

## DAY PROGRAMS FOR OLDER ADULTS: CONTESTED MEANINGS

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By

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## **ABSTRACT**

Adult day programs are one of a number of community support services provided in Ontario for older adults who are living in the community. The purpose of this research is to compare the official policy accounts of adult day programs with the accounts of those who experience them directly.

Using the approach of institutional ethnography developed by Dorothy Smith (1987), the text embodied by the service definition used by Ontario providers of adult day care is compared with data gathered through in-depth interviews with clients, caregivers, a staff member, a volunteer, and a referring agent. This research seeks to deepen understandings of the function and value of these programs within the long-term care sector. Individuals' experiences with day programs (their stories), and their understandings of when day programs are needed by individuals, of how they are structured, and of what relationships are important in this context are explored.

The policy discourse about the function of day programs – supervised activities, caregiver support and respite, improved functioning, and avoidance of premature or inappropriate institutionalization – was found to be endorsed by participants. However, it emerged that “relational practices” in the delivery of the service did much more, by enhancing participants' identities and giving meaning to the day program experience.

Adult day programs have been relatively little studied and are not well understood within our health care system. In the current context of service restructuring and the longstanding invisibility of social care, such programs are increasingly jeopardized. The importance of the research lies in bringing forward the voices of those who are most involved with this programming. A potential benefit is that this important service may be given more attention within the system. It is hoped that these results will be useful to both program providers and policy makers working in this area of long term care.



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## **CONTENTS**

Abstract .....	iii
Acknowledgements .....	iv
Introduction .....	1
The Contexts of Service Delivery	
Canadian Political, Social and Economic Contexts .....	3
Managerialism and New Public Management .....	5
The Social Position of Older Adults – Essentialism, Embodiment and Social Exclusion .....	7
The Gendered Nature of Care Work .....	9
Review of the Literature .....	11
Methodology	
Epistemology .....	13
Methods .....	14
Ethical considerations .....	15
Analysis .....	16
Findings	
Voices .....	18
The Dominant Discourse .....	20
Another Discourse – A Discourse of Relationships .....	24
Discussion	
The Text-in-Action .....	30
Relational Practices .....	32
Looking Forward .....	33
References .....	35
Appendices	
Appendix 1: Letter of Information .....	41
Appendix 2: Interview Guide for Clients and Caregivers .....	42
Appendix 3: Interview Guide for Service Providers and Referring Agents ...	43

## INTRODUCTION

My journey toward this thesis began with over fifteen years spent in a mid-sized Ontario community developing, implementing, and supervising community support programs designed to help older adults remain independent and in their own homes. Among these were escorted transportation, meal programs, and adult day programs. This experience was followed by undergraduate coursework in social work which began a process of “looking underneath” what I knew from experience. It afforded me opportunities to examine issues related to long term care, including the evolution of home care services in Ontario, recent policy changes affecting service delivery, and competing understandings of support for caregivers. “Home care”<sup>1</sup> services are generally understood as care services provided by the state to individuals who are living in the community, but who may require support as they begin to move along an invisible continuum from independence to increasing dependence in some aspects of their lives. These include services such as the ones my agency offered, as well as the better-known homemaking and personal support services. Adult day programs, for me, are among the most interesting of these services.

Although adult day programs exist for a variety of groups, the focus of this research is on programs specifically for older adults living in the community. The policy discourse tells us that these programs are designed to stimulate and improve functioning for those who participate in them, while simultaneously relieving stress on their caregivers (understood to be close family members) and significantly reducing health care costs for the general population. In Ontario, the legislation that governs adult day programs provided for older adults is the *Long-Term Care Act, 1994*. Adult day programs are described in the legislation as “community support services” and defined as “a program of structured and supervised activities in a group setting for adults with care or support requirements” ([www.e-laws.gov.on.ca](http://www.e-laws.gov.on.ca)).

