostility between “institutional parents” and “community parents” ran deep throughout the organization, from the locals up through provincial Associations and soon leading to divisions at the national level which lasted for decades (Anglin & Braaten, 1978; Simmons, 1982). Tensions were expressed through a continuous war of words expressing tactical and strategic differences as each side lobbied the newly formed Association to take up their particular position publicly. In one of the early recorded examples, “community parents” on the Residential Services Committee in 1959 pressured the Association to host a table at the Scientific Conference of the College of General Medicine Practitioners of Canada, and display a sign that read: “Placement is not the Only Solution”(Minutes, 1959, Binder 2). But “institutional parents” led by mothers such as Betty Anglin, whose son Mark was in one of the largest Ontario facilities in Orillia, resisted this.

By 1960, the Institutions Committee was renamed the Residential Care Committee to reflect a broader range of interest in residential settings suited to children, adults, and their circumstances. But in those early days, the real emphasis was on improving the facilities. The committee’s agenda was consumed with identifying an ideal model, the best staff-to-patient ratio, and the most desirable number of children to group in an institution of a certain size. “Institutional parents” for example, sponsored a session in 1962 at the 5th Annual Conference in Nova Scotia titled, “Bricks have a Soul – Staff and Volunteers” (Minutes, 1962, Binder 5). They were encouraged in this pursuit by Gunnar Dybwad, the Executive Director of the American Association, who proposed a collaboration with the Canadian Association in order to arrive at a joint “national voice in recommending the most desirable types of facilities, purposes and programs”(Minutes, 1960, Binder 3).

Despite the name change, Eileen Kleinstauber, remained Chair of the Residential Services Committee. She set out to determine the ideal staff-to-patient ratio for each of three shifts during a twenty-four hour period. This involved gathering information on an array of public and private institutions, assembling briefs submitted to provincial governments, and categorizing and grouping residential populations. She concluded in her 1960 Report to the Board:

> Our explorations have shown that each provincial Association is requesting their government to establish smaller centres but the one debatable word is “smaller” – in some provinces small is interpreted to mean 20 patients to a unit; in others, smaller means 500-600 bed institutions (Minutes, 1960, Binder3).

The search for “best practice” led to closer scrutiny of institutions like the Woodlands School in British Columbia and the Rivière-des-Prairies Hospital in

Quebec. These were the very institutions in which Jo Dickey and Paulette Berthiaume placed their sons. From their experience with these institutions they eventually became key figures in rejecting the “best practice” approach and leaders of the deinstitutionalization campaign.

The Woodlands School was profiled at the Association’s 1961 Conference in Vancouver when the Administrator, Dr. Kerwood, was invited to give a guided tour of the facility and lead a discussion for 120 conference delegates. A decade later, the sports program at Rivière-des-Prairies Hospital was profiled at the National Conference as a model of best practice for having “demonstrated the value of teaching retarded children to ski.”(Mental Retardation, 1971, p.16). The drastic shortcomings of both institutions would only be revealed years later.

The first comprehensive statistical review of residential facilities for people with intellectual disabilities in Canada was initiated in 1963 by Betty Anglin in her role as the Chair of the Residential Care Committee. She described the challenge she faced in trying to gather comprehensive information:

> Attempting to present a clear picture of provincial facilities for retarded persons in Canada who must live outside their homes is like trying to put a bikini on an elephant (Anglin, 1964).

Over a period of five years, between 1963 and 1967, Betty Anglin circulated surveys and questionnaires to Superintendents of Hospital Schools, regionally and provincially. Based on her data, she was able to document approximately 16,000 persons with intellectual disabilities living in institutions in Canada. In addition to enumerating capacity and occupancy, she provided stinging commentary on the conditions in those facilities:

> Despite sincere efforts toward adequate programming, the traditional institution must be found sadly wanting due to traditional evils - overcrowding, understaffing, remote location and remote control…Children are lost in the crowd, denied the personal word and the personal touch. There are staff members who ridicule efforts to provide constructive programs on their wards. There are nurses who never smile. There are highly active young children who have scratches and missing teeth because they cannot fend for themselves and there is no one to teach them how…The protected child no longer has any protection; possessions are taken away; threats and terror take over. The child cannot tell his parents because he has to go back to the ward. The only way a large crowded institution can function is to fit the child to pattern; the pattern is docility and, in time, complete insanity (Anglin, 1967).

The results of the survey were published in two stages, the first in 1964 and the second in 1967. Notably, Betty Anglin's surveys included details about both Woodlands and Rivière-des-Prairies Hospital in Quebec. The first survey reported Woodlands had opened in 1952 with space for 1366 residents and, by 1964, 1295 children and adults had been admitted for long term care. The per diem cost per resident at the time totaled $6.99 which came from a National Health Grant paid to the British Columbia Provincial Department of Health, and a small parent fee of .75/per day for children under the age of 16. When compared with other facilities, Woodlands had a relatively high staff-to-patient ratio, providing one staff person for every two patients (Anglin, 1964). The second survey indicated its resident population had swelled beyond its capacity to 1375 (Anglin, 1967). This trend towards overcrowding continued. Such were the conditions at Woodlands when Drew Dickey was admitted in 1968, at the age of thirteen.

As for Rivière-des-Prairies Hospital, the first survey reported it was designed to accommodate 1088 residents from infancy to 18 years of age. The second survey indicated that by 1967 it too, had exceeded its capacity with a resident population of 1100. Louis Berthiaume was counted in both surveys, having been admitted in 1963 at eight years of age.[23]

Although Betty Anglin (1967) found that the conditions at virtually all the institutions were deplorable (including the one in Orillia, built in 1876, where her son Mark lived[24]) she concluded:

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[23] See also Craig Mooney (1971) for his account, in *Mental Retardation Developments in Canada 1964-1970*, undertaken as a national study and providing a province by province inventory of services, trends and research studies. It followed the first Federal-Provincial Conference on Mental Retardation held in 1964 and was commissioned to provide a general overview of gains and to identify future directions.

[24] Famous Canadian Journalist Pierre Berton toured Orillia in 1959. He reported on this visit in a scathing critique, published in the *Toronto Daily Star*, January 7, 1960, called *"What's wrong at Orillia: Out of sight, out of mind"*. The article was very influential and precipitated a series of attacks on provincial policies related to institutions. When Mark Anglin was admitted to Orillia in 1963 at the age of six, the institution was already significantly overcrowded. The first survey, published in 1964, reported Orillia having 2893 residents "on the books" even though the new facility was designed to accommodate 2100 when it opened in 1876. It was originally

> The large institution will always be with us but by reorganizing [them] into 300-bed autonomous sections where children lived in groups of 10 to 15, the child could retain his personal identity (Anglin, 1964).

In this, she was reflecting the dominant position of the Canadian Association at the time.

## The Leadership of Jo Dickey

Jo Dickey on the other hand, was an activist mother who came to reject the strategy of trying to “humanize” the institution. She wanted her son and others like him to be able to get out. That aspiration fuelled her activism at all levels of the Association but to make her dream a reality, she needed the Association to take a much stronger stand. 25 In 1970, she attended her first National Conference as a voting member of the British Columbia delegation. In 1972, Jo Dickey was recruited to join a

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known as the Orillia Asylum for Idiots. See also: Simmons (1982); Radford & Park (1999).

[25] Unless otherwise indicated all quotations are based on interviews conducted between January 2004 and July 2005. With Jo Dickey on January 15, 2004 (Vancouver), February 28/29, 2005 (Toronto), April 15, 2005 (Toronto), and July 10 (2005); With Audrey Cole on March 15, 2004 (Smiths Falls, Ontario); November, 2004 (Toronto) and July 10, 2005 (Toronto); With Paulette Berthiaume on March 14, 2004 (Ottawa)and July 10, 2005 (Toronto) . A focus group interview was held with all three on July 10, 2005 (Toronto).

nationwide Task Force on Residences chaired by Margo Scott 26 as she was becoming known for her interest in residential options and her activism provincially. The Task Force produced a manual on residential services that addressed such matters as types of care, program materials, architectural designs, staffing issues, and various resources used for staff training. But Jo Dickey, demonstrated her skills as a catalyst and used this opportunity to mobilize support for community-based residences as an alternative to institutions. She was elected President of her Provincial Association in 1973, a position which entitled her to a seat on the National Board. That year, she introduced the first resolution calling upon governments to create small home-like community-based residences instead of further expenditure on new or existing institutions. In so doing, she instigated a not-so-quiet revolution. (See Appendix 2: A Resolution Urging Governments to Establish Small, Home-like Community Based Residences for the Mentally Retarded of All Ages, Minutes, 1973, Binder 16). This resolution was passed unanimously, but it provoked a backlash within the year.

In October, 1974 the Canadian Association held its first National Planning and Policy Conference at Geneva Park, Ontario. One hundred and fifty delegates attended this “retreat” and the opportunity it provided for reflection. President Roland Lutes welcomed the delegates and said that after 16 years it was time to take a “harsh and possibly painful look” at the national organization and its relationship with provincial and local bodies. He singled out two important campaigns - the “institutional dilemma” and “securing human rights” (Anglin,1975). This gathering marked a turning point in the life of the Association, defining its future role. It also demarcated

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[26] Margo Scott served as President of the Canadian Association from1975 to 1977, and  President of the Provincial Ontario Association from 1973 to 1975.

a significant moment in the lives of Jo Dickey and Audrey Cole. Jo and Audrey remembered meeting one another for the first time at Geneva Park. They launched a life-long friendship amidst an uproar at the 1974 annual general meeting which cut to the heart of the "institutional dilemma."

In 1974, the British Columbia delegation of which Jo Dickey was part, drafted a resolution and submitted it to the 16th Annual General Meeting which followed the 1974 retreat at Geneva Park. It urged the Association to concentrate on the development of community alternatives to existing institutional programs. The debate on the resolution - which became known somewhat infamously as "Resolution 9" - was heated because many delegates who represented the position of "institutional parents" objected to its dismissal of institutions. They detected that it was building upon the direction set the previous year (Anglin & Braaten, 1978). Jo Dickey remembered that:

> Geneva Park was the first time I met Audrey Cole and she stood up and spoke in favour of a motion that the Canadian Association support the closure of all institutions across Canada. We were right in the middle of it [in B.C.] and I was so grateful to her.

However, despite this intervention by Audrey Cole and others, the resolution was successfully amended with significantly more cautious wording. Any suggestion of "replacing" institutions was gone. Moved by Margo Scott (Ontario) and seconded by Muriel Clarke (Ontario) Resolution #9 was amended to urge the Canadian

Association not only to “refrain from generalized condemnation of institutions” but also to commit to the “continued improvement of institutional programs” and to recognize that “that many of our colleagues in institutions have goals which are identical to ours” (Minutes, 1974, Binder 17).

Jo Dickey, firm in her vision and determined to rouse others to share it, did not let the matter rest. She returned home and wrote a letter to President Rollie Lutes on December 2, 1974 in which she apologized for not having been “sufficiently organized to successfully debate [the amendment] on the floor of the AGM” or “sufficiently alert to anticipate so strong and emotional” a reaction in support of it. But having had time to think and frame her argument, she now shared with him what she considered to be the key implications of this development (Minutes, 1975, Binder 18):

> The British Columbia delegates were deeply distressed at the direction given by the Annual General Meeting to our Canadian Association with respect to Resolution 9 presented on Saturday morning, October 5th [1974]…We are gravely concerned that in the amended form accepted by the AGM…[it] could be seen as a complete reversal of our previously clearly stated position on community based services. At this time when both the Canadian Association and Provincial Associations are making the strongest possible representations to government for more and more support for community programming and the phasing out of the institutions, such an admission of ambivalence on basic

> policy puts into their hands a ready-made reason for refusal – to say nothing of its impact on our sincerity.
>
> Further, it appears to us that in accepting such a compromise we are doing our friends and colleagues in the institutions (who have the same goals as ourselves) a grave injustice. They desperately need the strongest possible philosophical and uncompromising support from our Associations if they, too, are to provide the kind of programmes we want for the mentally retarded. To allow this inference of compromise and lack of confidence in our own beliefs must surely be the most damaging kind of admission our Association could make at this time…

Rollie Lutes responded by circulating the amended Resolution 9 to the Board. He pointed out that it did not express Board policy as had been defined in 1973. At a Board meeting in March, 1975, Jo Dickey reiterated her concern that Resolution 9, as amended, weakened the position of the Associations when they approached government for support of community-based services. After Jo Dickey's presentation, an "in-depth discussion followed on the pro's and con's of the resolution", after which a new motion was passed stating that since Resolution 9 "does not express Canadian Association policy, be it resolved that it be amended to read as follows: that the Canadian Association for the Mentally Retarded actively and publicly promote the replacement of institutions for the mentally retarded by suitable community alternatives" (Minutes, 1975, Binder 18).

Jo won that round but she knew that the opposition to replacing institutions stemmed in large part from “fear.” Recalling that period, she said “parents were afraid because they only knew what they had and they ignored the possibilities of something better.” She also knew the provincial Associations were also afraid, not wanting to “upset their governments”.

> They didn’t want me to bring it up, didn’t want me talking about it anymore...The blind eye came into effect…I was new, I was young, and what did I know…and it was almost like one single person’s campaign.

She was prepared to be singled out and leave herself open to criticism if it meant advancing her mission. She knew she was making waves by taking her sphere of operation from the community up through the provincial to the National Association. The experience was transforming her own life in profound ways, and although it not always comfortable, she was building a constituency. In 1975, Jo Dickey was elected National Vice-President (to President Margot Scott) at the 18th Annual General Meeting in Calgary. It was not surprising, given her heightened visibility; nor was it surprising that she saw her executive position as an opportunity to focus increased attention on the “institutional dilemma.” With a vision that was radical and clear she took aim at privately run boarding homes and for-profit residential facilities, and secured provincial reviews of their operations (Williston, 1971). The provincial reviews showed that the process of institutionalization was “unjust” and presented “grave problems in human rights” (Minutes, 1976, Binder19).

She considered these matters too important to be dropped and recognized the position of the Provincial Associations had to be shifted as well.

In 1976, the National Annual General Meeting approved a resolution to establish the Ad Hoc Committee on the Rights of the Institutionalized Mentally Retarded. A representative from each Provincial Association sat on the committee which was mandated to conduct an in-depth study on the rights of institutionalized persons and to report to the Annual General Meeting in 1977.  The study focused on the right of individuals and their advocates to “due process” in light of institutionalization, including the right to a fair hearing before an impartial body, with respect to such issues as admission, placement, programming and discharge. The Ad Hoc Committee concluded in its final 1977 Report that:

> The official pronouncements over recent years in support of deinstitutionalization and community living options carry the implication that, very possibly, significant numbers of mentally retarded individuals have been wrongly placed…[yet] only a slim trickle of the estimated 19,000 mentally handicapped in institutions were moving toward [reintegration in the] mainstream. The demand for urgent action stands clear (Minutes, 1977, Binder 20).

The Committee singled out the one province where the evidence was more encouraging, reporting that, “in the far west a revolution may be in the making.” This was a reference to the effective networking and political lobbying by Jo Dickey and the other mothers in the Woodlands Parent Group which resulted in the 1977 announcement by the British Columbia Minister of Human Resources that 200 "patients in the long-established Woodlands School had been identified as …having the capacity to be placed in a fully serviced community living environment." The Minister also went on record to say that many of the 1700 institutionalized persons in British Columbia could be relocated. He pledged financial support for this and he said that he expected the involvement of the British Columbia Association and other external agencies. The Ad Hoc Committee noted that there was no reason to think that the need to review suitability of placement was unique to British Columbia (Minutes, 1977, Binder 20). By deploying her activist style as a catalyst to bear on transforming communities and families into a political force, Jo was making "closing institutions" a priority.

Ironically, even as British Columbia was commended and held up as an example, the successful campaign of the Woodlands Parent Group was becoming a problem for the National Association. The very fact that this parent group had originated outside the Association structure, suggested an emerging trend whereby parents were beginning to "take action on their own, reflecting a 'giving up' on the Association movement" (Minutes, 1977, Binder 20). In February, 1977 at a Staff/Board planning retreat participants heard about a growing nationwide dilemma that the deinstitutionalization campaign faced. Many parents who supported community-based services, turned to institutions despite the well known problems when they were no longer physically able to coordinate services for their children. The Woodlands Parent Group highlighted this problem but it was not an isolated phenomenon. Other such groups had formed in Toronto and Montreal, and like the Vancouver group they were oriented to securing better community-based residences and services, not improving large institutions (Krugel & Wolfensberger, 1969; Roeher, 1990; Jeffreys & Sproul, 1993).

Jo Dickey made space for such new groups under the auspices of the Association but she was also prepared to go wherever she was invited and work with whoever asked her so long as this helped fan the flame behind the campaign to close institutions (Dickey, 1978). She believed that families and networks (as opposed to an individual leader) were the most effective agents of change and she welcomed each invitation for the opportunity it presented to galvanize support. In 1977, she was elected President of the Canadian Association and made this her national priority. She explained that her activism was propelled by getting Drew out of Woodlands: “It was because of my experience, you see? The only teacher we have is experience.” A resolution approved that year, offered the first clear definition of what the Association actually meant by an “institution”. It defined an institution as “any residence larger than a large family, where the environment distinctly differs from that of most families in society” (Wolfensberger, 1975). Jo Dickey established a National Ad-Hoc Committee on De-institutionalization and received a strong endorsement by the Board to mobilize “any and all resources” to this goal (Minutes, 1978, Binder 21). By 1978 she secured a commitment to deinstitutionalization politically and financially in her home province, which allowed her to take Drew out of Woodlands and get him established in a small home with the support he needed. She remembers that period well even twenty-five years later:

> There were people who didn’t want the institution to close because it would mean spending money they thought should go into the community on “those” people who didn’t look after their kids. That bitterness is still there. What is so interesting is that they think we chose to put our kids in institutions. Nobody chooses to do that…why would they?

As President she funded and supported regional deinstitutionalization strategies elsewhere, beginning in the Atlantic provinces. Her credibility was enormous. Wherever she was invited to speak as President of the National Association, she drew on the history of the Woodlands Parent Group (Crawford, 1983):

> First we addressed ourselves to changing the situation in which they were living – the institution. Before long, having inquired into the actual functioning of that facility, we realized that no matter how much money was poured into it, how much the effort was, how much we required that things change, there was never going to be an atmosphere developed that would really make the place a home and a proper living experience for our sons and daughters (Dickey, 1978).

She always included details of the early founders: “There were eight of us in the core and some, like Jackie were very nervous and I didn’t blame them.” Others, like herself, were more “determined and pig-headed.” She recalled that when they had over 300 names from Woodlands, “we made it impossible for parents not to know about the abuse going on there.” She credited her instinct for knowing just when to “go political” and for sensing that that there was “no point” going to the civil servants because they didn’t have “the authority or the motivation.” She detailed their confrontation with the Minister and how they refused to accept government funds and promises to make Woodlands “the best institution in the world.” But to this day she marvels, “I don’t know where that “strength of purpose came from but we all were of the same mind in that room.” She recalled the many meetings it took to persuade the government to allocate funding to people coming out of the institution on an individual basis by taking account of their basic living needs (food, shelter, clothing and utilities) and their disability-related needs and services (supports, attendant care, equipment and medications).[27] Yet those meetings were not always easy for her. She recalls that her small stature often made it uncomfortable for her to “walk into a room of men.”

In addition, her relationship with the Provincial Association was at times, difficult. She remembers the time she was “sent out into the hall” while the Board

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[27] In February 1977, a proposal, ‘Development of a Comprehensive Community-Based System of Service as an Alternative to Woodlands’ was presented to The Honourable William Vander Zalm, Minister of Human Resources for the Province of British Columbia by the Woodlands Parent Group. Jo Dickey often referred to it as “the red book”. In June 1977 he announced Project LIFE (“Living Independently for Equality 1977- 1981”) which expressed the government’s commitment to a major effort to deinstitutionalize services for the mentally handicapped. The Community Living Society received $238,000 for core funding for the first year, and funding for the purchase of services up to $18,000 per year per individual. By November 1979, 24 people had left Woodlands School assisted by the planning resources of the Community Living Society. See: *The Power to Choose* (1981) The Roeher Institute.p.155-180.

debated a request by the Woodlands Parent group for $5000: “They had a bird about that! Just a bird about that.” Jo needed the money to prepare a proposal for government:

> I had all these scribbles from the community consultations and open meetings [to discuss an alternative to Woodlands]. I remember sitting in the library and I had no idea what to do with these pieces of paper because I am not a writer. So I’m sitting there and I’m crying my eyes out and I have $5000 from the British Columbia Association for a proposal and all these pieces of paper and I haven’t a clue what to do with them, not a clue.

She recruited a colleague to help her and in response, the government committed resources. The parents group began by taking residents from Woodlands’ back wards, not wanting to be accused of only “taking only the easier ones.” Jo remembers how she felt when the task of administering the project fell to her: “I hate managing and I was scared to death but it was either do that or let it go down the tubes.” Reluctantly, she took on this additional responsibility, but protested, “I’m just a parent, I have no background in economics.”

Closing institutions was the top issue on Jo Dickey’s agenda but it was by no means the only one. The individualized planning and funding arrangements devised by the Woodlands Parent Group to bring Drew Dickey and others out of the institution was promising and timely, but of equal significance to Jo was its message about the power and muscle of a strong, dedicated and determined parents’ organization that was made up of mostly mothers. However this message was at risk of not getting through. Indeed, a sharp decline in volunteer activity across all levels of the Association was raising questions about the very sustainability and future of the parents' movement. The increasing professionalization of human services meant that professionals rather than volunteers were providing disability-related supports and services (Wolfensberger, 1972). In addition, in the context of women's growing labour force participation, the number of volunteers potentially available to serve as Board members, service providers or fundraisers, was dropping.

But not least important was the problem internal to the Association as Jo Dickey expressed in an open letter to the membership:[28]

> As I traveled across the country as President, as I spoke with many of you in your home or at meetings, I began to understand from you the concern that individual needs no longer seem to be the priority for this organization. It appeared that the structure you and I had put into place to try to meet those needs was getting in the way and the person was being lost in the process. Wherever I traveled there were individuals or pocket of people who were working by themselves... But within those isolated groups of people within our communities was an energy …attuned to the desires and hopes of men and women who have handicaps. There is a gold mine of energy available – but

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[28] CAMR Newsletter, 'Reporter' 1980. This letter was written in the context of informing the membership about a Board Retreat, held in Montebello, Quebec, in 1980, which provided a forum for the movement to review its values, goals and commitment.

> those energetic people…are not necessarily part of the structure we have set up.

At the core of this initiative was Jo's concern that there was no social base to carry out her deinstitutionalization campaign and her fear that the staff and board did not appreciate, as she did, that a decline in membership "threatened" the Association. Looking back to that period, she knows her ideas were "radical" but, she speculates, "I honestly think they underestimated my stubbornness, and maybe a little bit, my ability." In 1978, at Jo Dickey's instigation, a Special Policy Resolution was passed committing the Association to an exercise in organizational renewal (See Appendix 2: Resolution on Association Renewal, Minutes, 1978, Binder 21).

Jo Dickey appointed Audrey Cole to Chair a new Committee on "Involvement" with a mandate to stimulate an intensive campaign to attract groups of volunteers and to build a network across the country (NIMR, 1981). The renewal strategy was multifaceted and addressed two of Jo Dickey's priorities. Firstly, it linked her passion for solving the "institutional dilemma" with a plan to attract volunteers by constructing a more stimulating and important role for them. In her mind, the Association needed skilled and committed volunteers to monitor services and advocate for improvements in the face of violations taking place in institutional settings. She envisioned a network of legislative, monitoring and review groups across Canada with a powerful voice to "entrench the concept that mentally retarded persons as well as other disadvantaged groups have the same rights as other citizens of Canada".[29]

Secondly, the renewal strategy enabled Jo to support the development of "People First", a national self-advocacy movement (Dybwad & Bersani, 1996).[30] She was concerned that the rights of many people with intellectual disabilities remained constrained because they found it difficult to speak for themselves. She established a Consumers Advisory Committee and appointed Barb Goode its first Chair, which came with a seat on the National Board (Park et al., 2003).[31] Over 100 people with intellectual disabilities participated in the 1979 Annual Conference in response to Jo's inclusive gesture to bring in self-advocates, and to feature Barb Goode as a speaker at the Closing Plenary. This was a "first" in the Association's history (NIMR, 1981).

But under Jo Dickey's leadership it was the deinstitutionalization train that was moving the fastest, and every Annual General Meeting brought fresh evidence of her determination to keep the issue before the membership. She used her visibility to

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[29] "Partners for Progress" proposal prepared by the Canadian Association for Submission to the Federal Government, Department of National Health and Welfare, February, 1979, p. 23. This proposal was never funded although related activities were conducted by Provincial Associations.

[30] People First is a national organization of people labeled "mentally retarded" who come together to advocate for themselves. The first chapter in Canada was formed in Vancouver, British Columbia in 1979, and took the name People First to make the statement, "We are people first, our disability is secondary." People First is an international organization.

[31] Barb Goode was then President of People First of North Vancouver.. Significantly this development established a foundation upon which the Consumer Advisory Committee could take up a critical position during the Eve case in 1981. In 1981 (at the Special Board Meeting, held June 13/14 1981 to discuss sterilization), a change to the constitution of the Canadian Association was approved which made the Consumer Advisory Committee a standing committee of the Board.

tell success stories about people who had come out, to prove, “that everyone could live in the community, that nobody got murdered, and that nobody died of neglect, all those things that institutions were said to be a safe have against.” In 1979 she encouraged another controversial resolution that called for a moratorium on new admissions to institutions in light of what was known about their “dehumanizing, restrictive and damaging” nature; it too underwent many rewrites and amendments before being approved (See Appendix 2: Resolution Calling for a Moratorium on New Admissions, Minutes, 1979, Binder 22).

It was debated and amended before it was passed. A number of delegates asked to have their opposition recorded along with their reasons for voting against the resolution, suggesting that “institutional parents” were still a force in the Association. As one delegate, Marguerite E. Chown, put it: “I cannot risk further alienation from life-long friends who are faced with no other alternative than placement of their child in an institution at the present time.” And another, Ken Yeo said: “At the moment this Resolution could do nothing but create bad feelings with the staff of institutions and with government” (Minutes, 1979, Binder 22). To Jo Dickey, they were “good people” but they just had not had the same experience as she had. “If they had I am sure they would feel the same way. But those walls are pretty high and what happens behind those walls was stuff they just could not imagine.”

She remembers taking a “lot of heat from the Board” but pressed on. In February 1980, she urged the Executive Committee to approve an unprecedented $50,000 loan to the Nova Scotia Division to complete the purchase of a house in Sydney Mines for a group home for people with serious intellectual disabilities.

Though the Association was not in the habit of lending money, Jo defended that financial decision to the Board as follows:

> The Executive Committee was fully conscious of the possibility that their action could be interpreted as establishing a precedent, and indeed it does just that. The important thing to observe is exactly what kind of precedent is it that has been established…[it is] a means of stopping the growth of institutions and institutional populations in Nova Scotia (Minutes, 1980, Binder 23).

Years later she defended that action in an interview, saying, "I just don't follow the rules." Meanwhile, the Committee on the Rights of Institutionalized Persons[32] which had been meeting since 1976, brought a Report to the 1980 Annual General Meeting. They had uncovered widespread incidences of abuse and forms of neglect taking place within institutions across the country (Williston, 1971; Welch, 1973; Sobsey, 1994; Roeher, 1995). The evidence, said Committee Chair, Mildred DeHaan, "should convince anyone that the institutional model has serious and long term defects with respect to our retarded citizens" (Minutes, 1980, Binder 23). In addition, a further Resolution passed in 1980 tightened up the definition of an "institution" to apply to "any place larger than an ordinary family home," thereby replacing the 1977 definition, "any residence larger than a large family." It also directed the Association to "oppose the use of the institution model in any future provision of residential services" (Canadian Council on Social Development, 1985).

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[32] Formerly, the Committee on the Right of the Institutionalized Mentally Retarded.

This resolution was cited frequently when Jo Dickey, as Past President, waged a highly visible confrontation with the Metro Toronto Association over “Project 81”. In 1981, the Toronto Association, the largest local in the country, proposed to build a residential facility for over thirty profoundly disabled people. Alarmed, the National Executive reacted quickly. They characterized the proposed residence as a “mini–institution” to discredit it, but underneath, they were troubled by the potential of Project 81 to establish a precedent for residential care for “medically fragile people”. Although similarly large scale developments were under consideration in other provinces, none had been brought forward by an affiliated local Association. So while the Executive did not appear to want an internal feud they wished to thwart the project as evidence by the trail of memos and letters written in an attempt to defuse the situation. Ultimately, Jo Dickey and other Association officers cited the various resolutions on Institutions passed in Annual General Meetings, notably in 1977 and 1980, to demonstrate that the position taken by the Canadian Association, including the recently adopted definition of an “institution” as “any place larger than an ordinary family home”, conflicted with the plans being proposed (Minutes, 1981, Binder 24).

In May, 1981 Jo Dickey conceived a strategy that became an especially important part of her legacy. Through another resolution she went on record as being the first leader of the Association to propose that in recognition of the high costs involved in making the transition from institutionally based services to establish community supports and services, a special fund be made available by the federal government to the provinces to help overcome the hurdle of the deinstitutionalization

(See Appendix 2: Resolution on Transition Funds to Stimulate Deinstitutionalization, (Minutes, 1981, Binder 24).

Once approved by the membership, she presented this idea during the International Year of Disabled Persons in 1981 to the House of Commons Special Committee on the Disabled and the Handicapped. Her timing was excellent. The recommendation was incorporated as a recommendation in the Committee's famous *Obstacles* Report, and later a deinstitutionalization transition fund was proposed by a Parliamentary Task Force on Federal-Provincial Fiscal Arrangements.[33] From that point forward, Jo Dickey's idea of securing a federal commitment to transitional funding remained on the Board's agenda though it took several years before it was enacted. Her clear sense of "what the future could look like" and her political astuteness continued to catalyze support.

Hugh Lafave, newly appointed Executive Vice-President under Jo Dickey's Past Presidency, took on her commitment to overcoming the "institutional dilemma" at the administrative level. In his 1981 Annual Report, he affirmed that the Association's focus remained a "clear resolve to actively deal with institutions throughout Canada", and that this resolve would shape the committee structure and their activities (Minutes, 1981, Binder 24). On the ground, a National Task Force on Community Living was established to investigate the proliferation of "mini-institutions" and the investments being made in institutions and expansion projects

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[33] Jo Dickey presented to the Committee in Ottawa, September 17, 1980. See: Special Parliamentary Committee on the Disabled and Handicapped, Obstacles Report (1981) Recommendation 20: Funding and Implementation. pp 142-145.

across the country. When members of the Task Force reported their findings, they described an “atmosphere of crisis” and a problem that was “far more extensive than first realized” (Minutes, 1982, Binder 25). They made a series of recommendations and identified sites of best practice; they pointed to the success of the Woodlands Parent Group which now supported over 50 people to leave the institution and establish homes in the greater Vancouver area (Crawford, 1983; Dickey, 1985).

Looking back over that period Jo remembers:

> Many people thought we were going to fall flat on our face, or that something drastic would happen. I don’t think I could go through that all again. When you’re determined, you do things that are pretty rare.”

## The Campaign in Quebec

One of the members of this National Task Force on Community Living was André Blanchet, who in 1982 became Vice-President of the Canadian Association and in 1984, its President. He was Chief of Psychiatric Services at the Granby Hospital in Quebec, and Director of Adult Services at Rivière-des-Prairies Hospital, the large psychiatric facility where Louis Berthiaume was a resident (Taylor, 1971; Anglin, 1972). André Blanchet was very aware of the deinstitutionalization developments in British Columbia, and with a vision for replication in Quebec, recruited Paulette Berthiaume, an active mother in the Rivière-des-Prairie Parent Group, to join the Task Force. While serving on that national committee Paulette first met Jo Dickey and learned about the work of the Woodlands Parent Group. She invited Jo to Montreal in 1982 to meet with her parent group followed by a trip to British Columbia in 1983 to meet the Woodland parents.

André Blanchet, as Director of the Adult Section at Rivière-des-Prairies, began to involve parents in planning for community reintegration. As a result Paulette and other mothers began to hope and envision a more promising future in the community. Kathleen Ruff, a human rights advocate for the Canadian Association followed the deinstitutionalization struggle in Quebec closely and put it in the context of Quebec's "Quiet Revolution":

> Just as the province of Quebec underwent a revolution in its attitudes towards itself, refusing any longer to accept second-class status for French-speaking Quebecers, so did some of the parents undergo a revolution in their attitudes and expectations regarding their sons and daughters (Ruff, 1986).

The parents' group at Rivière-des-Prairies asked for changes at the institution but soon realized the limits of taking a polite approach. It was not getting them anywhere. Paulette remembered that when the parents presented the Director with the "long list" of problems they identified at the institution, he "threw it on the table" and told them, "Nobody will believe you!" They felt they had to fight. The more they observed and questioned, the more they saw what was wrong and documented it. Paulette and the other parents were getting an unexpected education. Although they considered themselves "innocent" and "unorganized," what they observed and learned on the ground propelled them because of their strong sense of obligation to the children inside. They requested a meeting with the Minister of Health and Social Service in which they enumerated a long list of concerns. When they asked him to intervene, he agreed and called for an evaluation of the parents' complaints. The report he received was very disturbing; there was evidence of abuse and theft in addition to a poor quality of life for residents.

Throughout this period Paulette attended meetings of the Advocacy Committee in Toronto, where she worked with Audrey Cole who was the Vice-Chair. On the Advocacy Committee, Paulette was introduced to an extensive number of legal and human rights issues some of which, institutional abuse, for example, she took up in her own province. In 1984 she heard Jacques Pelletier, Executive Vice President (following Hugh Lafave who retired early for health reasons) report that Canada was "fast entering a massive deinstitutionalization phase." This presented many new challenges to the Association and its role to help governments put in place the "right types of community-based services."(Minutes, 1984, Binder 27). Pelletier was referring to developments in British Columbia where the Government was starting to move residents out of the Tranquille Institution not to community settings as had been agreed, but instead was admitting them to another extended care facility (Lord & Hearn,1987; Roeher Institute, 1991). Once again, Jo Dickey mobilized support at all levels of the Association to ensure news of this situation went before the court in an attempt to get the decision reversed.[34] But Pelletier may also have been speaking about developments in Quebec.

In May, 1985, President André Blanchet advised his Executive that the Quebec media had just released a story alleging abuse at the Rivière-des-Prairies institution in Montreal. Many parents with relatives inside were shocked as were members of the local and provincial Associations. The Quebec Government appointed Richard Shadley, a criminal lawyer with no knowledge of persons with intellectual disabilities or integration, to head the Shadley Commission of Inquiry into Rivière-des-Prairies. Paulette Bethiaume became President of the Parent Group of Rivière-des-Prairies.[35] Exercising her skills as a capacity-builder, she worked informally and strategically to bring community people together to expose poor conditions at the institution. She found a lawyer and called a meeting in his office. This lawyer was "just getting started" and was willing to work for "free". Paulette remembers that having "worked hard" to get parents out, the response was "unbelievable" and that over a hundred parents attended. She then turned to the National Association for moral and financial support so the parent group could be represented in court. The Board approved funds "up to $4000…to allow the parents' group access to comparable legal advice that the hospital administration would receive from public funds" (Minutes, 1985, Binder 28). This way, anyone giving testimony at the public hearing was assured of having legal representation. Over the

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[34] Reports of demonstrations and candlelight vigils protesting the B.C. Government's decision to transfer disabled people from the Tranquille Institution in Kamloops to the Glendale Lodge in Victoria, instead of to group homes in the community, was widely reported through the month of September 1984 in *The Globe and Mail.*

[35] Le Regroupement pour l'integration dans la communaute in Quebec.

summer of 1985, parents, workers, and professionals testified before the Shadley Inquiry. “We had guts”, Paulette remembers, and not only at the Inquiry. Later, when the parents returned to the institution, they were “booed.”

Paulette and her group wanted the institution placed under trusteeship and the residents moved out into community settings. However, by October, the Inquiry was halted while the Quebec Superior Court heard arguments over the extent of the Inquiry’s mandate. This was widely seen as a tactic by the Council of Doctors at the facility to stall the process. Rather than wait, the Rivière-des-Prairies Parent Group conducted their own “people’s trial” and gathered nearly 200 sworn affadavits outlining conditions at the hospital, which the press publicized and which formed the basis of a renewed demand to the Government that the hospital be placed under trusteeship.[36]

Paulette remembers how the parents were completely taken by surprise. They wanted good services but suddenly there was a criminal investigation which galvanized a broader involvement by parents than she had ever seen before.

> Of course it was crimes when you consider what they were doing to our sons and daughters… You know, we were not organized, we were not organized at all…we called meetings, people came from all over, we typed things and put them in envelopes, and sent them off to parents so everyone would know. I

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[36] A Position Paper prepared by the Rivière-des-Prairies Parent Group and presented to Mr Guy Chevrette, Minister of Health and Social Services on September 17, 1985 summarized the affidavits from parents, educators, paid staff and professionals of the Hospital. The parents claimed the evidence was really “only the tip of the iceberg” but damaging enough to request the Hospital be placed under trusteeship.

> used to receive calls from a parent …sometimes at twelve or twelve thirty at night. We talked quietly but it was so big for us ...I thought we were too innocent to be meddling in this.
>
> We didn't have a penny …but we got ourselves a lawyer, we went to court and we were always five or six …in the front row. We were all mothers. I could name them for you…Mme Gerard, Mme des Ouches, Mme Simard, me…we used to replace ourselves. We were all mothers…they were always talking about parents but no, we were mothers.

One day during the inquiry, Paulette, no longer able to bear listening to how lawyers described their sons and daughters as less than "nothing" led those mothers on a walk-out from the courtroom in protest. Newspaper reporters were waiting outside and the widespread media coverage brought the case to national attention. At the next Annual General Meeting, two mothers from the Quebec Association brought forward a resolution asking Associations across the country to support Quebec in calling for the hospital to be put under trusteeship. They were warmly received and their resolution was carried unanimously (See Appendix 2: Resolution on Rivière-des-Prairies, Minutes, 1985, Binder 28):

The President, André Blanchet, indicated his personal support for this action by writing his own letters to the Premier of Quebec and the Prime Minister of Canada informing them of the stand taken by the Canadian Association with respect to

Rivière-des-Prairies. In his 1985 President's Report, he highlighted the significance of the parents' activism in creating this institutional "hot spot":

> The question of deinstitutionalization has become, through the institution of a Public Inquiry, an immense debate in Quebec society. A day doesn't go by without it being mentioned in the press or radio or television. At the moment the concrete gains that have been made are as follows: an ombudsman, answering directly to the provincial government, is constantly in attendance at the hospital; a parliamentary committee on deinstitutionalization has been established as a result of the public debate, and equally important, an announcement by the government of a green paper on mental health policy which will devote a large part to the question of the health of persons in psychiatric hospitals (Minutes, 1985, Binder 28).

The Advocacy Committee took their inspiration from this victory and now set as its agenda the right of all persons, not only those already in institutions but also those in danger of becoming institutionalized; the latter they saw as "the major advocacy issue [now] and …for some time to come" (Minutes, 1985, Binder 28).

In December, the Superior Court in Quebec ruled that the Shadley Commission of Inquiry could continue to hear evidence of abuses which pervaded the programs and services of the Rivière-des-Prairies institution. The Commissioner held several months of hearings before making his recommendations.[37] He concluded that strong intervention was needed to make the services more humane but as the existing administration was incapable of implementing these, he supported the parents in recommending that the institution be placed under trusteeship. The Minister would not go this far but agreed that 300 persons could be moved from hospital to community settings and he promised that a separate agency would be set up to deal with the move (Ruff, 1986; Roeher Institute, 1996).

Paulette and her group won a great deal of support at the facility including from union employees. There were however, consequences for André Blanchet who as Paulette explained, was "punished for supporting us" and fired from his job as Director of Adult Services. The parents were offered direct staff assistance and a $7000 loan from the National Association to cover their costs and to implement plans to begin to move people out. Louis Berthiaume was not among them, but Paulette's rise in the Association was meteoric. Her leadership style, her courage to confront authorities, and her capacity to build networks had made an impression. Although she had just attended her first National Conference and Annual General Meeting in 1985, as part of the Quebec delegation, within the year she was elected to the National Board, appointed to the Executive, and invited to be a member of the newly

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[37] "The 247-page Report released in May recommended putting the Montreal hospital under trusteeship and carrying out sweeping reforms…The Minister [Therese Lavoie-Roux) adopted recommendations to improve hospital conditions but rejected trusteeship of the hospital. Instead she named an ombudsman, M. Reynald Gagnon to protect the rights of 595 patients in the institution. …Parents and deinstitutionalization advocates admit they only won a partial victory so they will continue to lobby for the closing of the hospital." *Entourage*, editorial 1986 1(3).

established fundraising vehicle, the Community Living Canadian Foundation. Jo Dickey recalls:

> Paulette was very respected in the community, and she learned…quite a bit about the things to watch for from others' experiences. She had quite a bit of contact with parliamentary people, and in Quebec, that kind of thing means something…they're a close-knit civilization and I think she was listened to. It took her a long time to realize first she wanted Louis out of there, and second that she could get him out of there. They came to see us and they had me down there two or three times. And I think in her heart she always knew she wanted him out of there, but there was just that fear of stepping out into the dark.

In 1987 Paulette Berthiaume was asked to join a new national Task Force called "Replacing Institutions" which took as its vision, "no further admissions to institutions" within five years, and a gradual evacuation of residents that would proceed at the rate of 10% a year (based on 1986 populations). When Task Force members met in Ottawa in April, 1987 to conduct a federal lobby, they were advised by President Gordon Porter that the single most important issue for the Association to stress with government officials was "closing institutions" (Minutes, 1987, Binder 30). The matter of transitional funding to entice provincial governments to close institutions was still on the agenda and raised with senior policy advisors. There were signs that the concept was being positively received when a meeting was confirmed later that year with the Minister of Health and Welfare himself, Jake Epp.

This campaign to close institutions found its voice in Quebec once again through Paulette Berthiaume, and her activist skills came to the fore in developing the capacity of other mothers and family members to organize. In 1988 she helped a group of parents engineer a dramatic "kidnapping" to free 88 residents from Pavillon Ste.Theophile, a private institution, in an action that included buses and an evacuation at midnight. Paulette remembers the kidnapping:

> I was in charge of one house so I went there a few days before to put the main things in the fridge. The furniture was there, they just had to bring their clothes. The Rehabilitation Centre rented buses. Four of them came one night and a few days later I went back for their personal things. This is how we did it for four of them – but there were 88 in all.

With "tenacity and doggedness"[38] the group convinced the Quebec Human Rights Commission to undertake public hearings into the misappropriation of funds, poor quality of care, and the exploitation of people with intellectual disabilities who lived there. Paulette, with her rehabilitation credentials, was given the status of "professional" when she was appointed a member of the assessment team established by the Government of Quebec to evaluate all the residents living in the Saint

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[38] These were the words used in the Citation in the 1990 President's Award given to Mme Yvette Carpentier, a sister of one of the residents who was instrumental in the kidnapping, at the 33rd AGM, October 13, 1990 Victoria, B.C.

Theophile Institution. She kept her parent status quiet to enhance her credibility. The institution was closed in 1990,  and residents moved to the community where they were supported by friends and advocates (Roeher Institute, 1996).

Investigators for the Human Rights Commission discovered allowances allocated by government for personal spending by residents were never distributed. Instead, the operator of Pavillon Saint Theophile retained them for “expenses” even though the institution received separate grants for operating costs. Much that was designated as “care” moreover, was more accurately characterized as “punishment,” “deprivation” and “infantilization.” The Commission found the administration guilty of exploiting the residents contrary to Section 48 of the province’s *Charter of Rights and Freedoms*, and awarded the former 88 residents the largest settlement ever recorded in Canada for human rights violation, an unprecedented $1,400,000 in personal damages.[39] Significantly, the case recognized the rights afforded to all other Canadians also belonged to people who have been institutionalized.  In 1988 Paulette saw to it that the Association’s prestigious President’s Award be given to Mme Yvette Carpentier, the sister of one of the residents who was a moving force behind the group that got the institution closed.

In 1993, Paulette Berthiaume became President of the Canadian Association after serving for four years as Vice President. She announced in January, 1994 (Minutes, 1994, Binder 37):

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[39] The Quebec Human Rights Commission v Jean Coutu and Centre d’accueil Pavillon Saint Theophile Inc., 1991. Source Canadian Human Rights Reporter, Vol. 16, Decision 14, August, 1992, D/129-D/138.

> I have just learned that my son Louis will finally be moving to the community after living for 30 years in an institution. This time it is really going to happen. I couldn't ask for a more beautiful way to start the year!

It had been 14 years since she visited British Columbia for the first time and saw for herself the success of the Woodlands parents. By then the British Columbia activists had advanced enough along in bringing people back to their communities to offer some evidence that it worked. But Paulette was not completely convinced. One factor made her hesitate: she was reluctant to bring Louis out and "leave the money inside." She knew that his care cost the Quebec government $85,000 to keep him in the institution, and she was adamant that this money would be needed to follow him to cover the costs of adequate services in the community. Even though she was eager, the authorities made no effort to move him out until she decided to "get political". (Berthiaume, 1995; 2001). Being President, no doubt helped:

> I went straight to the Minister of Health and Social Services – I didn't talk to her, I didn't phone her, I wrote to her and said, "I'm giving you so much time, if you don't do something I'm going to act." And I was ready to [call upon] Associations all across Canada and the United States, all the people I had met.

But she did not need to take further action. When Louis came out in 1994, the money came with him.

## The Alliance with Self-Advocates

Local struggles combined with federal lobbying were beginning to reap benefits. In 1988, Federal Minister Ramon Hnatyshyn announced the government was prepared to offer incentive funding that would allow provinces which were committed to full deinstitutionalization to receive transitional funding to support both institutional and community services while their institutions were closing. He made this announcement at the at the Association's Conference and Executive Vice-President, Diane Richler, contextualized his speech for the membership (Minutes, 1988, Binder 31):

> The idea that special funds would be needed from the federal government to help provinces get over the financial hurdle of deinstitutionalization was first suggested by Mrs. Jo Dickey, President of the Canadian Association in the early 1980s.The wisdom of her suggestion was recognized by the Obstacles Report (1981) and Mr. Hnatyshyn's statement is a commitment by the federal government to provide the funding necessary to help the provinces move ahead- one million dollars over a five year period to the Canadian Association to consult with the provinces on deinstitutionalization.[40]

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[40] This was followed in 1993 by a Federal- Provincial partnership agreement for a demonstration project, worth 15 million dollars over 5 years, beginning with Newfoundland to bring out 126 people from the Waterford Hospital. It was called "The Right Futures Project- a Future with Rights." This was the largest single item in the federal government's National Strategy for the Integration of Persons with

This was a major success in the campaign to close institutions. It also led to a new phase in the campaign characterized by the alliance between the activist mothers and self-advocates, disabled activists who advocated on their own behalf. In June, 1988 the National Board passed a series of resolutions to increase self-advocacy participation in the decision-making process at the Board and Annual General Meeting levels (Minutes, 1988, Binder 31).[41] Given greater visibility and voice, self-advocates on the Consumer Advisory Committee became strong spokespersons for closing institutions as many of them had either lived inside themselves, or knew someone who had. Notably they turned for support to Jo Dickey, Paulette Berthiaume, and Audrey Cole as national leaders they could trust.

Jo Dickey had been the first to create the organizational space for them to participate when, in 1979 as President she established the Consumer Advisory Committee. She stated, "Here we had an organization in which the people affected had no voice. I thought that was a travesty." Paulette Berthiaume was the Self-Advocates' choice to chair a Public Awareness Committee in 1988 after a volatile Annual General Meeting in which self-advocates noisily rejected a series of posters and public service announcements whose cartoon imagery and belittling text they found demeaning. They were hurt at not having been consulted and found in this another instance of what they saw as the paternalism of the Association. They swayed

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Disabilities announced in 1991 and a significant moment in the history of the Canadian Association.

[41] These included designating 6 of the 12 Director-at-large positions for self-advocates and providing staff support and financial resources for members of the Consumer Advisory Committee to attend all Board meetings.

the delegates to vote against a motion to approve the actions of the 1987-88 Board. Paulette, respected and trusted by all sides, was asked to step in and guide the Board on this sensitive front. “I know where they come from and I know what they have to go through. I can feel it. I’m just that way.” Audrey Cole provided help to self-advocates in crafting resolutions over many years. As she said, “They are impatient but when you get put down all your life you want to change things now.” She did so again in 1989, when they decided to target one of the central problems that had emerged with deinstitutionalization (Park, et al., 2003). Self-advocates were concerned that people were moving out of large institutions only to be re-institutionalized in group homes (See Appendix 2: Resolution on Problems with Deinstitutionalization, Minutes, 1989, Binder 32).

Two years later, at the 1991 Annual General Meeting, self-advocates nominated Audrey Cole from the floor, as their candidate for President. They credited her ability to see the big picture in the campaign to close institutions. She had urged the Association, for example, to lobby the federal government for more affordable housing, recognizing that people coming out of institutions were poor. She also took up the cause of Native Canadians with intellectual disabilities (Minutes, 1989, Binder 32).[42] By nominating her, the self-advocates challenged the slate proposed by the Nominations Committee. Audrey remembers there was “quite a campaign” both for and against her candidacy, but as she said, “you know me, I’m not very political so I didn’t know what was going on.” She did not win.

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[42] Audrey had moved a resolution at the 1989 AGM urging the Association to “promote and provide culturally and linguistically appropriate services and supports within native communities in Canada to those labeled developmentally handicapped”.

Although Audrey Cole was not involved as a major figure in the deinstitutionalization campaign directly, her expertise in legal advocacy and human rights led the Canadian Association to appoint her for legal issues associated with people coming out of institutions. In 1982, for example, she was asked to represent the Association in the famous Justin Clark case. Justin Clark was a 21 year old man with cerebral palsy who lived in Rideau Regional Centre, an institution in which he had lived since he was two year old. He wished to leave and move to Ottawa with friends. He was opposed in this by his father who moved to have him legally declared mentally incompetent and in need of a guardian to make his decisions. It was the father's expectation that Justin would be declared incompetent and he, as his father would be appointed guardian to make all the decisions, including the decision that Justin remain in the institution. Justin, with the help of residential counselors, retained a lawyer to represent him in court where he asserted his right to make his own decisions. In November 1982, the case came to court as *Clark v Clark.* [43] It was heard under the Mental Incompetency Act of Ontario. After six days of hearings, Justin Clark was vindicated by Judge John Matheson's decision:

> We have all of us, recognized a gently, trusting, believing spirit and very much a thinking human being who has his unique part to play in our compassionate independent society. And so in the spirit of that liberty which Learned Hand tells us seeks to understand the minds of other men, and

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[43] Clark v Clark (1982), 40 O.R. (2nd) 383, 4 C.H.R.R. D/1187 (Co.Ct.)

> remembers that not even a sparrow falls to the earth unheeded, I find and declare Mathew Justin Clark to be mentally competent.