Most, if not all programs offered in Ontario are at least partially funded by the Ministry of Health and Long Term Care. In entering into service agreements with agencies who are “service providers”, the Ministry broadly outlines the parameters of service using “service definitions”. In funding these programs, the Ministry distinguishes different categories according to the population served. The Ontario Community Support Association (OCSA) draws on the service definition to define “Adult Day Services” as follows:

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<sup>1</sup> Home care is an area dominated by women. In fact, a brochure advertising a recent conference on *Women and Home Care* noted that “Women provide more than 80 % of paid home care and unpaid personal care for the elderly and for those of all ages with long-term disability or short-term illness. Women make up the majority of clients. Almost every aspect of home care is ‘a women’s issue’” (Ontario Community Support Association, 2005).

A community support service which provides supervised activities for adults to assist in achieving and maintaining their maximum level of functioning, to prevent premature and inappropriate institutionalization and to provide respite and support for caregivers. Service components may include transportation, meals, supervision, social and recreational activities, personal care, counselling and minor health care. This service is for frail older adults and adults with acquired brain injury and Alzheimer's Disease ([www.ocsa.on.ca](http://www.ocsa.on.ca)).

The puzzle examined here is whether there are other ways in which these services and their contributions can be understood. I experienced the day program offered at my agency as engaging. Clients, volunteers and staff alike appeared to value the time spent together in a way that seemed to go beyond the definition above. It led me to question how participants' perceptions of their experiences compare with the dominant discourse.

Neysmith highlights that "persons...who live the experience of belonging to particular groups in our society are experts in what they experience" (Neysmith, 1995: 108). From this, she argues, we can recognize that each of us experience events from within our social location, and that it shapes the way we are able to understand and describe our experiences; an understanding of the framework within which individuals express themselves can help to reveal aspects that are normally hidden. The importance of this research lies in the fact that the voices of those who are involved with this programming have not been heard, and that an understanding of the context for adult day programs will be helpful in hearing these voices. It is hoped that the research results presented here will be of use to both program providers and policy makers working in this important and little studied area of long term care.

Before addressing the technical aspects of this research, it is useful to consider the larger context of the sector in which the delivery of adult day programs for older adults takes place. Shifts in Canadian political, social and economic contexts are shaping current social welfare policy. In Ontario, economic restructuring, a "local" effect of globalization, is contributing to the changing character of the state and of the delivery of services. In addition, the position of older adults in society and the gendered nature of care impact how care is constructed by those most involved.

## **THE CONTEXT OF SERVICE DELIVERY**

### **Canadian Political, Social and Economic Contexts**

We are currently experiencing “the most fundamental redesign of the planet’s social, economic, and political arrangements since the Industrial Revolution...a power shift of stunning proportions, moving real economic and political power away from nations, states, and local governments and communities toward unprecedented centralization of power for global corporations, bankers, and the global bureaucracy they helped create” (International Forum on Globalization, 2002: 18-19).

The social welfare responsibilities of nations are deeply affected by this shift, and in Canada, health care is one of the most affected areas. “In this new global era states play a lesser role than they have previously. The workings and logic of nations have been thrown open to the enhanced power of transnational corporations. What had previously seemed solid and inevitable now appears fragile and contingent. Nowhere is this more true than in regard to health-care systems” (Armstrong, et al, 2001: 1).

The privatizing of the Canadian health system began with the federal decision in 1995 to implement Canada Health and Social Transfer (CHST), reducing funding to the provinces while increasing their autonomy; this was followed by the reduction of universal services by the provinces through the technique of de-listing (Silver, 1996). Williams et al term this “the profitization of health care”, noting that “in Ontario, much care has been ‘restructured’ out of hospitals onto the much more complex and less visible terrain of the community, where it is not subject to the rules of Medicare” (Williams, et al, 1999: 23).

Thus, services are no longer guaranteed; individuals are only assured of being *assessed* for service, which may or may not actually be provided (Ibid.: 19).