Audrey Cole’s involvement in this case reflected her longstanding interest in designing a form of supported decision-making as an alternative to guardianship that did not remove an individual’s right to make their own decisions. She was closely supported by Paulette and Jo, each eager to see their sons’ right to self- determination protected (Cole, 1991; Dickey, 1991; Berthiaume, 1991). The campaign to close institutions aligned with a parallel campaign to secure human rights, as will be seen in the next chapter.

In a Guest Editorial in *entourage,* the National Asssociation’s magazine, in an issue celebrating the 40th Anniversary of the Canadian Association, Audrey Cole (1998) looked at how far the campaign to close institutions had come, not least in changing the attitudes of the members of the Associations themselves. She noted that at the first conference in 1958 guest speakers included four Superintendents of Hospital Schools in Canada:

> In earlier days we tended to accept the professional view that some people would never be able to take their place in society. We believed that only after having been trained to do so within the institution could any resident return to the community.

It had taken years of persistent commitment by activist mothers and their supporters to change this. A significant milestone marking their success was the unprecedented mobilization by self-advocates in the early 1980s who lobbied the Association at the local, provincial, and national level to change its name from the Canadian Association for the Mentally Retarded to the Canadian Association for Community Living (Dybwad & Bersani, 1996; Park et al, 2003). Leaders on the Consumer Advisory Committee proposed a new name to reflect the Association's progressive goal of living in the community, not institutional living in facilities, and to replace what self-advocates viewed as the stigmatizing label of "mental retardation." In June, 1985, a Special General Meeting voted in favour of the "Name Change Resolution." President Andre Blanchet called this achievement a "natural progression in response to the changing needs of the Association's constituents", one that spoke positively to the organization's "future direction" (Minutes, 1985, Binder 28).

## Conclusion

The campaign to close institutions has continued to shape the Association's agenda even though the activist mothers in this study are no longer in leadership positions (Richler, 1998; Sayeed, 2005).[44] A National Task Force on Deinstitutionalization continues to monitor and report on progress towards

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[44] Zuhy Sayeed, President of the Canadian Association, 2005 wrote a letter to the editor in response to a column by Margaret Wente "When cruelty become official policy" in which Wente criticized provincial deinstitutionalization policy. See: *The Globe and Mail*, January 11, 2005.

community living across the country. It publishes a regular newsletter, *Institution Watch*. A 2004 issue reported on recent developments in each of the provinces where the three activist mothers live and work. It profiled the important announcement by the Province of Ontario and its commitment to close its three remaining large institutions (Ministry of Community and Social Services, 2004; Mackie & Philp, 2004). It reported on the slow progress at Rivière-des-Prairies where decision-makers were described as “too lax” in bringing the remaining hundred residents out. The same issue detailed the chilling discovery of a cemetery at Woodlands where 3300 residents were buried from the 1920s to the 1950s. Grave markers had been removed and were used as paving stones for a patio and barbeque pit on the site. This story was reported in *The Globe and Mail* (Hume, 2005) which described a restoration project undertaken by the Provincial Association and self- advocates to salvage the stones and use them to create a memorial wall.

This memorial wall may also serve as a metaphor for the success of the activist mothers’ campaign to close institutions. It will speak to why the deinstitutionalization movement became aligned with a human rights campaign. The growing recognition that the existing service system, particularly large institutions, were outdated, ineffective, and dehumanizing paralleled new notions that services to disabled people and their families needed to be understood as a matter of right, not the result of charitable impulse. Together, they prompted inventive and ground-breaking debates about the importance of locating “disability” in broader emerging discussions about human rights (Peters, 2003; Russell, 1998; Driedger, 1989; Valentine & Vickers, 1996). In their campaigns, activist mothers were supported by those who believed in human rights principles, not only to the problem of institutions, but to every other issue facing the Association. It is to this uncharted territory for the Association and its activist mothers that the next chapter turns.

# Chapter Six

# The Campaign to Secure Human Rights

## Historical Overview

The roots of the Canadian welfare state can be found in the English Poor Law of 1834. From the outset the principle of less eligibility pervaded the administration of public assistance. Ideas about the failings of the poor were modified in the late nineteenth century and distinctions made between the worthy and unworthy poor. The “undeserving poor,” were considered to be able-bodied but unwilling to work, and therefore worthy of blame for having brought their misfortunes upon themselves. People with disabilities were seen as the “needy poor”; deemed incompetent to function in society, they were considered “deserving” of charity and help. Over the succeeding years, the state assumed some obligation to provide for disabled people through systems of segregation in prisons and institutions. The immediate post-war framework for securing the welfare of Canadians, entrenched their exclusion further through extensive investments in institutional facilities and a range of services exclusively for people with disabilities (Crichton & Jongbloed, 1998).

A number of forces converged to complicate the issue of how best to provide disability-related services. These included new concepts of community-based supports and services, experimentation with comprehensive approaches to service delivery, the discovery of institutional abuse on a vast scale, and the rise of the human rights movement around the world. In 1948 the United Nations passed the Universal

Declaration of Human Rights; in 1971 the United Nations General Assembly adopted the Declaration on the Rights of Mentally Retarded Persons and in 1975 it passed a still broader Declaration of the Rights of Disabled Persons. Such declarations could not be used in courts of law, but they could provide a reference point and guide for social legislation (Roeher Institute, 1996). The civil rights movement in the United States and the women's movement mirrored a climate in which disability began to be understood as an equality issue. The United Nations encouraged further interest in disadvantaged groups by designating international years of concern for the problems of particular groups (Crighton & Jongbloed, 1998). They designated 1981 as International Year of Disabled Persons. These events had a significant impact in Canada. In 1982 the Canadian Constitution was repatriated from the British North American Act with its appended Charter of Rights and Freedoms. Increasingly voices were raised to entrench the equality rights of people with disabilities in human rights legislation and the Canadian Constitution.

## Background

In the early years the issue of human rights was not on the Association's agenda. In 1965, for example, when the Canadian Association was invited to join a national coalition with other disability groups, such as the Canadian Council for Rehabilitation of the Disabled, in presenting a brief to the Ontario Royal Commission on Human Rights, very few Board members supported this proposal (Minutes, 1964, Binder 7).[45] The next year, the Board rejected another “rights” invitation, this time from the President of the Canadian Human Rights Commission to join in activities celebrating the International Year for Human Rights in 1968. Declining, the Association’s President explained that, “in spite of the significance of the work being undertaken, our limited resources, both staff and volunteer, make it extremely unlikely that we would find ourselves in a position to accept” (Minutes, 1967, Binder 10).

In 1971 the National Board debated the advantages and disadvantages of having a “special Bill of Rights for the Retarded” with some members insisting that disability-targeted legislation was necessary, while others claimed that the Canadian Bill of Rights provided adequate coverage for everyone (Minutes, 1971, Binder 14). Board members learned about variations in provincial policies through these discussions, particularly those which governed education, training, and employment and their differential impact on people with intellectual disabilities. But they went no further than defining a national role for the Canadian Association in persuading provinces to take account of disability when introducing and changing legislation.

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[45] On the pretext that there was no need to take this up at the Provincial level when rights were already protected in the Federal Canadian Bill of Rights, no action was taken. Mrs. Reid, Chair of the Liaison Committee, expressed her frustration at this non-decision: “the day arrived long ago for the serious thought and constructive effort that should have been made towards the function of a Canadian Council composed of representatives of all national organizations working to provide training, education and rehabilitation for all children and adults who deviate from normal no matter what the deviation is – for legislation and to be a better bargaining agent of change.”

## Federal and Provincial Human Rights Legislation

Audrey Cole had immense impact in bringing human rights consciousness to the Canadian Association. Her campaign to secure human rights began in July, 1975 at which time she was following the debates in Parliament on Bill C-72 which later became the Canadian Human Rights Act. She noticed that disability was not being included as a "prohibited ground of discrimination."[46] At the time she was on the Board of her local Ottawa Association but she says,

> I realized very early on that the issues I was interested in were not the service issues. Not that I wasn't interested it was just that to me what we were doing didn't necessarily contribute to what we said our purpose was. I felt the issues were more fundamental. That's where I wanted to work.

Audrey was prepared to tackle complicated issues and to raise the consciousness of the Association. She could find "no evidence from reading Hansard" that the omission of disability "was a burning issue for any party." She crafted a resolution urging the Canadian Association to make immediate representation to the federal Minister of Justice to ensure the Bill was amended to include mental and

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[46] Unless otherwise indicated all quotations are based on interviews conducted between January 2004 and July 2005. With Jo Dickey on January 15, 2004 (Vancouver), February 28/29, 2005 (Toronto), April 15, 2005 (Toronto), and July 10 (2005); With Audrey Cole on March 15, 2004 (Smiths Falls, Ontario); November, 2004 (Toronto) and July 10, 2005 (Toronto); With Paulette Berthiaume on March 14, 2004 (Ottawa)and July 10, 2005 (Toronto) . A focus group interview was held with all three on July 10, 2005 (Toronto).

physical handicap as a “prohibited ground of discrimination.” As she remembers it, “there was nothing in there, and I felt there should be so that’s why I wrote it.” The resolution was approved locally and provincially. In October, 1976 it was put before the general membership at the 19th Annual Meeting in Ottawa, where it also passed (Minutes, 1976, Binder 19). A prominent lawyer attending the conference told Audrey he was intrigued to learn there was a resolution on “rights” at the Annual Meeting. “That was my resolution,” she told him. (See Appendix 2: Resolution to Amend Bill C-72, the Canadian Human Rights Act to include disability as a prohibited ground of discrimination, Minutes, 1976, Binder 19).

In 1977, as directed by the membership, the Association prepared a brief and submitted it to the Minister of Justice and the Commons Committee on Justice and Legal Affairs, but to their disappointment the Bill passed the House of Commons without the requested amendment. In 1978 Audrey arrived at the 21st Annual General Meeting as a voting member of the Ontario delegation, to carry out what she described as “my second attempt.” She introduced another resolution urging the Association to keep up the pressure on an amendment to the Canadian Human Rights Act (See Appendix 2: Resolution (1978) to Amend the Canadian Human Rights Act, Minutes, 1978, Binder 21).

Although these resolutions also passed without any difficulty, Audrey began to feel a suspicious, speculating that perhaps the membership had not fully understood what they were voting for:

> … I don’t think rights were on anyone’s mind. To my knowledge there was certainly no opposition, but nor was there any discussion. I don’t think anyone really thought about it. I know people look at me and say “she’s very serious about this, it must be important, but we don’t have a clue what she’s talking about.”

The Federal Human Rights Act became law March 1, 1978 without the requested amendment, thereby offering no protection to people with intellectual disabilities. Organizational records indicate that several follow-up meetings took place to develop a case for including “mental handicap” as a prohibited ground of discrimination in the various Human Rights Codes in Canada. At the national level, Association representatives met with Federal and Provincial Human Rights Commissioners and members of their staff. Jo Dickey, as President, attended a Canadian Human Rights Conference in December 1978. At the Provincial level, several Associations submitted briefs on the issue to their own legislatures and commissioners. Overall, the Board felt that by the end of the 1970s a “generally positive climate has been felt in both the Commissions themselves and in the government departments responsible for human rights legislation…[which] signals the increasing momentum to secure protection in law for the rights of mentally handicapped people” (Minutes, 1979, Binder 22).

To capitalize on that momentum, the Ontario Association was ready with another resolution, written and introduced by Audrey Cole. This resolution suggested that despite the “encouraging response” from the Human Rights Commission of

Canada, pressure be renewed, “vigorously,” at federal and provincial levels (Minutes, 1979, Binder 22). The Association was encouraged when the 1979 Annual Report of the Canadian Human Rights Commission included in fact, the following recommendation under Section 1.2.3 titled “Mental Handicap (Retardation)”:We recommend to Parliament that Mental Handicap be added to the proscribed grounds of discrimination under the Canadian Human Rights Act (Minutes, 1980, Binder 23).[47]

At the provincial level in Ontario however, developments were not so encouraging. Despite briefs presented by the Provincial Association to the Ontario government to get the Ontario Human Rights Code extended to include “intellectual disability”, such protections were omitted even as the Ontario Human Rights Commission called for a complete revision of the Code in 1977. Audrey recalled that the Commission was only prepared to recommend the inclusion of “physical disability.” Two years later, in response to the exclusion of intellectual disability in the Code, the government introduced *An Act to Provide for Rights of Handicapped Persons pertaining to freedom from discrimination with regards to services, goods and facilities, accommodation, employment and advertising (Bill 188)*. As seen in an earlier chapter, Audrey considered this a pragmatic solution to a political problem that she was not prepared to accept:[48]

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[47] In June, 1982, Bill 7 – The Human Rights Amendment Act was proclaimed which extended full coverage to people with an intellectual or physical disability.

[48] Audrey Cole, Chronology, Rights and Related Advocacy, Ontario Association for Community Living, May 5, 1995.

> The government was unwilling to risk opening the Human Rights Act for fear that the opposition would have tried to get ‘age’, ‘sexual orientation’ and ‘sexual harassment’ included, so they devised a separate Bill. The Bill was initially supported by some members of the Executive Committee as well as by some members who did not see “separate as unequal.” Internal pressure convinced the Executive it must oppose an Act which was in itself segregationist. On December 6, a coalition of over 60 disability organizations held a Press Conference at Queen’s Park opposing Bill 188. The Bill was withdrawn but many of us felt the government had caved in to publicity but did not understand what was so upsetting to disability groups.

In September, 1978 the Canadian Association hired an attorney, Orville Endicott, to establish and coordinate a National Legal Resource Service at the National Institute on Mental Retardation. Not everyone understood or agreed with the Association’s shift towards a “rights” approach, but Endicott remembers that Audrey Cole saw his appointment as a turning point: “I was sitting with Audrey the first time I met her at a Board meeting and I remember her saying, “your joining the staff of the National Institute has made such a difference in everything.”[49]

Audrey, who recognized the importance of changing “the bigger picture,” understood the significance of this development. Her activism for human rights work

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[49] Personal conversation with Orville Endicott, April 21, 2005, Toronto.

would now have the critical legal and intellectual underpinnings it needed and she would no longer be the only voice on matters she considered “fundamental.” Endicott’s resource centre began by preparing a position paper on the Human Rights issue to be used by Provincial and National Associations in their lobbying efforts with the government.[50] It took five years of concentrated effort, but in 1983 the Canadian Human Rights Act was finally amended to extend protections against discrimination to persons with mental disabilities. In addition to amending the Human Rights Act, the National Legal Resource Service focused on particular cases that exemplified the need for legal remedies for problems experienced by people with intellectual disabilities and developed a network of lawyers across the country willing to take on such cases (Savage, 1983).

Not surprisingly, the earliest “rights-based” cases related to institutionalization. The first such case involved Emerson Bonner, a New Brunswick man who spent over 16 years of his life in an institution after he attempted to snatch a woman’s purse (Minutes, 1981, Binder 24). He been found “unfit to stand trial” and was being held under a Lieutenant Governor’s warrant.[51] Sections of the Criminal Code of Canada established that a person could be held at the pleasure of the

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[50] By 1978 each Province had their own Provincial Human Rights Act or Code that was monitored and enforced by Provincial Human Rights Commissions. While four provinces provided protection for “physical handicap” no province included “mental retardation” as a protected category. The exception was Quebec whose 1977 legislation ensured a full exercise of rights to all “handicapped persons” which included mental and physical handicap.

[51] At the core of this case was the indeterminate detention of people accused of criminal offences but having been found unfit to stand trial were then admitted under a under a Lieutenant Governor’s warrant that had no finite term; the Canadian Association argued that he should no longer be detained in an institution under a Lieutenant Governor’s warrant.

Lieutenant Governor should he or she be found unfit to stand trial or by reason of insanity. Even as the legal experts investigated possible human rights violations, Audrey Cole used her influence as the Association’s representative on the National Associations Active in Criminal Justice to call for the repeal of such Lieutenant Governor’s warrants arguing that keeping people in institutions because they were considered unfit to stand trial was a deprivation of their rights (Savage, 1983).[52]

## Canada’s Charter of Rights and Freedoms

At the beginning of 1980, Canada was transfixed by the Trudeau government’s moves on the repatriation of the Canadian Constitution. Constitutional reform was suddenly the hottest political topic in the country. It centered on Trudeau’s determination to include a Charter of Rights and Freedoms with the equivalent constitutional status as the American Bill of Rights in the Canadian Constitution. Central to this discussion was prohibiting discrimination against certain groups of people (Peters, 2003; Lepofsky, 1985; Vickers & Endicott, 1985; Valentine & Vickers, 1996). As Audrey Cole had feared, the implications of earlier decisions made without debate by the membership in support of including disability as a protected category in human rights law, started to emerge. Thinking back to that period, she doubts very much if “anyone really seriously, including the Board at

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[52] When Emerson Bonner was eventually released in March, 1981, Marie Gallagher, Chair of the Advocacy Committee credited Audrey for her persistence: “The addition of Audrey Cole to our delegation and as a member of the National Associations Active in Criminal Justice Planning Committee has strengthened our influence in this important coalition.”

either level, had any discussion about rights" or considered what the implications might be of "not being in the Human Rights Act."

With time running out to intervene in the constitutional debate, arguments raged within the Association over what impact creating a special category for disability might mean. In particular, there were concerns over "the effect of further labeling people with mental retardation" by including the category of "mental retardation" in the Charter. There were other concerns about what implications would follow from being excluded when discrimination against all other groups was explicitly prohibited by the constitution (Minutes, 1980, Binder 23). In Audrey's view the ongoing debates meant the "Association was slow to get off the mark on the Charter issue." It was however, helped by the "massive move to get women in" and the mobilization by the women's movement to ensure gender was admitted as a protected category (Rebick, 2005).

In June 1980, President Jo Dickey asked the Board to consider possible actions the Canadian Association might take to ensure the rights of people with intellectual disabilities were considered during those constitutional discussions. Her assumption was that "if women got in" then "we had the same kinds of rights." But she remembers that the Board resisted: "They were all so afraid of government and they didn't want to be seen as a nuisance." Finally, they approved a resolution in which they recommended the entrenchments of human rights within the constitution, and vowed to recommend this to the Annual General Meeting. Jo Dickey's term of office was up. This was the last meeting she chaired.  In her final President's Report she asked delegates to base their decisions on "basic values rather than a desire to maintain the status quo.” She invited them to embrace an advocacy role with “courage” and she invited people who lived with a disability to continue to “challenge” the Association (Minutes, 1980, Binder 23). The resolution came before the membership as the last major item of business on the agenda. It was passed unanimously, thus ending her three-year term. Although she received the Board’s thanks and appreciation for her “many contributions to the Canadian Association while President”, it was arguably the support she won from the membership in this vote that had the most long-range effect (See Appendix 2: Resolution on Canadian Constitutional Reform, Minutes, 1980, Binder 23).

Getting the Association to support the resolution was one thing, it was quite another to convince the Parliamentarians to include disability as an entrenched right. In September, 1981, officers of the Association were advised that in its draft form, the Charter of Rights and Freedoms under Section 15, the equality clause, named certain groups of persons who were to be protected from discrimination under the law, but failed to include people with disabilities (Peters, 2003, Lepofsky; 1985; Vickers & Endicott, 1985).

In the end, Paul Mercure, Jo Dickey’s successor, on the advice of the Executive, agreed that “telegrams would be sent immediately to the Prime Minister and Provincial Premiers [attending a First Ministers Conference] protesting the exclusion” (Minutes, 1980, Binder 23). A month later, in flurry of activity, representatives of the Association appeared before the Joint Senate and House of Commons Committee on the Constitution of Canada, lobbied individual committee members and members of the opposition and collaborated with other equality-seeking groups anxious to improve the Charter and made representations to Prime Minister Pierre Trudeau and the Minister of Justice, Jean Chretien. The Advocacy Committee made it clear that if categories of protected groups were specified in the Charter, the designation of "mental retardation" should also be included, although they preferred a broader indication of the positive rights of all citizens. Audrey remembered the effort and said, "By that time we were getting better at the task and had the good sense to include members of People First in delegations. That had a significant effect on Members of Parliament."[53]

In March 1981, the Board was advised that as a result of their efforts and others, the proposed Charter of Rights had been amended to include the words "mental or physical disability" in Section 15.[54] Jo Dickey seconded a motion to express the Association's "appreciation to the members of the Joint Senate and House of Commons Committee on the Constitution of Canada and each of the leaders of Canada's national political parties represented in the House of Commons for their support" (Minutes, 1981, Binder 24).

The inclusion of "disability" in Section 15 was a fundamentally important event that had a significant impact on the Association. It signaled a new era in the field of human rights; it renewed optimism for meaningful improvement in the quality of people's lives; and it promised a new corporate mission based on challenging obstacles arising from discrimination and the arbitrary use of power. Committees and campaigns began to articulate their mandate on principles of equality and human

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[53] Audrey Cole, Chronology, Rights and Related Advocacy, Ontario Association for Community Living, May 5, 1995.

[54] Constitution Act, 1982. Canadian Charter of Rights and Freedoms.

rights, and the Association sought intervention when it sensed the rights of disabled people were being violated. The Committee concerned with the "institutional dilemma", for example, responded by adopting a new name, the "Committee on the Rights of Institutionalized Persons" and by identifying a new mission focused on reporting abuses and neglect across the country.

Audrey Cole and two lawyers were invited to prepare a paper on the implications of the Charter on the rights of people with disabilities. They titled their report, "The Canadian Charter of Rights and Freedoms: A Manifesto of the Canadian Association for the Mentally Retarded" (Minutes, 1982, Binder 25). The Manifesto equated how the renewed constitution established the full autonomy of Canada within the community of nations with how the provisions of the Charter of Rights and Freedoms introduced a new history for people with disabilities as valued, participating members of the community. It concluded cautiously:

> The Charter of Rights and Freedoms obviously has very important implications for Canadians who live with a mental handicap. It is not possible to determine fully what those implications might be until the provisions of the Charter are considered by the courts in the contest of real life situations.

One such real life situation emerged to test this new instrument. It also tested the Association and exposed its fledgling commitment to human rights.

## The Issue of Sterilization

The real life situation involved a case known as “Eve”, the name used in court documents to protect the plaintiff’s identity. Eve was a 21 year old woman with an intellectual disability who lived in Prince Edward Island (Roeher Institute, 1996; Endicott, 1987). As a child, Eve lived with her mother, “Mrs. E.”, and attended a public school. When she reached 21, she was sent to a school for “retarded adults” in another community where she became close friends with a male student at the school and they talked of marriage. The matter led Mrs. E. to fear her daughter might one day become pregnant. She felt Eve could not cope with motherhood because she was a 60 year old widow, she feared the responsibility of raising a child herself. She applied to become Eve’s guardian in order to legally authorize the sterilization. After the trial judge who first heard the application ruled against Mrs. E., her appeal was heard by three judges of the Prince Edward Island Supreme Court. They overturned the decision and found in Mrs.E’s favour. The Official Trustee for Prince Edward Island had retained counsel to act for Eve in the appeal, and, when the decision went in favour of sterilization, counsel was instructed to ask for leave to appeal to the Supreme Court of Canada, which was granted early in 1981.

Details of the Eve case were first presented to the Executive Committee of the National Association at their meeting in January, 1981 (Minutes, 1981, Binder 24). Jo Dickey immediately introduced a motion committing the National Executive to assist the Prince Edward Island Provincial Association to support the appeal to the Supreme Court. However, it became clear that if the National Association wanted to place its own Motion of Intervention before the Supreme Court, they would first need to have a clearly defined position on sterilization, which they did not yet have. The Advocacy Committee prepared a motion to begin the discussion on non-therapeutic sterilization at the Board meeting in March, but the subject proved divisive. With no agreement reached, they voted to table the motion and convene a special board meeting in June that would be dedicated to a discussion of the sterilization issue. There was sufficient time for the Association to apply for a Motion of Intervention should it choose to do so. The proposed motion that came before the special Board meeting in June, as introduced by the Advocacy Committee, read as follows (Minutes, 1981, Binder 24):

> ***The proposed motion on non-therapeutic sterilization:***
>
> *WHEREAS it is a fundamental right in our society that all individuals have freedom of choice with respect to their own bodies; and*
> *WHEREAS any act of non-therapeutic sterilization in the absence of informed consent is a violation of that principle,*
>
> *THEREFORE BE IT RESOLVED*
> *THAT in the absence of informed consent no non-therapeutic sterilization shall be performed; and*
> *THAT informed consent shall not be deemed to be given if it is provided under duress, by means of manipulation in any form; by reason of undue influence or threat; and*

> *THAT in the absence of informed consent a court may approve sterilization for therapeutic reasons only; and*
>
> *THAT therapeutic reasons shall mean medically sound and clinically supported procedures to alleviate the risk to life and health.*

Staff prepared and circulated background papers in an attempt to raise all the relevant questions in the search for consensus. Definitions of relevant terms were provided to focus the discussion. The term “sterilization” itself, was addressed with the explanation that it was not used as a medical term but was in popular usage to refer to any surgical procedure which had the effect of leaving the person permanently unable to procreate.[55]

However this did not minimize conflict. At a special Board meeting the discussion was agonizing. The debates were bitter, and there was vast diversity of knowledge and opinions.[56] Some members with an historical perspective knew that involuntary sterilization had been conducted routinely in the past, without regard for “degree of retardation”, assessment, exploring less restrictive alternatives; and for reasons as trivial as easing the problem of off-grounds supervision of institutionalized patients (Law Reform Commission, 1979; McLaren 1990; Pringle, 1997; National Film Board, 1998). They saw the Eve case as an opportunity to reverse this history and argued for “no sterilization without consent.” Yet others, many of them raising

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[55] Orville Endicott, ‘The Sterilization of Persons Who Are Mentally Handicapped – What Should CAMR’s Position Be?’ Discussion paper prepared for Special Board Meeting, Toronto, June 1981.

[56] This was the way the meeting was remembered in my interviews with participants including Jo Dickey and Audrey Cole.

daughters (and the discussion almost always focused on parents wanting to have girls and young women sterilized) supported individually-based decisions. One mother, Jean Oldfield, a Board member from Ottawa, sent National President Paul Mercure a letter in which she wrote, “theoretical arguments carried to extremes allow us to turn our backs on real needs in the real world, and to turn a blind eye and deaf ear to suffering” (Minutes, 1981, Binder 24). On the one hand, some embraced the universal principle of the inviolability of the person; on the other, there were parents who upheld a paternalistic position, feeling they knew best what was good for their daughters. They appealed to the rights of the potential offspring to maternal nurturing and the rights of parents to the peace of mind knowing they will not have to care for an unwanted grandchild. After hours of adversarial arguments and “amendments to the amendments” the only consensus the Board could reach was to postpone any further discussion on the matter of sterilization.

Activist mothers, in their campaign for human rights, risked being unpopular. They recognized that many parents, making difficult decisions about what they thought was best for their sons and daughters, did not feel the National Association should take a position on such issues. But as activists, they believed the Association needed to have a clear and credible position on such a basic human right as this. To Audrey Cole, the right not to be sterilized without informed consent was clearly about the right to self-determination. She held a set of values and principles that she expected the Association to embrace, and, as an activist, she took up the work of enabling others to see inequities as she saw them. But, as she recalls, many parents identified with Eve’s mother.

> The majority of opinion at the time, certainly in Ontario at the time of the Eve case, was that parents should have some say in whether or not to sterilize. I thought it was an issue of rights. There was a complete split in the Ontario Association and that's when Harvey Savage [an Association lawyer] and Muriel Clarke- Beechey [another mother] and I were delegated over lunch to draft a resolution we thought people might be able to support…but the debate deteriorated again and we ended up with no solutions.

In a strategic move, conceived with Audrey Cole, Jo Dickey and others in the corridors of the hotel, Barb Goode, Chair of the Consumer Advisory Committee, prepared a motion that had the potential to provide a way out of the impasse. The motion proposed that, since the Board did not seem to have made sufficient progress following up its statement of policy to seek status as an Intervenor in the "Eve" case before the Supreme Court of Canada, then the Consumer Advisory Committee, which fully accepted the position put forward by the Advocacy Committee, should be provided with whatever funds were required for it to intervene in its own right and to represent the views of handicapped people (Minutes, 1981, Binder 24; Endicott, 1987)  David Vickers, a lawyer who was himself a father of a disabled daughter, had already agreed to represent them (Park et al, 2003). The Board agreed, offered them $5000 and, with that, they were off the hook.

Audrey Cole remembered just how personal the debate had become:

> I think it was the toughest decision that's ever been made at the Canadian Association. I mean, there were tears… It was very emotional on the part of parents …[who] felt it was dreadful that people were saying that families shouldn't have this right… I'll be honest, I couldn't identify with the emotion because it seemed to be emotion about something that was fundamentally wrong…that somebody else should be able to make that determination.

For Jo Dickey, whose orientation to families was generally more sympathetic, it was more complicated. But having just won a major victory to have "disability" recognized in the Charter of Rights and Freedoms, she cast her vote with Audrey:

> For the families, particularly the families of women, I could understand all this. But I wasn't going to be defeated on it because we just put in what we wanted in the Charter, and we got it! So then do we do that with one hand, and then take it away – or allow them to take it away from this woman? That was when I was just about off the Board [as Past –President] and it was just about the heaviest duty I ever had, to decide for myself where I was going to be [on this issue].

In August, 1981, the Consumer Advisory Committee was granted Intervenor status at the Supreme Court of Canada to make their case. At the following Board meeting, held in October in Quebec City, the question of defining a social position on sterilization surfaced again, but the Association chose to defer taking a stand until the

Supreme Court made its decision. However, the Ontario Provincial Association decided to introduce its own Resolution in support of non-consensual sterilization. Audrey, a member of the Ontario delegation vigorously objected, and seconded a motion to have it tabled, suggesting the proposal was "untimely" in light of the court case taking place in Prince Edward Island. By that action, she was seen to be "breaking with Ontario." She remembers there were consequences:

> My opposition to Ontario's position on sterilization was what got rid of me on the Board. Jim Montgomery (President) said to Claude, being the only man, that "he'd get us for this" so Claude was out very quickly, then Muriel was knocked out and I managed to survive another year but it was very bitter.

Audrey's activist style and commitment to shape the Association's consciousness, which often meant working behind-the-scenes, writing and talking to others, was crucial for the development of a dynamic organization. Yet it could prove difficult and personally unrewarding. In 1986, when her name was put forward on the slate for Vice-President, the Ontario delegation, still angry, refused to support her and nominated their own candidate from the floor instead.

On October 23, 1986, the Supreme Court of Canada released its decision to allow Eve's Appeal. The nub of the judgment, written by Mr. Justice La Forest with all eight of the other Justices concurring, read as follows:[57]

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[57] Re Eve, [1986] 2 S.C.R. 388, 31 D.L.R. (4th) 1.

> The grave intrusion on a person’s rights and the certain physical damage that ensues from non-therapeutic sterilization without consent, when compared to the highly questionable advantages that can result from it, have persuaded me that it can never be safely determined that such a procedure is for the benefit of that person.

Audrey Cole was in Court to hear the Judgment and later explained to reporters the significance of the decision. She encouraged members of the Consumer Advisory Committee, some of whom had themselves been sterilized, to grant interviews about what the decision meant to them personally. Across the country this was pronounced a monumental decision in Canadian law and of great importance in international human rights given that sterilizations without consent were performed all over the world (Mosoff &Grant; 1999).

However just as the campaign to close institutions led to divisions between “institutional parents” and “community parents”, from local Associations up through to the provincial and national levels, the campaign for human rights in the “Eve” case exposed another fault line in the Association: the Canadian Association was a federation and formed out of the provinces. Audrey Cole, given her deep commitment and respect for democratic process was troubled because she recognized that if the issue of sterilization “had to go from the bottom up” and had to be debated by the primarily parent board of a local Association, “it would not go through.” This was not only because parents were closest to this level, but also, according to the activist mothers in this study, because the locals were becoming increasingly controlled by professionals whose vested interests and inward focus on their own constituencies meant they were more attentive to “practical” matters than “philosophy.”

The debate over sterilization illuminated how the three-tiered structure limited the National Association’s capacity to take up a social position on controversial matters if provinces and locals given their own power base, and “turf”, felt threatened. For Audrey, the debate cemented her belief that “families are not always right”; the “wonderful bond” she often felt when working with other mothers and fathers similarly affected became “irrelevant” when the majority of opinion came down on the wrong side of a fundamental human rights issue. To her the horizon had to be bigger than the family. All the same she remembered “feeling very saddened in 1981 by what happened in the Association and the nastiness in provincial circles.” She remembers that she was “very disappointed” when she wasn’t re-elected in 1982, but she didn’t think “in terms of quitting.” Once again she could see the bigger picture and attributed her defeat to the fact that “people were just beginning to understand some of the issues I got involved in and they didn’t like the implications.”

Audrey Cole’s activism to defend the rights of disabled women against involuntary sterilization extended to another form of sterilization, the chemical use of Depo Provera as a contraceptive. Single-handedly she brought to national attention information that Depo Provera was being used in some Canadian institutions to suppress menstruation in disabled women, that there was little known about the drug. It had been refused licensing as a contraceptive in the United States, and there were reported side-effects, linking its use with cancer and other conditions. Jo remembers this issue, that “women in institutions were being fed this drug so they wouldn’t get pregnant. But they didn't know what it was and they didn't have a choice." In 1981 Audrey Cole drafted a Resolution urging a moratorium on the use of Depo Provera and submitted it to the Ontario Association who brought it forward to the 24th AGM in Quebec City (See Appendix 2: Resolution on Depo Provera, Minutes, 1981, Binder 24).

Following the resolution, letters were sent to the Ontario Minister of Community and Social Services as well as the Minister of National Health and Welfare, requesting a moratorium on the use of Depo Provera until there was further evidence as to its safety. But the drug continued to be used in several government-operated institutions in Ontario "to control fertility and menstruation" a use that contravened the provisions under which it was licensed in Canada. The Advocacy Committee continued to monitor the situation but both provincial and federal authorities took the position that it had not been shown to be a sufficiently serious threat to the health of women concerned for its use to be curtailed. Reporting on the situation a year later, Committee Chair Marie Gallagher wrote (Minutes, 1982, Binder 25):

> We maintain contact with the Ontario Association in its efforts to persuade the Minister responsible to re-examine the propriety of giving this drug to women without their informed consent, particularly in light of the suspicion which still exists to some its very serious side effects.

In 1985, as part of a Coalition on Depo Provera, the Association sought a meeting with the Minister of Health and Welfare to discuss concerns about the safe use of this drug as a contraceptive.[58] In 1988 the Association joined a broad coalition of women's organizations to counter the apparent intention of the Department of Health and Welfare to license Depo Provera for contraceptive use in Canada more generally, but this pressure had little effect (Meister, 2003; Palmer & Carey, 2005). This was an important reminder that the struggle for basic human rights continued.

## The Continuing Struggle for Rights

Audrey Cole could find rights issues everywhere – her challenge was to enable the Association to see them the way she did. In 1983, she was asked to serve on a Coalition marking the 35th Anniversary of the Declaration of Human Rights (Cole, 1983). Though eager to accept, she first insisted on a commitment from the Board that the Association would be behind her, and "identify the link between the Universal Declaration of Human Rights and the Association's activities with respect to human rights for people with handicaps" (Minutes, 1982, Binder 25).

She was well placed on the Advocacy Committee, whose primary purpose was to "ensure that the Association's foremost commitment is to advocate for the rights of individuals with handicaps" (Minutes, 1982, Binder 25). In the years that she served, between 1980 and 1983, it was not a matter of coincidence that an

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[58] The issue was profiled in the first issue of *entourage* published by the Canadian Association in 1986 and then again a year later, in 1987, under the headline 'Depo Provera stirs up more controversy', 2(2) pp. 19-20.

unprecedented number of cases were taken up by the Committee. She had a sharp legal mind, although untutored, and an ability to go to the heart of the issues. She elicited implications of national significance from local cases. She illuminated many issues of suspected threats to or violations of legal and human rights, a number of which are briefly referenced here.

Audrey was involved in publicizing the case of Dr. Ruth Wiens which brought to public attention the responsibility of the medical profession to respect the rights and dignity of all citizens. Dr. Wiens showed her students at Queen's University how to perform rectal examinations, and then allowed them to practice on residents of Ongwanada Institution in Kingston. For engaging in this form of teaching practice, Dr Wiens was charged with assault in 1984 and later pleaded guilty (Gould, 1985). Audrey remembers how she first heard about the case:

> Two of the students disclosed this was happening. They refused to perform the rectal examinations and then raised the issue in a seminar on Medical Ethics at Queen's. That was how everyone learned that it had been going on for years. The parents of those residents certainly did not know about it – they had signed blanket treatment orders. The doctor's defense was that students have to learn. They had absolutely no idea of the enormity of what they were doing.

Similarly, the Ogg-Moss and Nixon cases revealed institutional abuse at Rideau Regional Centre very near Audrey's home. Both men were staff persons who were charged with assault following attacks on residents. Ogg-Moss was acquitted in1981 by a lower court but that decision was reversed by the Court of Appeal which established that it is a criminal act when a staff member of an institution physically attacks a mentally handicapped resident.[59] This was appealed by the Ontario Public Service Employees Union, but was upheld by the Supreme Court of Canada in 1984.[60] The Nixon case which followed in 1985 was heard by the Supreme Court; it was similar to Ogg-Moss in that an appeal against a guilty verdict was also dismissed.[61]

The case of Candace Taschuk in 1982 prompted the Association to develop a position on the “right to treatment” (Minutes, 1982, Binder 25). Candace was a baby girl who died the day she was born in an Edmonton, Alberta hospital as a result of a massive overdose of morphine. The doctor who ordered the lethal injection was charged with murder and left Canada shortly after Candace’s death (Endicott, 1989).[62] The Stephen Dawson case was another “right to treatment” case that went to the Supreme Court of British Columbia in 1983. The B.C. Judgment determined that Stephen had the right to life-sustaining surgery. This vindicated staff at the institution where Stephen lived who had alerted child protection authorities. As a result, Stephen was removed from his parents’ charge and the treatment he needed was authorized,

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[59] R. v Ogg-Moss (1981) Canadian Criminal Cases (2d). 60: 127 – 128.

[60] Ogg-Moss v R (1984) Criminal Reports (3d). 41: 297 – 318.

[61] Nixon v the Queen. (1985). Dominion Law Reports (4th) 12: 762-763.

[62] In the Matter of the Death of Candace Lynn Taschuk, Provincial Court of Alberta, August 23, 1983.

overruling his parents who sought their right to refuse treatment (Pappert, 1983; Roeher Institute, 1996).[63]

In addition to making certain that such cases were taken up by the Advocacy Committee, Audrey Cole also involved a coalition known as the National Associations Active in Criminal Justice. They took up the case of Emerson Bonner and other persons who were charged with an offence and institutionalized indefinitely without trial on the grounds they were "retarded." She was vocal in discussions related to the inequities of Lieutenant Governor's warrants and the need to replace them with a system based on the principle of "least restrictive alternative." In 1986, the Association Board was informed that the Minister of Justice was considering amendments to the Criminal Code to address these concerns (Minutes, 1986, Binder 29; Endicott, 1986).

The Advocacy Committee pushed this and an array of other issues onto the national agenda. In 1985 the Association made a submission to the Federal Committee on Equality Rights, a committee concerned with federal statutes related to the new Charter of Rights and Freedoms. In its submission the Canadian Association stressed its positions on a range of issues taken up by the activist mothers: Lieutenant Governor's warrants; sexual assault; medical treatment, both the denial of necessary medical treatment and the performance of unnecessary surgery; immigration; financial assistance for Charter litigation; voting rights; and employment equity (Minutes, 1985, Binder 28; Endicott, 1986; Richler, 1995; Vickers & Endicott, 1885).

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[63] *S.D. v Superintendent of Family and Child Services* (1983), 42 B.C.L.R. 173 at 183 (S.C.).

Although Audrey Cole had stepped down from the Advocacy Committee by this time, in 1985 the Committee also led the Canadian Association to make a submission to the Standing Commons Committee on Privileges and Elections under the equality clause of the Charter of Rights and Freedoms. They requested a section of the Canada Elections Act be repealed because it disqualified individuals living in institutions from voting in a federal election (Minutes, 1985, Binder 28). It took three years and the mobilization of a broad-based disability coalition until this section was eventually repealed in 1988 (Roeher Institute, 1996).[64]

It was through the Advocacy Committee that Paulette Berthiaume was first introduced to the workings of the Canadian Association in 1984. Committee members provided Paulette with a network when she sought support as President of the Parents Group at Rivière-des-Prairies Hospital during the Shadley Commission of Inquiry (Ruff, 1986). Her activism in that inquiry was provincially-based, but the leadership she demonstrated by building an informal organization of community people to expose poor conditions in the institution, gave her a national profile and soon, a position on the National Executive. In 1986, she once again led the call for a public inquiry, this time over a right to treatment case called “Baby Dan” (Endicott, 1989; Roeher Institute, 1996; Blanchett, 1995). In the Montreal Children’s Hospital, in December 1986, a child was born with Down syndrome and oesophageal atresia. A section of about 5 centimeters was missing from his oesophagus which interfered with his ability to digest food. Surgery on his digestive tract was necessary if he were

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[64] In October 1988 the Federal Court of Canada declared S.14(4) (f) of the Canada Elections Act unconstitutional on the grounds that ‘the assumption that a person suffering from any mental disability is incapacitated for all purposes is simply a false assumption’. *Canadian Disability Rights Council v Canada* [1988] 3 F.C. 622.

to survive. His parents decided not to authorize corrective surgery and the child was put in a corridor with a sign on the incubator which stated: “Nothing by mouth.” Baby Dan died after 11 days as a consequence of the discontinuance of all intravenous nourishment and fluids. Paulette was a member of the Executive Committee from Quebec. She was asked to represent the Canadian Association and take action in this case (Minutes, 1987, Binder 30).

She attended a strategy meeting with representatives of the Montreal and Quebec Associations, and together they met with the head of the department where the baby died, and requested a review of the case. The Quebec Association argued that the decision not to operate was discriminatory under Canada’s Constitution because the decision was based on the grounds of intellectual disability. They demanded a coroner’s investigation. The subsequent coroner’s report however identified Down Syndrome as a “cause of death” and vindicated the hospital: “The presence of Down Syndrome was another element [in the decision not to operate] since mongolism implies a quasi-vegetative life of severely diminished quality of life”.[65] The provincial College of Physician and Surgeons also investigated the child’s death but found the medical team had handled the case appropriately both medically and ethically.

Paulette Berthiaume was outraged, and she was not alone. There was an uproar in the Association, and a human rights complaint was filed with the Quebec Human Rights Commission alleging that treatment had been withheld because of the child’s disability, contrary to the Constitutional Charter of Rights and Freedoms

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[65] Carmen Crepin, Deputy Chief Coroner, Coroner’s Report No, A-10939, June 5 1987. See: Endicott, 1989.

(Richler, 1995). The Commission reviewed the case and reported that there was potential discrimination on the grounds of disability but claimed it could not undertake a full investigation and so closed the file.[66] The Canadian Association called for a public inquiry:

> Down Syndrome is not a cause of death nor does it imply a quasy- vegetative life. If the decision not to treat Baby Dan and to deprive him of food and water was based on factors like those quoted in the coroner's report, then we fear for the life of every child with an intellectual disability who needs corrective surgery.

In January 1988 the Canadian Association decided to "go public" and hold a press conference in Montreal on the issues raised by the Baby Dan case (Endicott, 1988). This was widely reported on television, radio, and in the newspapers with Paulette playing a prominent role (Scott, 1988; Harting, 1988; Gagnon, 1988; Rowan, 1988).[67]

Following this case Paulette proposed to the Executive that a protocol be developed to deal with such cases so that any child in a similar situation in the future would have their rights protected by an independent advocate. She also proposed that this protocol be distributed widely among federal and provincial ministers of health and justice as well as medical associations and colleges of physicians and surgeons.

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[66] *Re* B, [1987] 1 W.L.R. 1421 at 1422-1424 (C.A.)

[67] Reporters from The Montreal Gazette, La Presse Montreal, le Devoir and Le Journal de Montreal quoted Paulette in their coverage of the case on January 15, 1988.

As a result the 1987 Annual General Meeting mandated the Association to develop guidelines for making decisions about appropriate medical treatment for children with an intellectual disability and adults who, because of an intellectual disability, were unable to consent to or withhold consent from, such treatment (Minutes, 1987, Binder 30).

As with the Justin Clark case discussed in the previous chapter, this question of people with intellectual disabilities giving consent had long intrigued Audrey Cole. As she wrestled in her mind with the nuances and complexities of the issues, she increasingly found herself questioning the sweeping powers of guardianship legislation. As institutions downsized and closed and more people with intellectual disabilities were living in the community, they confronted a variety of decisions such as signing a lease, making a purchase, electing to undergo surgery, that they had been “protected” from having to make before. The fact that people with intellectual disabilities need assistance in making such decisions was not at issue; the issue was whether the traditional appointment of a legal guardian was appropriate since guardianship laws remove decision making powers from the person completely. Civil libertarians regard this as an encroachment on individual liberties. The damaging consequences of guardianship was seen in the case of Justin Clark whose parents tried to use the courts to become his guardian to ensure he remained institutionalized. It was also seen in the case of “Eve” when her mother sought to have her daughter sterilized without her consent. It was also seen in the case of “Baby Dan” and Stephen Dawson when their parents sought the right to refuse life sustaining medical treatment for their sons. Any serious effort to reform guardianship had to balance the need for legally valid consent in cases of financial and medical matters, and the vulnerability of people at risk for abuse or neglect. It was a complex challenge to address these issues and still ensure that the individual's decision-making status was respected in the eyes of the law.

Audrey had been working on this issue for years. She became involved in guardianship issues in the mid-1980s when the Ontario Association asked her to comment on a report circulated by the provincial government. Having carefully prepared a response she brought it to the office for discussion and remembered an outbreak of "giggling" when she presented it: "I had no idea what [they] were muttering about but I think they must have expected a kind of third grade document because it was written by a volunteer." In 1991 she was invited to Chair a National Task Force on Alternatives to Guardianship. She immediately recruited Jo Dickey to join. Throughout the following year, the Task Force explored new approaches, alternatives to guardianship founded on the notion of human interdependence. They evolved the notion of "supported decision-making" and argued that personhood should be the basis on which rights are upheld, not "capability." The 1992 Report of the Task Force was a 50 page document and contributed to Audrey's reputation as being, in her own words, "something of an expert." In the words of the Provincial Lieutenant-Governor in awarding Audrey Cole The Order of Ontario in 1997, she was "one of the province's most knowledgeable and respected authorities on guardianship legislation…[conducting] workshops and seminars in many parts of

Canada on decision-making in the interest of persons with disabilities."[68] This, for an activist mother with no formal legal training, was no small tribute.

Audrey had run workshops for years for self-advocates who themselves had taken up the issue of reforming guardianship, and they enlisted her to educate their members. The self-advocacy caucus, as seen in the last chapter, nominated her for President in Ottawa, in 1991. It was immediately after she lost that election that she was approached to become Chair of the Task Force:

> I suspect that it was a consolation prize for me after being defeated as President in 1991 …that was what my instinct told me…but that didn't stop me because it was what I wanted to do...It was good, it was one of the best times, one of the best committees for me…I like to actually work on things. I don't get any kick out of just looking at something. I think that's why the committees have been important to me, because we were actually producing something.
>
> I still get calls from people having trouble with guardianship and I tell them "I'm not a lawyer! This is just me!" But somehow it gave me a presence that none of the other things would have given me.

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[68] Official Citation, June 1997: The Order of Ontario.

## Conclusion

In March, 1993, leaders of the Association gathered in Ottawa for a federal lobby. Paulette Berthiaume was then First Vice-President and only months away from being elected President of the Canadian Association. She was invited to present the Association's case to the Prime Minister of Canada, Jean Chretien, as part of the lobby. She was well-armed by the Association's staff with briefing notes and statistics, but Paulette was determined to focus on the human aspects of the problem. As she recalled, she told the Prime Minister:

> Our sons and daughters are people like you and I and they should live in the community. When [a] man or woman is told by a doctor they have an illness and they go into the hospital [they] take all his clothes away, all his cards away, all his money away – he has nothing…the only thing they can remember is their name…This is not what we want. For me, my son is equal with you who has a university degree… he's a human being…And when I talk about Louis, I talk about all of them.

Participants in the federal lobby were briefed and directed to give a consistent message to every Member of Parliament. That message stressed two key areas in which federal intervention could better the lives of Canadians with disabilities.

The first of these was deinstitutionalization. The briefing notes prepared by the Association's staff included evidence that there were still "approximately 15,000 [intellectually disabled] Canadians living in institutions… and another 15,000 living in nursing homes and other institutional facilities…[and] it is estimated that the annual cost of keeping a person…in an institution can be up to $100,000 a year" (Minutes, 1993, Binder 36).

The second area was human rights. The briefing notes on "human rights" documented that "despite the protection afforded to people with disabilities in the Charter of Rights and Freedoms, many barriers to participation still exist in employment, immigration, education and the criminal justice system." Association representatives called on the government to reform existing legislation that did not conform to the Charter and to take account of intellectual disability in the development of new laws, policies and programs (Minutes, 1993, Binder 36). Significantly, closing institutions and securing human rights were the very campaigns the activist mothers and many others who had worked with them had struggled for years to make the most prominent ones.

Jo Dickey used her outstanding interpersonal skills, her status, and public role to rally others to support her passion to close institutions. She served the organization well, emerging as a "catalyst" for a critically important issue that gave the Association a constituency and a "cause" that no other group had claimed. More than once she "took a lot of heat from the Board", because her ideas were visionary, her approach radical, and her activism beyond the cultural expectations of women of her generation. Audrey Cole came forward to claim that disability rights were human rights long before others thought to do so, and with her own "conscience" as a guide, dedicated her activist career to raising the consciousness of the Association. She encountered threats, intimidation and put-downs from those who disagreed with her democratic principles, her legal intellect, her principles and her outspokenness. While this did not make her popular, her activist style proclaimed a challenge to cultural stereotypes of women as passive and reticent. Paulette Berthiaume did not start out knowing how to “get political”, but she acquired that skill as she organized people on the ground to bring attention to poor conditions in institutions in Quebec. She did what she knew best; she built networks, mobilized support and the strengthened the bonds needed to tie a community together. Those activities flowed from her sense of gendered obligation (Abramovitz, 1999); she was doing them for Louis, not because she was necessarily good at them, but because she felt she had no choice. But this sense of obligation was expansive. Each woman found ways to resist traditional thinking about what constituted “good mothering” by promoting a more inclusive view of motherhood, one not so narrowly focused on the “ideal” of the “normal” child. Their success in making their issues “the” issues for the Association might be attributed to three critical dimensions of activist work they brought to their campaigns: advocacy, personal commitment and the capacity to look beyond themselves and into the future.

# Chapter Seven

# Listening in Stereo to Activist Mothers

## Accidental Activists

The point of entry for this study began in “the everyday world” (Smith, 1987) of activist mothers with disabled children. It examined how and why mothers of disabled children became activists, how their various encounters with social health and educational services integrated with broader struggles for social justice and human rights, how this contributed to broadening their vision for their children’s futures and what they did with this new consciousness. They came to recognize the importance of becoming advocates for change beyond their own families and to hold a notion of “good mothering” that included social activism. They went beyond the traditional confines of families, households and neighbourhoods and contributed to building an organization to place their issues on a more public scale.

Leading campaigns to close institutions and secure human rights, they learned to mother as activists, struggling in their homes and communities against the debilitating and demoralizing effects of exclusion. But for the most part they came to their activism “accidentally”, out of an event about which they had little choice, and certainly little foreknowledge. The question guiding this study was “how disability prompts women’s activism” and the narratives of individual mothers themselves were seen as a very important data source.

Jo Dickey, Audrey Cole, and Paulette Berthiaume gave accounts of their lives and struggles that were exceptional in many ways, but broadly speaking, their narratives mapped a similar path. Each woman began with the “personal”, rooted in the moment they first were given a diagnosis. “I remember like it was yesterday,” said Paulette, nearly fifty years later. As they continued, they expanded outward providing a record of small events and larger political campaigns, uncovering what it meant to women in their time and place to have a disabled child, and how the social and material framework in which they operated transformed into their activism. Their narratives richly rendered what sense they made of that experience; their own perceptions of the choices they made; and the cultural patterns they faced and challenged. They had a large supply of stories to relate, decades of struggle and experiences to share. The richness of these activist mothers’ narratives confirmed the research strategy to attend to their voices. It also confirmed that investigating both lived actualities and social relations that are not plain to see demands as Dorothy Smith argued, further institutional encounters: “We want to know more so she can also” (1987 p.127).

The examination and analysis of historical records and organizational documents of the Canadian Association for Community Living allowed for an investigation of the relationship between the experience and knowledge of activist mothers and the broader practices of administration, institutional and gender relations with the organization they founded. This was important given that the activist mothers’ own narratives were rooted in memory. The oral history was absolutely necessary but it was not in itself sufficient. The question of the objectivity of oral sources has been widely debated by oral history theorists (Perks & Thomson, 1998). More recent debates relevant to this study have focused on the theoretical dilemmas encountered by feminist historians employing oral history (Sangster, 1998).

This raises some important considerations about the theory and practice of oral history especially as it relates to gender as a category of analysis. It confirms Anderson and Jack's (2004) argument that when women talk about their lives, the oral interviews are not raw sources of information but are already structured with complex codes and analytic meaning in which women often combine two, sometimes conflicting, perspectives:

> One [is] framed in concepts and values that reflect men's dominant position in the culture and one informed by the more immediate realities of women's personal experience…inadvertently, women often mute their own thoughts and feelings when they try to describe their lives in the familiar and publicly acceptable terms of prevailing concepts and conventions. To hear women's perspectives accurately we have to learn to listen in stereo, receiving both the dominant and muted channels clearly and tuning into them carefully to understand the relationship between them (p. 157).

As I listened to their taped voices, read and re-read transcripts of their interviews, the metaphor of "listening in stereo" provided a way to analyze their accounts. Women's perspectives, as uncovered in oral interviews, reveal that they express themselves in two streams. One is framed in concepts and values that reflect men’s dominant position in the culture, and the second is more informed by the realities of women’s experience. But when their experience is at variance with men’s and in the absence of alterative concepts, women tend to mute their expression giving rise to the metaphor of dominant and muted channels, requiring the researcher to “listen in stereo”. I listened to activist mothers’ accounts that sometimes communicated conventional expectations and at other times, fell outside the range of acceptable discourse. As they told their own story in their own terms, I learned to attend to meanings attributed by the narrators rather than my own research agenda, as the discussion below about gender will reveal.

An example taken from how activism itself is taken up in the dominant culture may illuminate what is meant by “listening in stereo” to women talking about their experiences in a patriarchal society. When I asked one mother I spoke to at an early stage of the study if she considered herself an “activist” her immediate response was “I hope you mean that as a compliment.” This comment is reminiscent of Temma Kaplan’s grassroots activists at Love Canal who reported having been called “hysterical housewives” or “crazy feminists” or “just not ladies.” To that latter accusation one replied, “I don’t know if “lady” is a compliment or not. I really don’t like to be called a lady because my momma used to tell me that a lady was woman who didn’t know which way was up. And I really think we know which way is up.” (Kaplan, 1997, p.44). This dominant view of activism was also important for the three women whose campaigns were detailed in earlier chapters.

While I was conducting the research for this study, and deeply immersed in the meaning of the “accident” that contoured the lives of Jo, Audrey, and Paulette, I had a chance encounter myself. In April, 2004, I attended a conference organized by the Family Alliance of Ontario[69], a family network of parents with disabled children which operates outside the Association. There I discovered a group of mothers who described themselves as the “second wave.” A generation younger than the activist mothers of this study, they came of age during the women’s movement and were strongly influenced by it. Five of these mothers presented a workshop called “Working Together for Change.” Both their presentations and the question and answer period that followed, helped me put into relief the schism between the two generations. It also enabled me to consider the question: “what is happening for the younger mothers?” The chapter begins by drawing conclusions about what it meant to listen in stereo to the first wave of activist mothers, and then puts that into relief by listening in stereo to the second wave. A final summary measures the accomplishments of the activist mothers of this study.

## The Narratives of Activist Mothers

Listening in stereo to activist mothers with disabled children provided a valuable means to generate new insights about women’s experiences of themselves in the world. Listening in stereo to activist mothers make sense of their past meant trying to hear what they said as well as recognize what they did *not* say about their personal accomplishments, listening to their claims and their silences. It meant attending to the ways they balanced their home life and their activist work, the private

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[69] Family Alliance of Ontario, Spring Conference, “Creative Supports for Vulnerable Adults,” April 28-29, 2004, Guelph, Ontario.

and the public, and how they explained actions which exceeded the boundaries of acceptable female behaviour for women of their time. It meant tuning into how they expressed the dual pressures they felt to be a “good” mother, how they both succumbed and resisted conventional expectations, and how they experienced sexism as activists in an organization largely governed by men. It meant listening not only for *what* they did, but what they *wanted* to do, what they *believed* they were doing, and what they *now* thought they did. Finally, listening in stereo meant listening for how these activist mothers want to be remembered (Portelli, 2004).

### Listening in Stereo to their achievements

The accounts the informants gave of their achievements were ambivalent. Sometimes they described their contributions as trivial and insignificant, but at other times they revealed a deep recognition of their authority and sway in the movement. Listening in stereo meant listening for concealed statements of personal power and influence. They claimed their activist roles only gradually, first with modest boasts about their favourite moments of resistance, later re-telling those same moments with brazenness and pride. Their Association work nourished them, bolstered their egos and fostered their creativity and vigour. Their organizational and public speaking abilities expanded along with their confidence. Audrey Cole recalled it was after a letter she had written about discrimination was published in *The Globe and Mail* newspaper that she first “caught the attention of staff.” They began to draw her in more deeply, encouraging her to write, serve on committees, travel, and make presentations through which she met other parents whose frustrations with exclusionary social policies and practices helped her form a political analysis.Through their activism they came to inhabit what Kaplan described as a more “conscious motherhood” (Kaplan, 1997) and Abramovitz identified as “gendered obligation” (1999).

There were battles where they felt strongly and asserted themselves such as when Jo Dickey risked taking residents out of Woodlands knowing others were watching, waiting for this scheme to “fall flat.” She also knew she was making waves when she took the unprecedented step of inviting people with intellectual disabilities to serve on the boards of Associations. She said about herself, proudly, “I just don’t follow the rules.” Paulette Berthiaume dared to lead a walkout of mothers from the courtroom during the Shadley Inquiry even though she was frightened about the possible repercussions, worrying they might include imprisonment. Audrey Cole felt demoralized being a lone voice campaigning for human rights, knowing how “fundamental” it was, yet also knowing that few were listening.

The ways the women signaled their own actions provided an insight into how they socialized their thoughts and feelings according to certain dominant norms, especially when it came to traditional notions of leadership (Sacks, 1988; Astin & Leland, 1991). Based on the generousity of their accounts, it was clear these activist mothers were passionate to secure a place in history for the campaigns they took up. But despite their principal roles in theses struggles and their key location in the Association, they were reluctant to place themselves at its centre. They spoke readily about one another’s accomplishments and what they had achieved together, but they minimized their individual contribution and abilities. They consistently underrated their own activities and frequently avoided taking a first person point of view. They were unable to recognize the central leadership role they played through creating a vision, shaping consciousness and building community capacity and support networks (Bernal, 2002).

How they minimized their work was expressed in different ways. Audrey Cole, for example, developed a sense shared by many progressive social movement activists, that reliable information and hard facts were a starting point in addressing social and political problems. Over time she learned to conduct detailed research, a skill which she used to good effect when addressing unpopular or controversial measures. She became recognized for her capacity to produce newsletters, draft resolutions, prepare briefs, and write letters to the editor. Yet she often expressed surprise when she discovered that her advice and counsel were sought on particular issues. In 1991, when she was invited to chair a National Task Force on Guardianship, an area in which had become, in her own words, “something of an expert”, she rationalized this invitation as a “consolation prize” for having lost an election for President that year.

Similarly, for Paulette Berthiaume, the activities of other mothers were always emphasized as more important yet even here there were differences. Thus while Paulette Berthiaume gained national recognition for leading the Rivière-des-Prairies Parent Group through the Shadley Inquiry, her narrative stressed the extent to which she had no idea of the magnitude of the problem when she first began. Nor did she anticipate the immense mobilization that was required to address it. This led her to say repeatedly, “we were not organized, we were not organized.” It was Paulette who convinced a lawyer to represent them even when she warned that there would be “no money.” Often as late as “twelve or twelve thirty” at night, Paulette answered calls from other parents looking for information, and she circulated information to help them keep track of developments in the court case. Yet she still claimed only to have “pushed the pin.” She always credited Jo Dickey for the accomplishments in the deinstitutionalization struggle in Quebec; even though it was Paulette who had been “on the ground” organizing for over twenty years. She consistently repeated that Jo had been the catalyst, the one who came to Montreal and taught parents how to take their sons and daughters out of institutions..

On the other hand, for Jo Dickey, it was always the collective, “families”, whom she acknowledged as the real instigators of change. She never named an individual and never herself. She steadfastly avoided using “I” and was uncomfortable describing herself as a leader. What she considered “so beautiful” about the Woodlands Parent Group was that it “wasn’t Jo Dickey and it wasn’t Jackie Maniago”, it was “just families.”

Some of this may be traced to women’s modesty and reluctance to profile their personal accomplishments. But on the whole these mothers saw themselves as participants building a grassroots movement among local people, not as leaders building a power base. Like the social activists presented in studies by Kaplan (1997), Naples (1998b), Orleck (1995), Abramovitz (1999), Reinharz (1984), and Herda-Rapp (1997), they believed they were ordinary women doing what needed to be done, which for them meant improving services for their sons and setting a course of action for their organization. The women in this study never denied their role in the various campaigns they undertook, but they all found a way when recounting those events, to highlight a moment where they felt most vulnerable and not up to the task. Jo Dickey remembered how panic-stricken she felt when, after refusing the Premier's offer of two million dollars to upgrade Woodlands, she was invited by the provincial government to articulate her vision of an alternative and submit a proposal. She remembered having countless "pieces of paper" from community consultations but "not a clue" what to do with them.

These feelings of inadequacy were obviously not paralyzing as the previous chapters have detailed. In this case Jo Dickey approached an ally who agreed to write the proposal for her. It is notable that when Jo Dickey talked about this fear later, she reported that she was able to find a person who refused to accept any payment. Rather than giving up in the face of a sense of her own inadequacies, one of Jo Dickey's skills as an activist mother was developing sharp antennae for how to make use of the skills of others. Thus, Jo Dickey saw in Audrey Cole someone who had a unique capacity to "read and ferret things out from a legal side"; as someone who loved to "get hold of a document and pull it apart." Those were skills she admired even as she admitted that, she "could not imagine that a torture chamber would be much worse than that [kind of work] for me."

Audrey Cole became involved in guardianship issues in the mid-1980s when the Ontario Association asked her to comment on a report circulated by the provincial government. Having carefully prepared a response she brought it to the office for discussion and remembered there was an outbreak of "giggling" at the sophistication of her draft. While it annoyed her that they might have limited expectations (because she was a mother? a woman? a volunteer?) of her capacity to produce serious work, she often said, “I’m not a lawyer. This is just me.”

But this sense of being “just me” also fuels - despite their many significant contributions - a certain sense of failure and remorse that each mother harbours about what they might have done differently, or what they might have done better. Jo Dickey deeply regrets having accepted “No” for an answer when she first went to the British Columbia Association looking for services for Drew. She laments not having had the self-confidence to protest when they refused to serve him. Paulette Berthiaume grieves that Louis had to live so long in the institution and believes he could have come out earlier, if only she had “worked harder.” Audrey Cole is second guessing what Ian may have been denied as a result of the time and effort she devoted to advocating for “all the kids like Ian” and not him in particular.

### Listening in Stereo to how they balanced home life and activism

Listening in stereo meant discerning how activist mothers’ views of their contribution meshed with how they saw the balance between home life and activism. Their homes existed at the intersection between their public and private lives and their embeddedness in familial life shaped their view of the world. There is no question that their experience within the organization in which they acted transformed their lives in profound ways, but everything they did grew out of what they knew as homemakers and mothers. They were propelled by their sons.

> *Audrey Cole*: “I always used Ian as my base. I would ask myself, what would this [action / policy / decision] mean to Ian and nine times out of ten it would mean bloody all.”

> *Jo Dickey*: “I measured everything I did against what I wanted for Drew. I was just doing it for Drew.”

> *Paulette Berthiaume*: “I knew right away I had to be there for Louis and defend him all my life.”

They emphasized the role of other family members in their accounts but the dynamics were always complicated, especially when they attempted to use their homes as a site for caring work (Fisher & Tronto, 1990). Paulette’s extended family welcomed and included Louis but she was constantly on the alert to leave when he got agitated, careful not to overstay their welcome. Her older son resented Louis for demanding so much of her attention, and her husband found it hard financially and emotionally to accept having a disabled child. She noted that he supported her desire to go back to work after Louis went into the institution, but as she became more involved with the parent group, he stayed in the background. This was true of all the husbands of the activist mothers she worked with – they “stayed behind” and only emerged when there was a “scandal.” She learned to balance her work, activism and family life taking care to minimize conflict , knowing that if problems did arise she would be forced to “leave one or the other.”

Audrey Cole had her husband’s strong support for her Association work, but like Paulette, she managed the time commitments associated with attending meetings, out-of-town conferences, and speaking engagements with great delicacy. Running the household was mainly her responsibility and with the added stress of taking on extensive community work and feelings of guilt about being away from home often for days at a time, the load became overwhelming. With each new undertaking, she planned carefully how she would “break the news to Fred.” She said that he grumbled from time to time about her absences from home but it was really only when Audrey was personally hurt or publicly slighted in her Association work, that he exerted pressure on her to “give it all up”, which of course she never did.

While Paulette and Audrey were willing to reflect on what impact their activism may have had on family life, Jo Dickey was reluctant to do so. She drew the line when talking about her husband. She volunteered many stories about her older son, a medical doctor in rural British Columbia and his four children, but her husband was a subject she chose not to discuss. This reticence might could be seen as typical of women of her generation who tended to keep intimate details to themselves. In any case, it was necessary to tread sensitively with her silences and acknowledge the possibility that her reticence on the topic spoke to something troublesome and longstanding.

It is notable that all three women shared the view that having a child with a disability was particularly hard on men and could all point to fathers who had left home because they could not take the emotional and physical demands. “Home” became a site of delicate negotiation, where mothers balanced family life and activism, and in addition, the cultural and stereotypical expectations of professionals who had their own view of who “mothers” should be and what constituted a “good” mother (Traustadottir, 1988; 1991). Activist mothers mediated carefully between various members of the family, because as Paulette observed, the stakes were high, “you either lost your husband or your child.” This balancing act was an integral part of the maternal thinking and caring labour that went into their mothering work (Ruddick, 1995).

### Listening in Stereo to being a “good” woman/mother/wife

Tension in their personal lives made it important to listen in stereo to how they exceeded boundaries of expected female behaviour. Becoming political activists are still not the cultural roles society expects women to fulfill, and that expectation was even more pronounced in their generation. As activist mothers they extended their activities and sphere of influence to model an example for their children and others in their community along the lines identified by other researchers who study women’s activism (Naples, 1998a; 1998b; Orleck, 1995; Kaplan, 1997; Herda-Rapp, 2000; Reinharz, 1984; Abramovitz, 1999). However, by taking their work outside the private sphere of the family they knew they were defying the dominant definition of motherhood. They realized that by taking their private concerns into the public domain they were swimming against the current. That meant they were not only leaving themselves open to criticism as individuals, but they were also exposing their family life to public scrutiny. Thus, even as they acknowledged the social and historical context in which they lived and raised their families, they gave voice to a private inner conflict as they tried live up to being a “good” woman, a “good” mother and a “good” wife. Their attempts to assume the ordinary work of homemaking were not only thwarted by obstacles associated with the denigration of mothers’ care-giving work in society but the stigma that attached to them as mothers of disabled children (Brockley, 2004; Castles, 2004; Read, 2000).

Each woman recalled ways in which they were judged by others as unfit for having had a disabled child. Jo remembered being ostracized in her own neighbourhood, ignored in shops, and treated rudely in church by people who complained her child was making too much noise. She claims she never went back to any place she was asked to leave. For her part, Audrey often recalled her fury at various medical practitioners she encountered: the obstetrician who at her six-month check up said “you’ve given birth to a mongolian idiot”; the general practitioner, who upon being introduced to five-year old Ian, expressed his regret that amniocentesis had not been widely available in 1963 so that she could have been alerted (and presumably, in his view, had an abortion) rather than giving birth to a child with Down Syndrome. When Paulette became ill and was forced to place Louis in an institution, no one objected because as she said, “society wanted that, even my family wanted that.” Paulette felt trapped between what she knew she needed and what her family said she should need. She did not blame her family who out of love wanted what they viewed was for her own good, but she felt like she was sending her son to "prison."

These ordinary women judged themselves and their feelings against a dominant standard that said your child is different and should be treated differently. Accustomed to "polite" dealings with those in authority, they nevertheless learned to confront those who called them hysterical, indifferent, cold, aggressive – in short, bad mothers. They all insisted they did not want to cause discord but frequently were forced to do so over issues that seemed clear to them. When attempts to secure services for their children failed, given limited resources and their own as yet undeveloped capacities, they took risks and turned to direct confrontation of authorities. They withstood the criticism and opprobrium so often accorded to social activists. Here again, they were exceedingly aware that their actions often exceeded the boundaries of acceptable or expected female behaviour - particularly for women of that generation - and for which they were branded "trouble-makers." Paulette remembered being labeled a "cage-rattler" when she first confronted the hospital administrator over wrong-doing at Rivière-des-Prairies. Jo Dickey knew the very moment her name became "mud" amongst institutional staff at Woodlands. As activist mothers they learned the power of speaking from the experience they gained in confronting authorities. Through their commitment to their children and in solidarity with other mothers, they became challengers rather than passive subjects. Even so, their capacity for speaking out was seen as rude in a culture where activist mothering went unacknowledged as a strength.

They came to understand that their experience and that of many other mothers in similar situations was not merely personal, it was social. Turning points disrupted the “taken for granted fabric of their daily lives” and politicized them even though they never viewed themselves as activists (Krauss, 1998).

Listening in Stereo to how they view “politics”.

None of the mothers described their work as “political”, and their experiences can be seen to support the argument that when women differentiate their activist work from “politics” they curtail their ability to claim a more powerful political role (MacIvor, 2001; Naples, 1998b; Fisher & Tronto, 1990; Abramovitz, 1999; Orleck, 1995). Jo Dickey, who modestly depicted her work as “just doing it for Drew”, never portrayed herself as a political leader despite the fact that during her three-year Presidency and even later, as Past-President she continued to influence almost everything that went on in the Canadian Association. She put her energy behind closing institutions, but in her view, what was really at stake was building a strong social movement that involved hundreds of vigilant citizens who would be on guard to protect the rights of people with intellectual disabilities and their families over the long haul. She constructed a large and impressive agenda, yet she insisted she was “not a brilliant person”, merely someone with “some notion” of the goal. Paulette Berthiaume failed to recognize the significance of her struggle in Quebec until she joined the Advocacy Committee of the Canadian Association and learned about strategic deinstitutionalization initiatives across the country. Until then she humbly described her own activism as merely “working in my own backyard even though it was a big, big institution.” She never claimed for herself what was achieved, only that she never worked alone, “it was always [with] mothers.” Yet, like Jo, she became political when, in 1994, as President of the Canadian Association, she contacted the Quebec Minister of Health and Social Services. Using the weight of her office, she demanded that Louis be released from the institution and his money be released with him. She threatened to “act” if something were not done, and by that she meant she would go public and “call Associations all across Canada and the United States.”

Audrey Cole adamantly refused to have anything to do with what she called the “politics” of the organization, insisting that as she was “not very political” and therefore had little idea of “what was going on.” To Audrey the term “politics” held an extremely negative connotation, one associated with unethical behaviour and infighting. To say she avoided “politics” was not the same as saying she lacked opinions, beliefs and views or refused to engage in electoral politics. By speaking out from the beginning, when programs operated by the local Association excluded her son and demanding they “do something” not just for him but for all the “kids like Ian”, she was engaging in a form of political activism and community caretaking of those who were not part of her defined household or family (Naples, 1998b; Kaplan, 1997; Reinharz, 1984). Although her demand for action appeared straightforward, Audrey Cole could see what many others could not, the ways in which the issues of education, child care, transportation, housing, and other needs were interconnected under the umbrella of human rights. Her outspokenness posed a threat to established social service agencies, including the Associations. More than once she was electorally sidelined within the Association.

Like Kaplan's (1997) "homemaker citizens" these accidental activists were participating in a form of politics that brought people together to meet and talk, plan, confront authorities, and to work towards institutional, social, and policy changes (Sacks, 2000; Taylor, 1999; Bernal, 2002; Bookman & Morgan, 1988; Astin & Leland, 1991). This was a process which enhanced individual and collective capacity to stand up for one's rights. In the mother's view, justice was not limited to those rights that existed under law, but operated more broadly and involved what the law was designed to protect, i.e., access to the necessary social resources that would sustain their lives. They realized that if that were to be achieved they would have to do it themselves working through their local, provincial, and national Associations. That meant never being able to sit down for a meal without the phone ringing and someone asking for information. Their grassroots work was about "talking to people" and "bringing them together." Notably they did not regard this activity as "organizing." They never used this term.

### Listening in Stereo to gender: the activist mothers

Listening in stereo to these activist mothers meant being especially attentive to the silences, to the notes that were not played. The most profound of their silences was related to gender. Their comments were at best vague and general, suggesting they did not consider the subject very important. They engaged with an organization governed largely by men, and they could readily identify instances of sexism that they had experienced in the movement. Men put them down, did not respect them and underestimated their abilities underestimated. Jo Dickey remembered that when she tried to mobilize support to close institutions, she “took a lot of heat from the Board.” When Audrey Cole challenged the lack of democratic process in her local Association by proposing by-law changes, she was publicly censured by the President (an elected municipal official) and a prominent board member (a teacher in a local high school). She was accused of being “rigid” and “obsessed with law and order,” told that her principles were “too inflexible” and that her objections to the process were clearly her own personal problems.

If these reprimands were a tactic to keep Audrey in her place, they did not work, but they were emotionally costly to her. They also demonstrated how the Association tended to reproduce gender distinctions and hierarchy though cultural codes and practices (Taylor, 1999; Acker, 1990). Overall, the influence of gender was perceived by the activist mothers in a rather nebulous way. This was well captured by Jo Dickey’s comment, “It’s hard to walk into a room of men when you’re 5’2” – it’s not very comfortable.” Not only did they not have any well-formed view on the multidimensional influence of gender, they were strongly resistant to invitations to formulate anything of the sort and gave many signals that they did not want to talk about it at all. Despite being asked about the gender relations within the Associations in many ways and in many contexts, Jo Dickey consistently replied that she had “never thought about that.” Yet by the late 1960s she was leading a mixed-sex community organization, running meetings, appearing before municipal zoning boards, competing for resources with more established community organizations, petitioning school boards, and in so doing, stepping well beyond stereotypically female roles. She insisted that the central participants in the Woodlands Parent Group were "families" and "parents" and even "couples" but when she named names, the primacy of mothers clearly emerged. When it was pointed out to her that as the President, she appointed mothers, including Audrey, to chair the new committees she created, Jo Dickey replied, "I don't know if I did that consciously or unconsciously. Maybe, but I liked having a lot of men on the Board." When asked if the charge of "trouble-maker" or "irrational parent" operated differently for mothers and fathers, she deflected the question, saying "but there's also the siblings."

Audrey Cole, was equally resistant. Right from the start she questioned whether she would even be a good candidate for this study because she arrived at her activism not "with any history of linking up" but "intellectually, out of some sense of what is right and that did not necessarily involve women." She remembered that it was not until the mid 1970s when Ian was 10 years old that she first met women on her "wave length." Until then she tended to connect with fathers who she claimed, had a better sense of what discrimination meant. What mattered most to her was the "issue", not gender, she insisted, adding "it wasn't women that drove me… Ivy [Ellingham, President of the Ontario Provincial Association from1979 to1981] and I were centuries apart. You tended to look for people who understood what you were talking about."

For her part, Paulette Berthiaume, went no further in discussing gender than acknowledging that "she always worked with mothers" in what she saw as her main role of supporting families. She accepted that as it was women’s place to look after the children and that men were not expected to give so much. She allowed that it was possibly “harder” on men to talk about the lack of services for their child, because in doing so they risked sounding “like a sissy.” She admitted to the delicate balancing act of keeping families intact but was reluctant to divulge too much, only that in her own relationship she had to be “tough.”

The fact that a gendered analysis of their experience contradicts these mothers’ self- image is a significant finding of this study. But it hardly negates the conclusion that their activist careers were not without feminist significance. Given the campaigns they took up and the ways their activism exceeded the boundaries of expected female behaviour, it is unlikely they would disagree with a core feminist principle that a woman has the right to live her life the way she wants to regardless of what society has to say about it (Borland, 2004). They worked with women who believed they should have a say in shaping the social and political world in which they lived, and they sought out allies where they could find them. Those allies, it often turned out, were women.

Paulette Berthiaume, as Vice-President, led a national initiative in1992 to identify, cultivate and develop “Leaders of Tomorrow”, developing leadership potential in other women. In 1994, the year designated by the United Nations as International Year of the Family, Jo Dickey chaired an “Assembly of Families” of parent activists representing each provincial and territorial Association to revitalize the national network of families. Those parent activists were, of course, mainly mothers, and Jo Dickey knew they would be.

These activist mothers were interested in justice and equality, but not "feminism" per se. They did not identify themselves as feminists never having participated in the feminist movement.  This label held negative connotations for them. They welcomed an exploration of their lives and work in a society which tends to ignore or trivialize women's culture, yet at no point in the interviews were they inclined to comment on the larger framework of women's political development. While they recognized that they had experienced sexism, by and large they let feminism pass them by. Very few feminist organizations concerned themselves with issues facing mothers of disabled children, and this cannot be left out of the account (Blackwell-Stratton et al, 1988; Hillyer, 1993; Fine & Asch, 1988). That said, these were women who accepted their roles as wives and mothers and who came to their activism out of a sense of "gendered obligation" (Abramovitz, 1999). As Paulette noted, being an organizer was not something she was necessarily "good at." It was more a question of "obligation" because, she said, "I didn't see I had any choice."

### Listening in stereo to gender: the Association

Although the activist mothers remained silent on gender, the gendered aspects of the Association emerged in this study in a number of ways in institutional and organizational contexts (Taylor, 1999; Acker, 1990; Sheppard, 1992; Gherardi, 1995; Kanter, 1977). These institutional processes included volunteering, governance, and fundraising. The Association made great use of volunteers but tended to trivialize women's contribution. While this was partly a reflection of the times, the effect of disregarding the economic value of the work women performed to maintain the organization placed women in a marginalized status. They experienced a gendered division of labour where they were cast not as leaders but as the “lifeblood of the organization” and as a “loyal and industrious corps” who worked “willingly and cheerfully at a variety of useful tasks” (See: Chapter 3). What little recognition was granted was belittling. In this division of labour, the analysis of the Association corroborates Kanter’s (1977) finding that women in organizations tend to be relegated to “office housework” which “skewed” the representation of men and women and the higher levels (p. 25). Getting active to many women meant a traditional mothering role of service; Paulette first became involved by collating newsletters for her local Montreal Association. To others, getting active meant getting on the board to shape the organizational agenda; it was here that Audrey targeted her efforts.

However, while women served in a variety of positions at many levels of the Association from the start, they were always in a disproportionate ratio to men. In this way, the Association maintained and reproduced gender inequality and an organizational hierarchy in which men occupied the main position of power and authority (Kanter, 1977; Taylor, 1999; Acker, 1990). Women were significantly underrepresented in leadership roles. The dynamics of male bias penetrated the organization so deeply it took 10 years for the first women to be elected President. A gendered pattern of committee appointments reveals that women were guided towards domestic issues and “women’s work” while men chaired the more influential committees, including research, policy, organizational procedures, resolutions, legislations and nominations, women were tracked towards education, home care, and recreation. Women were always assigned the work of coordinating the National Conference. It was the most labour intensive volunteer role of all and recognized as a "mammoth task." In addition to standing committees, they took on special assignments and often worked behind-the scenes on important projects for which they were recognized only occasionally. Their extensive networking and organizing activities were generally not appreciated as a dimension of women's grassroots leadership (Bernal, 2002). Even when women leaders were recognized for their contributions, there was internal pressure to recognize "women's auxiliaries," particularly those formed in the institutions. In this way women were further marginalized in the organization they founded. The pattern of leadership that dominated the Association was characterized by a male definition of leaders: hierarchical structure, positionality, and leadership traits (Astin & Leland, 1991). Yet as this study shows the successful leadership styles and skills of the activist mothers, as catalyst, conscience and capacity –builder, were characterized by support networks and relationships.

Gender also played a role in fundraising and was expressed through symbolic codes, language, and sexuality (Gherardi, 1995; Morgan, 1997). In the first decade, there were two types of fundraising efforts. On the one hand there was the well resourced, high profile "Crusade" campaign which was conducted by "busy men" from the corporate sector. On the other hand, the Flowers of Hope campaign, a woman's affair, was carried out door-to-door by thousands of mothers across the country. The Crusade excluded women and established an "entirely male" advisory committee that was restricted to the "top businessmen and industrialists" in Canada.

Campaign briefing notes explicitly directed “the right man to call on the right man.” The Flowers of Hope campaign was scheduled for May to coincide with Mother’s Day and increase the emotional appeal of the drive. In addition to these institutional processes, women encountered an organizational culture that of affected their participation in the Association and contoured their activist lives. They came up against constraining notions of motherhood that challenged their activism as being outside the realm of what was an “appropriate” role for women. But they resisted such narrow interpretations of their work because they knew that individual households were not well located to challenge the social and political factors that constricted their lives (Fisher & Tronto, 1990). They encountered male power and authority in an environment that was not always hospitable to women with independent minds and aspirations. But they resisted internalizing a sense of fear and instead, fought back against their own socialization. They faced attempts to characterize their concerns as “fringe” matters of little concern to the Association. But they refused to be marginalized and took their campaigns to centre-stage. They confronted embedded assumptions about gender that suggested women were ill-equipped to participate at some levels of the Association, but when they saw something that needed fixing (Human Rights Laws, Woodlands School, Rivière-des-Prairies Hospital) they decided to act , wherever that took them. Propelled into the public arena in defense of their children, they witnessed forms of power typically hidden from them and came to see their concerns as social, not individual (Krauss, 1998). Although activist mothers drew on their social position as mothers, given their discomfort with feminism, they prefer to be remembered for their competence than their gender.

## The Second Wave of Activist Mothers

None of this negates the significance of activist mothers as women nor invalidates this study’s analysis of their struggle for social justice as it relates to gender as well as disability. But it was a subsequent generation of activist mothers who themselves bore witness to this as feminists.

A second wave of activist mothers came of age during the rise of the contemporary feminist movement. They had their disabled children in the mid 1970s, and although for many years were active locally and provincially, they became increasing frustrated with the Associations. They sought to develop innovative strategies to strengthen and support their disabled family members in their communities beyond the sheltered workshop and residential programs developed in the 1960s.While they recognized that such community-based options marked an extremely important step forward in their day as an alternative to institutional care, the newer arrangements advocated by second wave mothers spoke to greater flexibility, responsiveness, person-centered approaches to disability supports, and funding. They supported an “Individualized Funding” model (Stainton & Salisbury, 2005) to distinguish it from block funding provided by government to agencies for operations. Notably, this model was first conceived by Jo Dickey and the Woodlands Parent Group to access public funds that followed each individual leaving the institution, but it was not a priority for the Association (Roeher Institute, 1993a). Jo Dickey's generation of activist mothers, now in their late 70s, were prepared to live with this. The new generation were not.

To illuminate this generational difference and shed light on the issues, I will draw on the testimonies and comments made by "second wave" mothers during their presentation at the 2004 Family Alliance of Ontario conference. Each mother talked about their struggles in the current climate. They reported that in the early 1990s they had been involved in a rebellion against the Provincial Ontario Association. This was prompted by their concern about how the Association was managing it dual alliance to its 120 local Association service providers on one hand, and it family membership base on the other. They felt the Association was showing preference to the interests and needs of the professionals, and becoming "too cozy with government." In their view, it was impossible to be both a service provider funded by the government and an effective advocate against the same government.

In 1995, they broke away and founded a new province-wide network called the Family Alliance of Ontario which offered a more open "network" structure than the hierarchical structure they saw the Association becoming and which extended its reach to adoptive and foster parents of disabled children. Operating through 15 Regional Councils and distributing a quarterly magazine, *The Compass*, to 2000 members, the Alliance stressed what was "not happening for families" such as their own. Just as the first wave mothers advocating for community based services collided with the goals of "institutional parents" seeking to improve conditions inside, these second wave mothers wanted their children included in neighbourhood schools and community programs and rejected the segregated services offered by local Associations. They respected the fact that in the past “the big push” by activist mothers to create those services was because “their kids were sitting at home.” But they also lamented that local Associations seemed to evolve over the years into primarily service-providing agencies and thus lost a sense of having been part of a social movement. It was to revive that sense of movement that the second wave mothers founded the Family Alliance of Ontario, following a similar group that had founded the Family Support Institute in British Columbia.

Equipped with a language and identify formed around feminism, the five women were comfortable applying the term “second wave” to themselves. In contrast to the first wave of mothers whose self-identity did not include gender, second wave mothers had a political analysis grounded in an explication of the dynamic of gender. They readily admitted that the “feminist push” in the 1960s “changed a way of thinking about a lot of things” and as one mother noted, it helped them get angry:

> Outrage by women is more acceptable since the feminist movement – outrage and anger over injustice is legitimate. You come out on a particular issue because you don’t give up on your kid.

Exposed to other social justice struggles going on at the same time they could see the connections between feminism, civil rights, and disability. They recognized and valued the power of women’s collectivity and readily claimed that they could never do as individuals what they did together.

Like the mothers before them, they looked to “gendered spaces” (Abramovitz, 1999) in domestic households to organize. They met around kitchen tables, over potluck dinners and “banana bread” which became the metaphor for their family network. In the early days when resources were lean, they pooled their “pocket change, stamps, and note-cards” and discussed how to “tweak other mothers’ interest” to build their membership base. They consciously set out to make their network “homey and fun.” They acknowledged they were building on the contributions of the women who came before:

> The only reason we’re sitting around here today is because moms in the 1950s sat around their kitchen tables and decided that something had to be done. At that point they were at home. They could get together over coffee in the morning and make jams and jellies to start the funding process to start the co-op projects that turned into group homes that turned into agencies. Now of course the kitchen table includes a fax machine, computer, internet, e-mail and phone bills.

Consistent with the norm for women of their generation, in contrast with the earlier one, these five second wave activists had started out as two-career families. But each mother gave up working when her disabled child was born. Unlike most of the women of their generation who juggled home life and careers, they experienced the previous generation’s division of labour. Their husbands provided the only source of income, and they provided the very best mothering they could give their children.

They had given up their careers they had as a radiation technologist in a hospital X-ray clinic, a journalist, a social worker, a food columnist and caterer in a gourmet food shop, and a buyer for a retail clothing chain. They wondered “not with regret but curiousity” where their careers might have taken them had they continued working. They knew they would have been better off financially.

Unlike the first wave mothers who tended to evade the subject, these second wave mothers had an explicit point of view on male dominance. Speaking of the Ontario Association for Community Living and its 120 local affiliates, they noted immediately that “all of the Executive Directors are men.” Speaking of their husbands, they made it clear that in general, they resented their volunteer work. The men tended to be jealous of the close relationships that formed among the women, and they begrudged the costs in terms of time away from the family and the financial burden of telephone bills, internet fees, and travel. Speaking of parent meetings with officials from health, social service and education services, they described how “men tended to ally with other men around the table.” They all knew couples who had been “in tune” before going into the meeting, but once inside, men often “lined up with the superintendent” not wanting to “make waves.” It was mothers who “were the big risk-takers,” the ones who were “less likely to compromise” and “would not be put off.” At the same time they were willing to work with men tactically, for example, they always made sure there was a man on their side of the table when money was being discussed.

Unlike the first wave mothers who responded to the term “activist” suspiciously, the second wave readily engaged with the idea. One mother said:

> Activist is not something I would have chosen as a label for myself because pacifist is philosophically where I'd rather be. But we've fallen into this mode because of having to defend what we treasure most.

To her, activist mothering was natural; what was not natural, was walking away.

> You know when I thought about being an activist mother I thought activist mothering isn't rare. Activism is what mothers live. What's really rare is a mother who will say "my baby is very ill and going to die so I don't want to get attached."

They knew that their behaviour and outspokenness at times resulted in professionals dismissing them as "some kind of pariah, some kind of rare rebel." Even though it did not make them popular, they were more than willing to step outside women's cultural role to redefine what it meant to be a "good mother."

> My mother was the "good mother" according to the professionals, because she did what she was told. I had a brother with Down Syndrome who my parents never took home from the hospital…and that was considered "good." I don't think she was a good mother at all because she completely abdicated her responsibilities. What makes me angry is when I help other people struggle

> against the authorities of schools and social services and medical services we [are the ones who] get seen as the bad mothers….

There was a definite "turning point" which confirmed in them this sense that a good mother of a disabled child was not one who was compliant but one who was an activist. Turning points were moments of awakening, defined by one mother, as that instant "when you learn you have been lied to or a trust has been broken." For that mother, the turning point came when she encountered an issue that disrupted her natural inclination "to avoid confrontation at all costs," when she could no longer avoid taking a stand.

> Like most parents I was very naïve. I remember trusting a lot of professionals and being so shocked when I found out I had been lied to…when you have a child with disabilities you need to trust other people, you want to – you need to feel other people are on your side. And then you find out there are people going to great lengths to oppose you.

For another, the turning point came when she found that the neighbourhood school would not admit her son.

> When the principal locked the door I had no choice but to move to get integrated education. We sold our house at the bottom of the market and bought one at the top – it took us 15 years to recover financially.

For a third it was joining the board of a local treatment centre to introduce what she thought was a minor change in practice, but which erupted into a major conflict.

> The change, by the way, was getting parents copied on reports on their child. That was it! And it caused such a big battle in the treatment centre that they turfed out my son who they were mandated to serve… Suddenly I was a pariah.

These public stands often resulted in being “spotted” by another mother or a staff member as someone who “was willing to stick their neck out”, someone to be mentored and encouraged, someone who “could do things.” This too marked a turning point as they began to appreciate and develop new capacities and skills. Despite being conscious feminists, it is notable that it often took these turning points to bring them to do things they never thought they would do – travel, speak publicly about what children and their families were up against and organize. Nor did they find it easy to get over a sense of modesty about what they were doing in their local struggles. One mother remembered:

> It was 1981 and I had just read Nicola Shaefer’s book, *Does She Know She’s There*. Wow I thought, that was my story too. Someone said we should invite

> her to Windsor. You mean I should just call her? On the phone? To come to Windsor?

Like the first wave mothers, they attended conferences at local, provincial and national levels where they encountered other “kindred spirits” and experts in the field. But with their feminist consciousness, second wave mothers were able as their predecessors were not to target other activist mothers “across the room.” They recognized that the best source of information, as one woman put it, “happens to be from the mother sitting next to you while you are listening to the expert at the front of the room.” In their experience, the real expert knowledge resided with the mother who could tell you, for example, how to find a bed and pillow when you have to stay overnight with your child at hospital and where to hide the pillow so the nurses would not take it away, which meant you could stay another night. They strongly believed that if mutual support was not there for mothers, they were subject to doctors. They grew stronger, because as one mother explained, “you can expect repercussions when you touch on people’s anger.”

Having been let down by a specialist they trusted at some point in their activist career, they had lost their sense of awe and reverence for professionals. At the same time they brought valuable information to decision-making forums when their child was being discussed; knowledge was their power. They learned how to be deferential strategically, recognizing that professionals did know how to keep their children alive but they also learned how to take back power. As mothers, they felt they were the ones who knew best what their children needed. When they came up against a bureaucratic “No,” they “made a couple of phone calls” to allies in the network.

Although they were much more prone to think of themselves explicitly as activists in all these respects than first wave mothers, they were responding exactly as the first generation who were the focus of this study. Where they differed was that the new generation developed a healthy cynicism about political processes within the Provincial Association. They described one “Catch-22” situation as especially noteworthy. When they formed the Family Alliance of Ontario, in 1995, the Ontario Association offered them office space. They needed the resource base to launch the network and accepted gratefully. However, they quickly recognized that their “family” presence operated to appease the Association’s conscience. They were consulted on issues and invited to bring the “family voice” to various strategic planning meetings only to find that the reports and proposals coming out of those meetings “adopted our language” but ignored the real concerns. One mother was further irritated to realize that, “everyone else at the table was paid and though all of my ideas went into the report, I was never compensated.” This was rarely something the first wave of activist mothers complained about.

For a time they were willing to be courted. The Ontario Ministry of Community and Social Services guidelines specified that organizations receiving provincial funding had to balance their board by including not only lawyers and accountants but also family members and people with disabilities. Similarly, many charitable foundations also required that proposals and applications for funding include broad consultations with disabled people and families. However, as with the other “turning-on points” they experienced, they reached a “turning-off point” with the Association when they felt they were beginning to be used as tokens.

From the beginning the Family Alliance hired a mother as full-time coordinator to focus “one hundred percent” on creating change, because as she said, “it takes everything…passion, enthusiasm and the raw energy that comes with pioneering.” Tensions quickly arose with the Association, who in light of their divided loyalty between the families on the one hand and affiliated service agencies on the other, found it hard to compete with the momentum being generated by the families. One second wave activist remembered that ill-feeling:

> Instead of supporting us, the parent organization made us feel like competition, and as mothers we were treated as though we were taking strength away from the Association. The way we see it is that we are all mothers.

Within a year the Family Alliance was asked to vacate their office; as they packed their boxes they also cut all formal ties with the Ontario Association

The second wave mothers were unwilling to argue for women’s community activism as an extension of female self-sacrifice, and they sought to be paid for their work as community caretakers (Traustadottir, 1998; Naples, 1998b). Reminiscent of the “wages for housework” campaign during the women’s movement, second wave activists argued for resources from Associations, governments and foundations to recognize and pay mothers to carry out the “important work they did supporting families.” In their view, a salaried position meant not only having an income but also having a seat at the table from which they could “infiltrate and influence” operations and governance. They resented how writing proposals deflected their energy from the real work for which they came together in the first place.  However even as they were successful in securing foundation funding to launch their network, they were ambivalent about accepting it, fearing what compromises might ensue.

As networkers and capacity-builders, they consciously fostered leadership by focusing on the people who had the most interest and energy, to “strengthen them.” They did not exclude those who did not “get it” but kept them at a distance. They tried to adopt a policy of not fighting with one another: “We do not judge other mothers and the choices they make because the ministry loves it when parents fight with one another, then they can divide and conquer.”

The personal and mutually supportive dimensions of the second wave of activist mothers’ activities were characteristic of the network style of women’s grassroots organizing reported by Naples (1998b), Kaplan (1997), and Bernal, (2002). Increasingly even the repertoire of phrases they used to describe their activities adopted a hyphenated, stringing together of words, practices and relations: “extend-a-family”, “parent-to-parent”; “telephone-trees” and “list-serves.” The links were on the ground and in the airwaves, making them ever reachable. Having a portable phone was crucial because, said one mother, “I still have to make dinner, but I can be talking at the same time.”

A more explicit aspect of their organizing strategy than had been the case with the first wave was helping families “transfer the big nightmares to dreams” and shift their expectation of the future so it became something “dreamed about, not dreaded.” They knew the rest of the world sympathized and pitied them, but however well-intentioned, this always felt draining. Strategically they devised opportunities for building relationships and creating environments in which empathetic expressions such as “I know what you are going through because I’ve been there too” could be exchanged.

Second wave mothers mobilized to offset the prevalent assumption that life with a disabled child was a series of crises interspersed with chronic sorrow (Olshansky, 1962). Determined to celebrate what their children had done for their families, they devised tactics to overturn the notion that having a disabled child was a tragedy from which the family never recovers because as one mother insisted, “it’s not always just been torture. Some of the funniest times in my life… have been in the company of parents.” They were creative when it came to “translating the symbols of mothering into political speech” (Ruddick, 1995, p.229). Sometimes organizing took the form of “storytelling”, **c**reating strong visual and oral messages that could be easily remembered and quoted widely, such as the following:

> Two things happen to mothers. We become like bears defending our cubs and when angry we will move mountains. But moving mountains is such a struggle that we want to be able to swim with like-minded people and so will go to the ends of the earth to find them.[70]

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[70] Another of these is: Mothers are like tea -bags; they don’t know their own strength until they get dunked in hot water.

Together they articulated ways to challenge labels and language that diminished their child and themselves. They particularly detested the word “cope”, as in “I don’t know how you cope!” because in their view what was really being said was “I love my child more than you or I would never be able to do what you are doing.”

They devised strategies of “reverse intimidation” to help mothers assert control at school meetings for example, which were an early “turning on point” in many of their activist careers. They told one story about a mother who was reluctant to go to a school meeting alone knowing her child’s progress was to be discussed. She invited her neighbour who wore a suit and sat at the table alongside the principal, the teachers and psychologist, posing as her lawyer. She never introduced him; he sat silently taking notes at the meeting. Another mother played to maternal stereotype and brought a batch of freshly baked muffins to a school meeting. When there was a major decision to be made they readily brought along their husbands. At other times, “when you know that they know who you are,” they brought someone new in as a “power hitter.” They were deliberate in such tactics to try to upset “business as usual” and though they were feminists, they did not consider these tactics a compromise in terms of their own dignity.

“Symbolic acts” were another of their mobilizing strategies, the most successful being that carried out by the one family who set up a classroom on the front lawn of their neighbourhood school when the principal, backed by the school board (Endicott, 1994),[71] refused to admit their daughter, an action which attracted

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[71] Till v North York School Board, (1994).

national media coverage.[72] They used popular theatre techniques to develop and deliver training events, such as a workshop provocatively titled, “Will the Real Tragedy Please Stand Up?” which they took on the road. They distributed fridge magnets promoting solidarity, (“Never Go to a Meeting Alone”) and supporting campaigns to close institutions, (“Let Our Children Go”). By these actions they engaged in the maternal practices Ruddick (1995) identified as the “politics of resistance.”

They reinforced each other’s spunkiness and courage to speak out. They coined for themselves the logo “Mothers from Hell!” and teased one another for being a “live one.” As one mother said to another, admiringly: “Are you still getting pushed off boards?  Oh, you’ve still got the touch!” The first wave of activist mothers’ great achievement had been getting on the boards of the Association at the local, provincial and national level. The next generation’s seemed to be to go off them.

## Conclusion: Taking the Measure of Activist Mothers

The first wave of activist mothers interviewed for the study were no longer in leadership positions in the Association by the time the second wave activists split from it.  It is notable that there was considerable agreement among them all about what was wrong with the Canadian Association for Community Living. There was ample evidence to show that the Associations were bigger and were serving more

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[72] The Fight for Right: The Story of Becky Till (1994) The Disability Network. Ontario, Canada.

people with disabilities, but what concerned them was the growing power of the service agencies at the expense of families. In the view of the first as well as second generation of activist mothers the agencies held all the strings. They all noted the trend led by service providers to shift the membership base of the Provincial Associations from individual members to local agencies, giving greater voting power to executive directors and board presidents.

The first wave of activist mothers recognized that there were groups of families leaving the Associations feeling disillusioned and angry because they were not supported; they saw the Family Alliance Ontario and the British Columbia Family Support Institute in precisely these terms. They recognized this as creating a strategic dilemma. Even if families and their new organizations were working outside the Association, at least they added to the sustained voices across the country making demands based on what families wanted. This erosion of members posed a serious risk for the future base of the Associations. Given her identification with the Association Jo Dickey could hardly hide her panic at this prospect:

> You know what’s going to happen? What’s going to happen is that they are going to develop a movement themselves and the Canadian Association and others are going to be left without any family members – it’s so close, it’s happening and I can’t not help it happen. If it does, the organization will lose its purpose.

Ever activists, even if no longer in leadership positions, the first wave of activist mothers have not been idle. Experienced with by-law reform, Audrey Cole devised a constitutional process to put the Association "back in the hands of its members." She proposed a scheme to offer individuals a form of membership in the Canadian Association that did not first require them to join a local and a provincial Association either due to political differences or because they were "little family organizations" like the Family Alliance of Ontario. [73]

Their concern is deeply felt because the Association has been their family over many decades. Like the radical women in Orleck's (1995) collective biography who broke with conventional life, they created alternative families and relational networks through their activist careers in the Association. During those years they were witnesses to and actors in many of the "fantastic changes" in the Association's history, changes brought about by many activist mothers of outstanding caliber and dynamism. What kept them engaged over time was their passion for the campaigns they took up. What sustained them were the loose networks and strong bonds they formed with other like-minded activists (Kaplan, 1997. p.182). Paulette Berthiaume thought more than once about "throwing in the towel", but she never did. She claimed the Association helped her stay grounded and believe in what she was doing in the face of opposition and people who constantly "questioned your thinking." Jo Dickey always said she worked with the Association because it was the only way she knew to get the Woodlands institution closed. The astounding success of the Woodlands

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[73] But this has yet to pass at the provincial level and the Canadian Association, being a federation, could not take this further without it having first come up from the provinces.

Parent Group taught her a profound lesson about the political power of families, a lesson that has propelled her work over the years. What mattered to Audrey Cole was that despite periods of turbulence and instability, the Association always found a way through it. That to her was critically important because, as she said “you didn’t lose the Association; there was enough commitment there to [its] purpose that it survived.” Despite many disappointments with the Association, Audrey Cole never walked away because she could not imagine any other social justice organization that would be “so right” for her and what she believed.

Family organizations such as the Family Alliance of Ontario and the British Columbia Family Support Institute did not amount to an effective alternative to the Canadian Association for Community Living and its local and provincial Associations. Together they have 4000 members whereas the Canadian Association has 40,000 members through 10 provincial and 2 territorial Associations and with staffs and budgets many times greater than the family organizations. Moreover, the second wave activists who built the new family organizations are as concerned as the first about their ability to mobilize a new generation.

Both first and second wave mothers are concerned about the future. The question uppermost in all their minds was “where are the younger mothers?” The first wave mothers observed that members attending Association meetings tended to be “over forty” and Jo Dickey speculated that was because younger families were still struggling on their own with little support and had no time to join Associations:

> What breaks my heart is I hear the same story from younger families now who, if they only had a little help, they wouldn’t be dying from overwork, stress and heartbreak. Here I am getting ready to leave this world and I see the same thing happening to them as it did to me. I can hardly stand it.

The second wave mothers noticed that among the “Generation-X’ers” and the following generations of families more than half the mothers were working outside the home in comparison to the volunteer pilot parents of the 70s and 80s. They concluded that the lack of active parent leaders was due to economic pressures families experienced in these neo-liberal times (Ouellette, 2001).

They feared what this might mean for the sustainability of the Association movement. Although they, as mothers spanning two generations, opened many doors, they knew how many still needed to be pried open. The older activists, whose lives were haunted by the specter of institutional care knew from experience what could happen if there were no vigilance and oversight – a critical role played by Associations - yet they sensed the younger mothers did not feel a need to belong, and this in their view was short-sighted.

A second question that plagued them was “where is the activism?” They could not see enough evidence of advocates making demands on government. In their view, the number of people prepared to go out on a limb seemed to be getting fewer and older. Not only that, the thousands of families across the country who benefited from the expansion of services in the last 15-20 years seemed reluctant to want to rock the boat but nor were they prepared to put time into securing what they had inherited or making it better.

After nearly 40 years of activism, Audrey Cole echoed the frustration of the other mothers when she lamented that overall there seemed to be little indication of the kind of progress for which she had campaigned. Somewhat disheartened by the slow pace of change, Audrey Cole doubted the focus of her life-long activism to "get something for everybody" not just for her own son. Re-evaluating this question as she approached her 80th birthday, she said,

> I have thought since that maybe I wasn't right and certainly the Jo Dickey's of the world have always said that you do this one person at a time or one family at a time. But I don't believe that because the ones that do get it become the only ones that got it – we can see that all over. Unless you're able to change the bigger picture it's always going to be like that and the next generation is going to have the same things to face.

# Chapter Eight

# Conclusion

## Overview

The major campaigns waged by the activist mothers in this study spanned a period of 30 years from the mid 1960s to the mid 1990s. Audrey Cole, Jo Dickey, and Paulette Berthiaume, are now in their late 70s and they continue to be engaged although primarily at the local level. In May, 2005, Audrey Cole, serving her third term as President of the Brockville Association, made a presentation to municipal councilors in support of the Provincial Government's decision to close its three large institutions, extending her organization's welcome to residents of the nearby Rideau Regional Centre.[74] Paulette Berthiaume continues to support families, and recently visited a mother whose daughter, still living in Rivière-des-Prairie Hospital, had become pregnant by a member of the institutional staff. Too late for an abortion, Paulette saw the young woman through her pregnancy and delivery, including the grandmother's decision to adopt the baby. Jo Dickey lost her son Drew in May, 2004 when he was 49 years old, but continues to monitor developments related to the Woodlands School. In 2001 she advised an administrative review of the institution commissioned by the British Columbia Ministry of Children and Family Development which recommended that all past residents receive partial reparation

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[74] 'Ontario Government Improving Support for Ontarians with Developmental Disabilities'. Press Release. Toronto: Ministry of Community and Social Services. September 9, 2004.

from the Provincial Government for the hardships they endured.[75] In March, 2005, the British Columbia Supreme Court certified a class action lawsuit by former residents seeking damages for abuse thereby enabling Woodland residents to have their day in court.[76]

Notably, only slowly in the course of participating in this study, did these women begin to speak in terms of how the "activist" roles they played as mothers of disabled children were threaded through their own life stories. But it did not take them any time at all to identify the "accidental" dimension, because there is no question their own lives changed dramatically when their disabled sons were born. Had things been otherwise, Jo Dickey would have opened her own physiotherapy clinic; Audrey Cole would have continued to work as a technical illustrator (though for a time in her early 50s she considered law school), and Paulette Berthiaume would have practiced nursing. Instead, they made their mark on the disability rights movement in Canada.

They complemented one another when it came to their activist skills and styles, which may have been a factor in their success. Jo Dickey was the "catalyst" who had a vision and the personality to persuade others to come to share it. Audrey Cole was the "conscience" who was committed to a set of values and principles that she expected the Association to uphold. Paulette Berthiaume was the "capacity-builder" who preferred to be on the ground, expanding networks, support systems, and guiding the leaders of tomorrow. They brought critical dimensions of activist

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[75] McCallum, D. (2001). Need to Know: Administrative Review of Woodlands School. Victoria: Ministry of Children and Family Development.

[76] 'Woodlands victims will be heard: Judge rules that province must defend history of abuse'. The Vancouver Province, March 20, 2005 A30.

work to their campaigns: advocacy, personal commitment and the capacity to look beyond themselves and into the future. These epitomized the very essence of what the Association represented.

## Contribution to the Literature

The literature identified several themes to help understand mother’s activism and these have formed the conceptual framework for this study. One theme explored how activist mothers negotiate the boundary between their active public life and their personal private life (Mills, 1959; Orleck, 1995; Naples, 2998b; Kaplan, 1997; Stehlick, 2000). A second theme pointed to the significance of informal networks to women’s grassroots organization (Reinhartz, 1984; Astin & Leland, 1991; Sacks, 1988; Bernal, 2002; Morgan & Bookman, 1988). A third looked at how “accidental activists” came to their activism through a sense of “gendered obligation,” fulfilling what they believed society expected of them as mothers (Abramovitz, 1999). A fourth theme dealt with the traditional notions of “good mothering” (Ladd-Taylor & Umansky, 1998; Sangster, 2001) and how this applied to activist mothers who resisted conventional thinking by promoting a more inclusive view of motherhood, not narrowly based on the ideal of the “normal” child. Finally, to bring women into view, gender was used as a category of analysis to investigate how mothers’ activism violated the cultural norms for women of their generation and exposed the sexist divisions in the organization they founded (Abramovitz, 1999; 2000; Naples, 1998a;

1998b; Orleck, 1995; Kaplan, 1997; Herda-Rapp, 2000; Taylor, 1999; Acker, 1990; Sheppard, 1992; Ferguson, 1984).

The literature shows that mothers of disabled children have been studied extensively from a therapeutic perspective which gives rise to mother-blaming and “bad” mothers. The literature also shows that the significant terrain of mothers’ activity involves finding new careers that started by trying to get their own children’s needs met and then carries into disability work more broadly (Traustadottir, 2000; Wickham-Searl, 1992; 1994; Darling,1988; Kittay, 1999). In that research however, “disability work” does not extend to mothers involvement in political work. This study fills the gap in existing research by discovering how mothers with disabled children are prompted to assume an activist role to challenge the structures that exclude their children and how this develops their capacities and desires. In addition, it fills a gap in existing literature on community activism that explores the range and varieties of contemporary women’s struggles in the United States and Canada but overlooks disability. Such studies bring into view a variety of exclusions based on gender, class, age, race and culture/ethnicity, but in this genre disability is consistently excluded. Naples, (1998b) for example, defines activist mothering as “self conscious struggles against racism, sexism and poverty” (p. 114). This study attempts to extend that definition to include “ableism” and bring disability discrimination into view. The significance of mutual support to the mothers of disabled children revealed in this study certainly corroborates Naples (1998b) findings on the importance of social networks to women’s constructions of community and political work. By the same token, uncovering mothers' disability activism in this study extends Naples' work into a new area.

## Key Findings

This study found that what these activist mothers shared was the impulse to swim upstream. Spurred by disability in their family, they conducted campaigns to close institutions and secure human rights though it was counter to the ideological current. The odds against them were considerable. They encountered gendered assumptions that expected men who committed themselves to activism to divide their attention between public and private lives. Women however, were not so permitted; for them the choices were more complicated and the risks greater. They struggled against sexism in an organization whose “gender regime” (Connell, 1987, p.120) inscribed difference in divisions along gender lines, symbols, images and patterns of interactions (Acker, 1990). They stood up to accusations of “mother-blaming” that cast disabled children and their mothers in the same demeaning light. They contradicted popular opinion and prevailing beliefs about what it meant to be a “good mother.” Being a “good mother” in an era when maternal absence was believed to be devastating for a child's emotional development meant staying home and caring for your child. Yet in the case of disability, the opposite was held to be true; being a “good mother”, where disability was concerned, meant handing over your child to state institutional care. These mothers' capacity to overcome the odds stacked against them speaks to their skills and styles as activists.

Listening in stereo to these activist mothers meant attending to their silences. At times, this silence related to gender. The fact that a gendered analysis of their experience contradicts these mothers' self-image is a significant finding of this study. While they rejected the label of feminist they nonetheless developed ideas and political concerns that fall within the repertoire of feminism, including sterilization, Depo Provera, institutional abuse, and replacing guardianship law with a form of supported decision-making.

Their activist careers had feminist significance because what was most important about these activist mothers was that they would not be silenced in the other sense of that term.  Both first and second wave mothers learned the power of speaking from experience and as such, took on the contested space of knowledge in its dominant bureaucratic and medical forms. Faced with constantly having to present an alternative view of their child to the world they became more confident and outgoing in what they knew and authorities did not. Their activist work included "arguing their child in from the margins" (Read, 2000 p.120). The first wave resisted the dominance of medicalized and institutional authority. The second wave, informed by the Civil Rights struggle in the United States and its "spillover" effect in Canada, attempted to shift public understanding of disability from a question of "charity" to one of "rights". The activism of these mothers illuminates how the experiences other mothers and children face are socially and politically constructed and how they might be changed by social and political means.

A key finding of this study has been the extent to which activist mothers have been central political actors throughout the life of the Canadian Association for

Community Living. Mothers in the 1950s were weighed down by knowledge heavily oriented to medical expertise and its solution to the disability "problem." Coming together to protest the institutional solution, they were able to break their socially induced silence. They were forced to consider the social processes that impeded access to opportunities others took for granted which was often taxing and upsetting. Their private work as mothers merged with the public sphere community activism and politics. As they became more confident and assertive, they came to recognize the imbalance in forms of knowledge that kept them and their families in a subordinate position. Their grassroots campaigns transformed a private understanding of disability into a public agenda and they drew together allies whose local concerns generated ideas about broader issues. They also succeeded, collectively and individually, in leading a redefinition of how equity and inclusion may be understood. They overcame the odds against them and their accomplishments in the Association were remarkable.

The forms of leadership adopted by women in this study to conduct their campaigns corroborates recent feminist research on women's leadership for social change (Sacks, 1988; Astin & Leland, 1991; Bernal, 2002; Taylor, 1999). Involvement with other like-mined mothers had a strong galvanizing effect on the development of support networks which in turn provided support for their concerns. At the core of these networks was a shared experience of discrimination, rejection, belittlement, and pain as women and mothers, and a passion for social justice. The power of having one another to call upon and act with, and the sense of common purpose in the work encouraged their persistence and sustained the momentum. The activist mothers in this study did not claim to be “leaders” in the traditional sense, but they spoke of having “influence,” something interpersonal and oriented to a set of values.

## Significance of the Study

This study makes a contribution in several ways. It contributes to existing scholarship on the social history of women’s activism. The critical concepts of gendered obligation (Abramovitz, 1999), female consciousness (Kaplan, 1997) and activist mothering (Naples, 1998b) informed the findings of this research. Their meaningful application to what this study has discovered about mother’s disability activism confirms their analytic resilience and theoretical breadth.

This research adds to the growing scholarship in disability studies. It recognizes recent changes in the political and social status of disabled people and is oriented towards a cultural and historical approach to disability. The issue for activist mothers was discrimination and prejudice – the same locus of concern identified by disability studies scholars who theorize a social model or social construction of disability (Linton, 1998; Oliver 1990; Priestley, 2001; Longmore, 2003). Since disabled people constitute one of the most powerless groups in society, a social disadvantage which also attaches to their families, it is not surprising that disability issues have been overlooked in historical writings (Hirsch, 1998; Longmore, 2003). The “medical model” with its emphasis on diagnosis, prescription, isolation, treatment and cure has tended to dominate the study of disability, influencing theory and practice in the helping professions. Hirsch compares this “sick role” to “confusing gynecology with the study of women in society or dermatology with the study of racism” (1998, p.216). This study of activist mothers includes disability issues as a dimension of historical scholarship and deepens our understanding of the cultural conditions in which disability policies and services are established and implemented. Longmore (2003) suggests that the “transformative analysis of the social sources and character of disability has generated new public policies and social practices” (p.2). These include concepts such as disability discrimination, equal access, reasonable accommodation, independent living and education in the least restrictive environment. This study, by focusing on the social and political context of disability, pays attention to how society responds to families rather than how families to respond to disability. In this, it offers an “angle of vision” (Longmore, 2003, p. 6) congruent with and contributing to, new knowledge based on social model analysis.

This study also makes a contribution to social work education, practice and research by demonstrating the interdisciplinarity of disability. This is different from the way disability is typically treated. Disability is often viewed as an isolated phenomenon in social policy, programs and services which has contributed to a set of parallel social arrangements that have isolated disabled people in segregated and special education, sheltered employment and specialized transportation systems. It is not the case that disability is neglected in research and teaching. But when social work curricula address anti-oppression and diversity, disability is frequently overlooked; when disability is included, it tends to be added-on, as an after-thought. Alternatively, when specialized courses are taught with disability as the major focus, the curriculum tends to address such topics as assessments, functioning and programming, but ignore more comprehensive questions that arise from how disability lives in an intersectional relationship with gender, race and class in an individual within their social environment. Uniquely, this study explored what might be learned about mothers’ disability activism not by studying mothers of disabled children but by researching women’s activism in struggles led by mothers similarly mobilized by a range of concerns for their children and neighbourhoods. In so doing this study suggests a model for thinking about disability, not as a narrow field but as a broad-based inquiry and a social and political problem.

It is also hoped this study will make a contribution to public policy. It is well recognized that families contribute significantly to the well-being and inclusion of their children and adult members with disabilities and that they need to be supported in this important work. In 2003, the Canadian Association approved a “National Family Agenda” to bring attention to some of the realities families in Canada are facing. This platform identified how the costs of disability are largely absorbed by families and in particular, how women have played the major unpaid care-giving role with many staying out of the labour market for this purpose with the result that they lose access to pension benefits in their senior years. It is hoped this research, by shining the spotlight on the everyday lives of a few mothers of disabled children and by inference, many more, will support advocates’ demands for resources from government and community so that supporting a family member with a disability does not mean lessening the economic security of families and of women.

## Imprint of the Activist Mothers

This study tells the story of three remarkable women whose vision and tenacity helped push the Canadian government into the business of creating disability-related public policy, abolishing discriminatory legislation, downsizing large institutions, and revising human rights legislation to include disability as a prohibited ground of discrimination. That much can be taken for granted today by younger families; that is their legacy.

How they won this adds fresh evidence, through mothers' disability activism, to analysis that explores the contradictory role of the state as a site for women's politicization. Discriminatory social policies and practices, educational regulations, discretionary decision-making by government officials, professionals and practitioners, were but some of the catalysts for mothers' action for equity, participation and inclusion. As Abramovitz (1999; 2000) notes, the gendered division of labour, though designed to keep women at home, inadvertently fostered collective action bringing together Jo Dickey, Audrey Cole, and Paulette Berthiaume, and all the other mothers with whom they worked, on major campaigns to close institutions and secure human rights.

This study is not an attempt to "lionize" these three women – they would resist that strongly. The three mothers of this study were not the only activists in their generation but there are few remaining who have been at it as along as they have. They worked with many more individuals at all levels who, like them, had personal experiences that filled them with a sense of urgency. Jo Dickey, Audrey Cole, and

Paulette Berthiaume came from different backgrounds but they shaped the origins of the Association. Maybe they succeeded in overcoming the odds because they had different activist styles and strategies, different approaches to securing the goals. But they shared a set of beliefs as women, and as mothers, which ensured the cohesion of their campaigns.

These three women became icons for the Association, women who were widely admired, and whose passion and conviction came to symbolize a new field of social activity. The imprint left by this original group of mothers is very strong today. The campaigns they undertook continue to serve as models for community activism. This study offers evidence, through the campaigns, that it is community-based struggles around basic needs that draw women into activism and that the creation of alternate families and emotional support networks is essential if activist work is to be sustained. Those who experienced these struggles were changed in the process and it is hoped their experience will shed light on how the Association might nourish and cultivate its young activist mothers.

For the older mothers in this study, activism was rooted in mothering disabled children. But it is tempting to speculate that it was also based in married women's desire to extend themselves beyond a narrow, socially defined marital role. Ironically, even though they were driven to act out of concern for their children, it was as activists that they came to achieve a sense of fulfillment and recognition as individual

It is hoped that this study, by making women's experiences visible and rendering them important, will contribute to further scholarship on women's activism. It certainly will add to the "pile of historical studies of women's activism on the left –

and on the right - that continue to question the myth of women’s passivity” (Rowbotham, 1997, p.3). It is also hoped that the analysis will help provide a perspective on what may seem a personal experience of exclusion and oppression so it may be more deeply understood and recognized in its shared forms and thus guide younger women setting out on their own path to activism.

## Appendix I:  Proposal to Institutional Review Board

# ACCIDENTAL ACTIVISTS:
# MOTHERS, ORGANIZATION AND DISABILITY

A Proposal for Review:

Institutional Review Board

Hunter College School of Social Work

Submitted by:

Melanie Panitch

Doctoral Candidate

Hunter School of Social Work

The Graduate Center, CUNY

October 20, 2003

## 1. Purpose and Design of Research

This study will examine the changing role of women in the Canadian Association for Community Living (CACL) by exploring it origins, evolution and development. CACL is a national parent-led organization that advocates for children and adults with intellectual disabilities. Founded in 1958 as the Canadian Association for Retarded Children, it came into existence as part of an international trend which also inspired the Association for Retarded Children (ARC), its sister organization in the United States.

CACL is a grass-roots movement that was founded largely by mothers who began their careers as activists in the post-war period by resisting the only option open to them, to “put their child in an institution”. Over the years key activist mothers who built an organization that now has 40,000 members in 400 local chapters across Canada have led it. Parent-led disability organizations, such as CACL, are typically represented in the literature as “parent’s organizations”, however “parent” obscures the gendered nature of the role for it has been mothers who have been at the forefront. Right from the beginning it has been women whose advocacy for their children with disabilities brought them into a broader relationship with social policy and the state. As they recognized the importance of becoming advocates for their own families, they built an organization to place their issues on a more public scale. Yet the organization they founded has not been one that has necessarily recognized or profiled women’s contribution. There has been no research to date that has applied a gendered lens to parent-led disability organizations. This research will contribute to our knowledge of women’s struggles, adding to the growing scholarship on women’s activism, acknowledging its contribution to our history.

This study will attempt to illuminate and deepen our understanding of how ordinary homemakers have become activists though the experience of having a disabled child, how they overcame the obstacles associated with the denigration of mothers’ care-giving work in society and the stigma which attached to them as mothers of disabled children; how they developed leadership skills in the context of working as part of a community and how they came to recognize that individual efforts alone are not enough to effect systemic change.

Guiding questions will explore: Who were the founders, who filled the leadership positions, who did the leg work, who chaired committees, who has been represented, how this representation has been decided and who has influenced the national agenda. Which functions/roles did and do women play? What patterns emerged? Who were leaders over time? How many were women? When women were involved did it make a difference? What impact did women have on the femaleness of the organization and to what extent were they able to influence and shape its agenda historically?

The study will draw on two main sources of data: a) Interviews with three expert witnesses, and b) the organizational records/archival documents of the Canadian Association for Community Living.

The three key informants now over seventy years of age, became active as young mothers and will serve as information-rich "expert witnesses" representing other mothers in the organization. Geographically, the three women come from different provinces in Canada. One lives in Vancouver, the second informant lives in rural Ontario, the third is a Quebecois woman who lives in a suburb in Montreal; accordingly, they will bring different local and provincial struggles, perspectives and issues to the research. Although activists may be found at all levels, only those whose work has had an impact in the national organization will be the focus of this study. Through conducting semi-structured interviews I will have an opportunity to capture their story, a rich history that may otherwise soon be lost. I would hope they would share with me some personal items, such as correspondence, photographs and other memorabilia, but that will be a matter of their own choosing.

The second key source of data will be CACL organizational records: minutes of annual general meetings including key resolutions passed, minutes of executive and board meetings, newsletters and other communication devices, and historical documentation gathered both from the national organization as well as from the local and provincial affiliates with which these women were also involved. Records related to court cases and legal challenges, policy briefs, records of lobbying strategies and specially convened meetings, newspaper and other media coverage as well as public education initiatives will provide additional sources of data. The executive director of CACL, Michael Bach, is enthusiastic about this research and has given me access to the organizational records and archives.

It is anticipated, at this early stage in the research, that three of the key social issues taken up at the national level - deinstitutionalization, sterilization and inclusive education - and by the expert witnesses - will form the organizing framework of the dissertation. The key dates for focused study are: the evacuation of residents from Woodlands Institution (BC) (1976); the year the “Eve” Case on sterilization was heard by the Supreme Court of Canada, (1987) and the formation and activities of the Coalition for Inclusive Education, (1990). These specific years and five years on either side will provide parameters for more focused organizational/archival research uncover the debates before key action was taken (when strategies were articulated and repercussions anticipated) and the aftermath.

### 2. Selection and Recruitment of Subjects for Participants in Research

Each expert witness is purposively chosen; each is well known for her seniority with the organization, for her reputation as a recognized social change advocate and for her strong association with at least one of the three key social issues that has captured CACL’s attention over the past decades: the closure of institutions; sterilization and the question of informed consent; and the campaign for inclusive education. All three women have recently been awarded a “Lifetime Achievement Award”, CACL’s highest public honour, in recognition of their contribution and their photographs have appeared in various organizational publications. Each woman has represented the organization internationally. One informant has received the prestigious Provincial Award, the “Order of Ontario” in which she was cited for her “disability activism”. Each individual is a legally competent adult capable of giving informed consent. I will call them by telephone; describe the study, and the context of my doctoral work before I request individual interviews with them. (See Telephone Script: Appendix A). They are not vulnerable people and their participation will be truly voluntary.

### 3. Procedures to be Followed

When I approach each of the expert witnesses by telephone and inform them about the study, I will then explain the significance of their participation and request their participation. I have met these individuals in the course of my 30 years of work in the disability field so the call will not be a “cold” call. However I will assure them they are under no obligation to participate.

I will provide them with a summary of the study. (See One-page Summary: Appendix B). I will also ask whether and what kind of accommodation they might require in order to anticipate their needs and facilitate their participation. After the initial contact, each participant will be provided with a letter of consent describing the study, ensuring confidentiality, the right to withdraw from the study at any time, the right to refuse audio-taping, the opportunity to review transcripts from interviews, and an offer to provide a summary of findings for the complete study upon request. She will be asked to sign the letter of consent and will receive a copy, which she retains for her records. She will also be asked to sign a separate consent form indicating her willingness to have the interview tape-recorded and offering her an opportunity to review the tape with the option to ask that it not be used (in whole or in part); she will also receive a copy of this form for her files (See Consent Forms: Appendix C & Appendix D).

I will conduct an initial one 2-hour interview with informants separately, on their home ground. As I then move back and forth between archival records, professional literature and interviews I would expect that I will need to do two more 2-hour follow up interviews with each informant which may take place at their home or at another comfortable and mutually agreed upon location. It is likely that each informant may suggest I speak to other key individuals involved in the early development of the organization. There may be between ten and fifteen people so identified through a snowball sample and I would provide and request signed letters of consent for these interviews as well. (See Interview Guide: Appendix E).

### 4. Risks and Benefits

The subject matter of the interviews will focus on organizational issues rather than personal matters. However, in the unlikely event that emotional issues surface, the informant will be assured they can skip any question they choose or stop the interview entirely, without penalty. In the final research, I will not include findings of a highly personal nature. I will exclude data that may embarrass another participant or distress others in the organization.

The benefit to the respondent of participating in this research is very limited, and may amount to no more than a personal journey of reflection, illuminating the their organizational experience through past and present involvements. I will pay attention to the extent to which this is stimulating and pleasant for them to reflect upon, or uncomfortable, in which case I will change the question or stop the interview.

## 5. Confidentiality and Anonymity

In seeking each participant's cooperation they will be reassured that this inquiry is to enable the researcher to discover women's role in the CACL, not to expose or to discredit them as individuals and assurances of confidentiality will be provided. Participants will be told that their participation is voluntary and that they are free to refuse to answer any particular questions, withdraw their consent and stop participation at any time during the study without penalty of loss and without influencing future relations with the researcher or CACL.

The tapes will not contain the name of individuals, but codes. I will be the only researcher who has access to the raw data. Similarly, each transcript will be given a code in order to separate it from the name of respondents. All data, including tapes, transcripts, filed notes, disks and official documents will be securely stored in a locked filing cabinet in a locked office in the School of Disability Studies at Ryerson University, Toronto. After five years all the raw data will be destroyed. Unless respondents specifically request otherwise, pseudonyms will be used in written reports and particular care will be taken in translating research data to text. They will have the opportunity to review the transcripts of the interview and nothing will be said about them without their consent.

The subject matter is not sensitive. I will be speaking to individuals who are already publicly self-identified as leaders. In other words, I am not “outing “people who would prefer not to be. Rather, the orientation of the research is towards CACL as an organization and the knowledge these expert witnesses have of the changing role of women in this parent-led disability organization.

6. Not Applicable

7. Informed Consent

Once I have recruited the informants, and after they have agreed to be interviewed, I will set up an appointment to meet with them. I will set aside time at the beginning of the session to discuss the process and complete the informed consent procedure.

Appendix A: Telephone/Oral Script
Appendix B: One-page summary of study
Appendix C: Consent form for study
Appendix D: Consent form for tape recording interview
Appendix E: Interview Guide

# Appendix A: ORAL TELEPHONE SCRIPT

## Accidental Activists:

## Mothers, Organization and Disability

Hello……….(expert witness)

This is Melanie Panitch speaking. How are you? I am calling to talk about some research that I am doing. As you may or may not know, I am working on my Doctorate in the School of Social Work, at Hunter College in New York.

The topic of my dissertation is broadly, the changing role of women in the Canadian Association for Community Living, an organization that you know very well. CACL is often referred to as "parent's organizations" but I am curious about the role women and mothers have played throughout its nearly 50 years history and that's where I want to focus my research. We do know, for example, that in the early days, it was mothers who came together when they refused to put their child in an institution. So I want to learn more about the role women played in CACL as an organization and that's the reason for my call.

I am interested in talking to you about your experience and the role you played in the development of this national organization. I would like to interview you and I am calling to see if you would be willing to participate. This is completely voluntary; while I would value your perspective, you are under no pressure to agree.

I will be asking you about the moment when you first discovered your child would have a disability and to describe your own pathway into this organization. I am interested in whatever barriers you may have encountered but also what you found helpful along the way. I will be asking about “turning points” in your advocacy work, and lessons you derive from your experience. I will be asking you about what you did in the early days to start an organization and where you experienced support and opposition. I will also be asking you to reflect on how women’s involvement influenced the issues taken up by CACL. Finally, I will be asking you to consider the ways in which your experience may have generalized to others.

I estimate that the initial discussion will last about two hours and I would be willing to meet with you in your home. It’s possible we may need more time, or that I will have further questions after our initial session. If so, we can arrange to get together at a later date at a convenient place when you are in Toronto for CACL work.

With your consent, I would like to audio-tape the discussion. If you agree, let me assure you that you will receive a copy of the transcript and will have an opportunity to change or add your comments. When we meet, I will bring the consent forms. We can discuss the study then at greater length and you can ask any questions that you may have. Only once your questions have been answered to your satisfaction and you are comfortable with the arrangements and are willing to sign your consent to participate, will we begin.

Are there any questions that you have now?

I will meet with you on ………date at………time.

I very much look forward to sitting with you and hearing about your experience with CACL Here is my home phone number in case you want to reach me before then. It is: 416 –537-8418,

Thanks again, and Goodbye.

Appendix B: SUMMARY OF STUDY

## Accidental Activists:

## Mothers, Organization and Disability

This study will examine the changing role of women in the Canadian Association for Community Living (CACL) by exploring it origins, evolution and development. Parent-led disability organizations, such as CACL, are typically represented in the literature as “parent’s organizations”, however “parent” obscures the gendered nature of the role for it has been mothers who have been at the forefront. It was largely mothers, who began their careers as activists in the post-war period by resisting the only option open to them, to “put their child in an institution”, who founded CACL.

Over time many women came to speak for themselves, to confront authorities, to “tell their story”. Standing alone and separate, one from the other, faced with the power of medical and education authorities, these women might have remained marginalized and intimidated. But, through their commitment to their children, they found other mothers, and together they became challengers rather than passive subjects. Not only did they become experts in education, medicine, transportation, recreation, equipment, and so on, they became effective community organizers. Across the country they organized into parent groups and exerted their influence on the public policy process to increase and restructure benefits for their own and other families. Right from the beginning it has been women whose advocacy for their children with disabilities brought them into a broader relationship with social policy and the state. As they recognized the importance of becoming advocates for their own families, they built an organization to place their issues on a more public scale.

Yet the organization they founded has not been one that has necessarily recognized or profiled women's contribution. There has been no research to date that has applied a gendered lens to parent-led disability organizations.

This study will attempt to illuminate and deepen our understanding of how ordinary homemakers have become activists though the experience of having a disabled child, how they overcame the obstacles associated with the denigration of mothers' care-giving work in society and the stigma which attached to them as mothers of disabled children; how they developed leadership skills in the context of working as part of a community and how they came to recognize that individual efforts alone are not enough to effect systemic change.

> Guiding questions will explore: Which functions/roles did and do women play? What patterns emerged? Who were the founders, who filled the leadership positions, who did the leg work, who chaired committees, who has been represented, how this representation has been decided and who has influenced the national agenda. When women were involved did it make a difference? What impact did women have on the femaleness of the organization? Were they able to influence its agenda historically?

The study will draw on two main sources of data: Interviews with three key informants and the organizational records/archival documents of the CACL. There is virtually no scholarly work on the significant struggles for social justice waged by activist mothers of disabled children. This research will add another chapter to the growing scholarship on women’s activism, too long “hidden from history”.

## Appendix C: CONSENT AGREEMENT (expert witnesses)

### Accidental Activists:

### Mothers, Organization and Disability

You are being asked to participate in a research study. Before you give your consent to be a volunteer, it is important that you read the following information and ask as many questions as necessary to be sure you understand what you will be asked to do.

**Investigator:** The Investigator for this study is Melanie Panitch, a doctoral student in the School of Social Work, Hunter College, Graduate Centre, CUNY

The Purpose of the Study: This study will examine the changing role of women in the Canadian Association for Community Living (CACL) by exploring it origins, evolution and development. Parent-led disability organizations, such as CACL, are typically represented as “parent’s organizations”, however “parent” obscures the gendered nature of the role for it has been mothers who have been at the forefront. Largely mothers who organized to resist the only option open to them, to “put their child in an institution”, founded CACL. Yet the organization they founded has not been one that has necessarily recognized or profiled women’s contribution. There has been no research that has looked at the role of women in parent-led disability organizations.

Description of the Study: I am interested in talking to you about your experience and the role you played in the development of this national organization. I will be asking you about the moment when you first discovered your child would have a disability and to describe your own pathway into this organization. I am interested in whatever barriers you may have encountered but also what you found helpful along the way. I will be asking about "turning points" in your advocacy work, and lessons you derive from your experience. I will ask you, based on your knowledge of other mothers with disabled children/adults, how much and in what ways your experience generalizes to others. I will be looking to you to for your perspective on the changing role of women in CACL.

I estimate that the discussion will last about two hours. It will be held either in your home or a convenient and comfortable place when you are in Toronto for CACL work.

I would like to audio- tape the discussion, with your consent. You will receive a copy of the transcript and will have an opportunity to change or add to your comments.

Experiments: None of the procedures that are being used in this study are experimental in nature.

Risk or Discomforts: You may be uncomfortable about going "on record" to relate your experience with other parents associations, professionals, government or the organization. The tapes will not contain the name of individuals, but codes. I will be the only researcher who has access to the raw data. This inquiry is to enable the researcher to discover women's changing role in the CACL, not to expose or to discredit you as an individual. You will have a chance to review the transcript, make corrections, additions as well as indicate what you would like to keep private.

Benefits of the Study: Knowledge gleaned from yours, and other mothers' experience could strengthen the organizational capacity of the CACL by offering concrete suggestions related to its policies and practices. More broadly, the lessons that emerge about organizing for change from the perspective of women, long "hidden from history", can contribute to building progressive movements in more inclusive ways.

Confidentiality: I, as the sole researcher will be the only one to have access to the study.

Each transcript will be given a code in order to separate it from the names of participants. Audiotapes, transcripts, field notes, disks and official documents will all be securely stored in a locked cabinet in a locked office in the School of Disability Studies, Ryerson University. After five years all raw data will be destroyed. In translating research data to text particular care will be taken that strongly identifying personal or contextual details are altered/disguised. Nothing will be said about you without your consent. However in the unlikely event that I become concerned about your safety or the safety of others, I am required to notify the proper authorities.

Voluntary Nature of Participation: Participation in this study is voluntary. Your choice of whether or not to participate will not affect your future relations with CACL or the researcher. If you decide to participate, you are free to withdraw your consent and to stop your participation at any time without penalty. At any point in the study you may refuse to answer any particular question or stop participation altogether. You will have an opportunity to review transcripts from the interview, and will receive a copy of the study results on request.

Questions: Please ask if you have any questions about the research. You may contact the study's principal investigator,

Melanie Panitch at

| | |
|---|---|
| Phone: | 416- 979 5000 x 6128 |
| Fax: | 416- 979-5209 |
| E-mail: | mpanitch@ryerson.ca |

If you have any questions about your rights as a human subject and participant in this study, you may contact the Graduate Centre CUNY Office of Research and Sponsored Programs and/or Ryerson University Ethics Review Board for information.

Office of Research and Sponsored Programs

Graduate School and University Centre

The City University of New York

365 Fifth Avenue New York NY

Phone: 212 817 7523 or 7525

OR

Research Ethics Board

C/0 Office of Research Services

Ryerson University

350 Victoria Street

Toronto, Ontario M5B 2K3

(416) 979-5000 ext 6332

Agreement**:** Your signature below indicates you have read the information in this agreement and have had a chance to ask any questions you have about the study and that all of your questions have been answered to your satisfaction. Your signature also indicates that you agree to be in the study and have been told you can change your mind and withdraw your consent to participate at any time. You have been given a copy of this agreement.

You have been told that by signing this consent agreement you are not giving up any of your legal rights.

Name of Participant ___________________________

Signature of Participant ___________________________ Date________________

**Signature of Investigator**______________________ Date_______________

# Appendix D: CONSENT FOR AUDIO-TAPING THE INTERVIEW

## Accidental Activists:

## Mothers, Organization and Disability

You are being asked to participate in a research study. Before you give your consent to be a volunteer, it is important that you read the following information and ask as many questions as necessary to be sure you understand what you will be asked to do. The purpose of this agreement is for you to indicate your consent that the interview you have agreed to give can be audio-taped and transcribed,

Investigator: The Investigator for this study is Melanie Panitch, a doctoral student in the School of Social Work, Hunter College, Graduate Centre, CUNY

The Purpose of the Study: This study will examine the changing role of women in the Canadian Association for Community Living (CACL) by exploring it origins, evolution and development. Parent-led disability organizations, such as CACL, are typically represented as “parent’s organizations”, however “parent” obscures the gendered nature of the role for it has been mothers who have been at the forefront. It was largely mothers who organized to resist the only option open to them, to “put their child in an institution”, who founded CACL. Yet the organization they founded has not been one that has necessarily recognized or profiled women’s contribution.

There has been no research to date that has looked at the role of women in parent-led disability organizations.

Description of the Study: I am interested in talking to you about your experience and the role you played in the development of this national organization. I will be asking you about the moment when you first discovered your child would have a disability and to describe your own pathway into this organization. I am interested in whatever barriers you may have encountered but also what you found helpful along the way. I will be asking about “turning points” in your advocacy work, and lessons you derive from your experience. I will ask you, based on your knowledge of other mothers with disabled children/adults, how much and in what ways your experience generalizes to others. I will be looking to you to for your perspective on the changing role of women in CACL.

I estimate that the discussion will last about two hours. It will be held either in your home or a convenient and comfortable place when you are in Toronto for CACL work.

I would like to audio- tape the discussion, with your consent. You will receive a copy of the transcript and will have an opportunity to change or add to your comments.

Experiments: None of the procedures that are being used in this study are experimental in nature.

Risk or Discomforts**:** You may be uncomfortable about going "on record" to relate your experience with other parents associations, professionals, government or the organization. The tapes will not contain the name of individuals, but codes. I will be the only researcher who has access to the raw data. This inquiry is to enable the researcher to discover women's changing role in the CACL, not to expose or to discredit you as an individual. You will have a chance to review the transcript, make corrections, additions as well as indicate what you would like to keep private.

Benefits of the Study: Knowledge gleaned from yours, and other mothers' experience could strengthen the organizational capacity of the CACL by offering concrete suggestions related to its policies and practices. More broadly, the lessons that emerge about organizing for change from the perspective of women, long "hidden from history", can contribute to building progressive movements in more inclusive ways.

Confidentiality: I, as the sole researcher will be the only one to have access to the study.

Each transcript will be given a code in order to separate it from the names of participants. Audiotapes, transcripts, field notes, disks and official documents will all be securely stored in a locked cabinet in a locked office in the School of Disability Studies, Ryerson University. After five years all raw data will be destroyed. In translating research data to text particular care will be taken that strongly identifying personal or contextual details are altered/disguised. Nothing will be said about you without your consent.

Voluntary Nature of Participation: Participation in this study is voluntary. Your choice of whether or not to participate will not affect your future relations with CACL or the researcher. If you decide to participate, you are free to withdraw your consent and to stop your participation at any time without penalty. At any point in the study you may refuse to answer any particular question or stop participation altogether. You will have an opportunity to review transcripts from the interview, and will receive a copy of the study results on request

Questions: Please ask if you have any questions about the research. You may contact the study's principal investigator,

Melanie Panitch at

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Agreement: Your signature below indicates you have read the information in this agreement and have had a chance to ask any questions you have about the study. Your signature also indicates that you agree to be in the study and have been told you can change your mind and withdraw your consent to participate at any time. Your signature indicates that you agree that the interviews can be audio-taped . You have been given a copy of this agreement.

You have been told that by signing this consent agreement you are not giving up any of your legal rights.

Name of Participant ___________________________

Signature of Participant ___________________________ Date________________

Signature of Investigator______________________

# Appendix E: INTERVIEW GUIDE (expert witnesses)

## Accidental Activists:

Mothers, Organization and Disability

1. Can you start at the beginning and tell me what happened, how you learned your child would have a disability?

**Probes**

What year was it? How were you told?  Where did this take place?

What was happening in the world around you?

How significant was this news to you?

What previous experience did you have with individuals considered to be "different"?

Were there any incidents that stood out for you?

2. Then what happened?

**Probes**

How did your immediate family react to the news? (husband, other children, your own and his own parents?

What did the next few years look like

What was happening in the world around you?

What held was available for up? Professionals? Programs, services, parent groups

What were some of the policies, rules, laws that you encountered?

4. How important were other parents in helping you learn what you needed to know along this pathway?

Probes

Were there any people who were an inspiration to you? Important lessons?

How were they helpful?

Where were they located? (family, partners, community organizations, disability activist and other activist groups, other)

Where were the places that you would get together?

5. What did you do in the early days to start an organization?

Probes

What were some of the obstacles you faced?

Where were the spaces you planned and carried out your activities/ your work?

Where did your support come from? Opposition come from?

What were some of the rules, laws and policies that you bumped up against?

What were some of the rules, laws and policies that worked for you?

6. What roles did women play in the organization?

**Probes**

What attitudes to women’s involvement did you experience?

What were the decision-making processes?

Did women’s involvement affect the agenda of the organization?

What were the major issues?

Did women work in different ways than men? How? Was there support from CACL?

What risks did women take in playing an active role?

7. Leadership – who provided it?

**Probes**

How did leadership get decided?

Did the involvement of women make any difference – on the femaleness of the organization?

Did women shape CACL’s agenda historically?

8. What advice would you have for other activist-mothers parents following in your footsteps?

Probe

How do you see the situation now? Are these good times or bad?

This has been extremely interesting and helpful. Just before we conclude I would like to ask you if there is any other information you would like to add that we haven't covered, to help me understand the role you played? Are there any questions that you have before we conclude?

Thank you.

## Appendix II: Resolutions

### 1. A Resolution Urging Governments to Establish Small, Home-like Community Based Residences for the Mentally Retarded of All Ages (Minutes, 1973, Binder 16)

> WHEREAS the subject of residential services for the mentally retarded is now receiving wide national attention; and
>
> WHEREAS it is now recognized as a normal and desirable right of handicapped persons, including the mentally retarded to live their lives as normally as possible surrounded by the everyday community and integrated with that community life; and
>
> WHEREAS leading professional and public opinion in the field of mental retardation holds that existing residential institutions are frequently inadequate, inhuman, isolated, substandard, misdirected and invariably segregated; and
>
> WHEREAS we as the CAMR have adopted the normalization as a principle for the 70's; and
>
> WHEREAS it is the function of the respective provincial governments to decide on replacing present residential institutions and to implement these decisions; and

WHEREAS such decisions should not be made without giving full consideration to the recommendations of those persons who can best speak for the mentally retarded.

NOW THEREFORE BE IT RESOLVED THAT THE CANADIAN ASSOCIATION FOR THE MENTALLY RETARDED

1. Recognizes that, in the public interest, additional residential facilities are needed for the mentally retarded of all ages.
2. Recommends that such residential facilities be community based and be integrated into the main stream of community life.
3. Recommends that such residential facilities be in the form of small home-like living units and that they be scattered throughout the community rather than forming a single complex.
4. Recommends that buying or leasing such facilities be considered before constructing new homes.
5. Recommends that unrealistic building and fire regulations, which might otherwise preclude such residential arrangements, be reviewed ad revised by the appropriate governmental authorities.
6. Recommends that such residential facilities be developed in place of any further capital expenditure on new or existing large institutions.

2. Resolution on Association Renewal (Minutes, 1978, Binder 21)

WHEREAS the needs of parents and people who are mentally handicapped are not presently being adequately met by this movement; and

WHEREAS there is a need for persons and people who are mentally handicapped to be more involved in this movement; and

WHEREAS there is a recognition of the need for a united force in one movement to meet these needs;

THEREFORE BE IT RESOLVED THAT the Annual General Meeting approve a nation –wide effort to encourage the development of programs such as Citizen Advocacy, Parent Support, "People First", developments and monitoring committees for people in all facilities; and commits the support of CAMR's resources to this effort; and urges a similar commitment from Local and Provincial Associations for the Mentally Retarded to set specific objectives to achieve these goals.

3. Resolution Calling for a Moratorium on New Admissions (Minutes, 1979, Binder 22)

WHEREAS:

1. The CAMR holds as a basic principle that all citizens are entitled to full human rights and specifically that all Canadians who are mentally retarded are entitled to human rights.

2. These rights should include but not be limited to:

a) the right to due legal process in the curtailment of any rights

b) the right to live in the least restrictive environment

c) the right to self-determination coupled with advocacy (where appropriate)

d) the right to appropriate individualized developmental programming

e) the right to regular review of their status and living circumstances

3. The CAMR holds that institutions, through organizational imperatives are dehumanizing, restrictive, and damaging to the individuals who reside in them;

THEREFORE BE IT RESOLVED THAT:

The CAMR work with each Provincial AMR to ensure that:

1. Plans be developed to achieve a moratorium on admissions to institutions for people with mental retardation throughout Canada.

2. Parents, institutional staff, governments, industry, handicapped persons, and trade unionists be cooperatively involved in a process of monitoring and change within institutions to ensure that full human rights are granted to all

residents of institutions; that individual program plans be developed and implemented for all residents; and that physical amenities be improved, and

3. An appropriate process be developed for use across Canada to achieve the implementation of a comprehensive plan for community living for all Canadians who are mentally retarded.

4. Resolution on Transition Funds to Stimulate Deinstitutionalization (Minutes, 1981, Binder 24).

WHEREAS it is inappropriate for mentally handicapped people to live in institutions (i.e. any residence larger than a family home) and

WHEREAS community supports and services must be in place before currently institutionalized people can be moved back into the community, and

WHEREAS the high costs of maintaining institutional services are seriously limiting the dedication of sufficient funds to develop adequate community services; and

WHEREAS Provincial Governments need support to effectively establish community based services; and

WHEREAS existing institutions require continuing support until they can be phased out; and

WHEREAS tremendous savings can accrue to Federal and Provincial governments if the necessity of maintaining both institutional and community services can be rapidly altered; and

WHEREAS THE LEADERSHIP OF THE Federal government and its supply of such transition funds to provincial governments could considerably accelerate the return of people to the community.

THEREFORE BE IT RESOLVED THAT:

The Federal government make necessary funds available to Provincial governments to support accelerated efforts to move from segregated institutional services to integrated community-based services. To encourage the rapid return of people who live with a mental handicap to the community and thereby establish a more efficient and effective service system, such funds should be available for five to seven years only to give time for the funds to flow from the institutions to the community. The level of support available from the Federal Government should be gradually reduced over that period.

5. Resolution on Rivière-des-Prairies (Minutes, 1985, Binder 28).

> WHEREAS 600 people are now living at Rivière-des-Prairies Hospital, some for more than 20 years; and
>
> WHEREAS their most fundamental rights are violated; and
>
> WHEREAS the living conditions in that establishment are unacceptable;
>
> THEREFORE, BE IT RESOLVED THAT the AGM of the Canadian Association demand that the Government of Quebec put the hospital under trusteeship immediately, and
>
> BE IT FURTHER RESOLVED THAT the AGM ask the provincial associations and the 430 local associations throughout this country to send a telegram or communiqué to the Minister of Social Affairs demanding that the hospital be put under trusteeship.

6. Resolution on Problems with Deinstitutionalization (Minutes,1989, Binder 32).

WHEREAS People First of Ontario believes that real deinstitutionalization has not happened yet. So far, deinstitutionalization has meant that people move to mini-institutions in the community called group homes.

WHEREAS many people First members find that moving from the institution to the community means that they are still not given the right to lead a life of equality because many of the practices that are used in institutions are also used in the community. Deinstitutionalization so far has meant:

- few friends
- few choices
- lack of privacy
- poverty
- being moved from place to place
- separation from relationships that were made in the institution
- other negative practices that stop us from leading a life of equality and being a part of our community

THEREFORE be it resolved that the Canadian Association Board look into the problem of deinstitutionalization and take action, so that deinstitutionalization is no longer done this way, and that people living in institutions and group homes can be involved in the process in a meaningful way.

7. Resolution to Amend Bill-C-72, the Canadian Human Rights Act to include disability as a prohibited ground of discrimination (Minutes, 1976, Binder 19).

> WHEREAS Bill-C-72, An Act to extend the present laws in Canada that proscribe discrimination and which protect the privacy of individuals, includes in its purpose the following:
>
> a) THAT every individual should have an equal opportunity with other individuals to make for himself or herself the life that he or she is able and wishes to have, consistent with his or her duties and obligations as a member of society, without being hindered in or prevented from doing so by discriminatory practices based upon race, national or ethnic origin, colour, religion, age, sex or marital status, or conviction for an offense for which pardon has been granted; and
>
> b) THAT the privacy of individuals should be protected to the greatest extent consistent with public order and well-being; and
>
> WHEREAS Bill-C-72 does not include reference to discriminatory practice against mentally or physically disabled persons; and
>
> WHEREAS Mentally or physically disabled persons can be of any race, national or ethnic origin, colour, religion, sex or marital status, and yet be subject to all the discriminatory practices named in Bill-C-72 and this

discriminated against solely on the grounds of disability, their ability notwithstanding and despite the statement of the U.N. Declaration on the Rights Mentally Retarded Persons that such a "person has, to the maximum degree of feasibility, the same rights as other human beings";

THEREFORE BE IT RESOLVED THAT:

The Canadian Association for the Mentally Retarded make immediate representation to the Minister of Justice for Canada to ensure that Bill-C-72 be appropriately amended to include MENTAL OR PHYSICAL DISABILITY as a "prohibited ground of discrimination", and that sections of the Act and/or of other Acts affected by the inclusion be amended accordingly.

8. Resolution (1978) to Amend the Canadian Human Rights Act Minutes 1978, Binder 21)

WHEREAS the UN Declaration on the Rights of Mentally Retarded Persons states that “the Mentally Retarded Person has, to the maximum degree of feasibility, the same rights as other human beings”, and

WHEREAS it is the norm in our society to proscribe by legislation those grounds upon which it is illegal to discriminate; and

WHEREAS the Canadian Human Rights Act does not proscribe mental disability as a prohibited ground of discrimination; and

WHEREAS the Canadian Human Rights Commission is consequently powerless to hear or intervene in cases of people who are or may have been discriminated against on the grounds of mental retardation (disability, handicap); and

WHEREAS the Canadian Association for the Mentally retarded has been assured by the Government of Canada that extension of the existing prohibited grounds of discrimination is possible under the provisions of the Act, itself;

THEREFORE BE IT RESOLVED THAT CAMR make representations to the Minister of Justice for Canada to amend the Canadian Human Rights Act to include mental retardation (disability, handicap) as a prohibited ground of discrimination.

9. Resolution on Canadian Constitutional Reform (Minutes 1980, Binder 24).

WHEREAS THE Canadian Association has historically been concerned with the human rights of all Canadian citizens who are mentally retarded; and

WHEREAS Canadians now look forward to a new constitution;

BE IT RESOLVED:

1. That the Canadian Association advise the Government of Canada and each provincial Government that it favours the entrenchment of basic human rights in the new Canadian constitution; and
2. That the Canadian Association and its members stand ready to assist, as may be required in the definition of such rights.

10. Resolution on Depo Provera (Minutes 1981, Binder 24).

WHEREAS the report on the “Utilization of Depo Provera in the Ontario Government Facilities for the Mentally Retarded” has been released; and WHEREAS, the report raises many concerns about the use of Depo Provera;

THEREFORE BE IT RESOLVED THAT

Since no citizens who is mentally retarded should be subjected to the potential hazards of this drug, the Canadian Association in convention supports the Ontario Association demand that a moratorium on the use of Depo Provera for the control of menses and/or contraception be instituted immediately.

AND FURTHER THAT

The Canadian Association petition the Health Protection Branch, National Health and Welfare to extend this moratorium to all Canadian jurisdictions.

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# Autobiographical Statement

Melanie Panitch has been a “founder” of the School of Disability Studies at Ryerson University, first as Coordinator to develop the new program proposal and since 1999 as Director of the School. She was instrumental in attracting a lead campaign gift from the Royal Bank of Canada to establish the Institute for Disability Studies Research and Education, which she Co-Directs. For thirty years she has been an activist, advocate, researcher and educator, and has strong roots in the community living movement. She has designed and taught courses on human rights and disability at the Universities of Guyana and the West Indies. She has lectured at international conferences in Guatemala, Mexico, Ecuador and Uruguay. Throughout the nineties she was Coordinator of Social Development and Public Education at The Roeher Institute, Canada’s national social policy institute on disability. She was also part of a research team examining disability-related policies in Canada. Her work focused on child care, literacy, violence and abuse, and care-giving from which she published numerous articles, chapters, reports and books. In 2004 she won the Nina Fortin Award from the CUNY Graduate Centre for her dissertation proposal on Accidental Activists.