This process was accompanied by constantly shifting long term care policy: “between 1985 and 1996 in Ontario...three successive governments proposed five different reform initiatives” (Baranek, et al, 2004: 258), and this process has continued at a rapid pace (Williams, et al, 1999). “The logic of competitive market forces ...[has been] established as a means of gaining efficiencies” in long-term care (Baranek, et al, 2004: 269) while capped budgets and restricted service eligibility criteria limit the state’s involvement (Ibid.).

For the provincial government departments involved (and the service providers affected by them) these policy shifts parallel the “corporate permanent reconstruction” identified by Katz (2000: 9) as one of several strategies that supports and maintains the globalization of the world economy as “a new capitalist system” emerges. This “endless

shakeup of corporate and workplace structure” (Ibid.) inevitably affects workers and service users throughout the system.

In researching the “reform” of community based services in Ontario, Williams et al (1999) found that informants were explicitly concerned about the prospect of “corporatization” and “Americanization” of care. They suggest that

...the rules and principles that govern community based long-term care are fundamentally different from those governing the mainstream of insured hospital and doctor services...thus the shift from hospitals to community changes more than just the locus of care in Ontario: it profoundly changes the rules under which similar services are provided to many of the same consumers. [Thus] “...Ontario’s reform ensures that macro-level expenditure can be contained without the political confrontation with organized medicine, the federal government and public which any straightforward assault on the Canada Health Act would inevitably precipitate” (Williams, et al, 1999: 146-147).

The realization of these fears is not difficult to visualize in the area of adult day programs. In the American context, adult day care has been identified as a new ‘product’ within managed care, funded by Medicare and Medicaid (Shriver, 1995) – one more commodity. In fact, the growth in adult day care facilities has led to the introduction of specialized insurance to address the risks particular to this “market” (Gilbert, 1996). For many U.S. nursing homes, adult day programs are both “an additional income stream” and “a very powerful marketing tool” (Kretchmann, 1994: 26). Further, long-term care appears to be particularly susceptible to privatization, as Dominelli and Hoogvelt note that in the U.K., “private provisions have been promoted primarily in the area of adult services, particularly elder care (Dominelli and Hoogvelt, 1996: 54).

Once established, this shift is difficult to reverse. As Armstrong, et al, note,

Once private (and most likely American) health-care corporations have their foot in the door, the North American Free Trade Agreement contains provisions that would hinder any attempt thereafter to “discriminate” against them or to favour public delivery. NAFTA and the World Trade Organization (WTO) are biased against the public provision of goods and services (2001: 2).

A prominent example is the recent review by the Ontario government of the delivery of home care services, which took the competitive structure established by the Conservative government as a given and focused only on reviewing service delivery within that structure (Caplan, 2005).

In addressing the growing marketization of community care, Aronson and Neysmith (2001) point out that “If public services are not distributed on the basis of need to people entitled to support but, rather, to consumers then citizenship is denied”

(Aronson and Neysmith, 2001: 163). Citing Murphy (2000), Gingrich (2003) suggests that as the rights of citizens are commodified, they become available for purchase or exchange; she suggests that “for those unable to trade money for citizenship entitlement, social programs will accept one’s identity, as diagnosis and assessed risk are currency in these systems” (14); and that this is exclusion as abandonment and indifference in action. Thus, one can be admitted to adult day programs on the basis of the “currency” of an assessment or diagnosis of frailty, brain injury, or dementia – or denied admission as criteria narrow and entitlements become limited.

### **Managerialism and New Public Management**

The non-profit, voluntary organizations that deliver adult day care are largely dependent on the unreliable financial support of the provincial government. As their funding has become more insecure, these organizations are experiencing in microcosm what the state itself has experienced. As Cohen, citing Hutton, 1994, notes, “reducing income security is...the epicentre of the marketisation process” (Cohen, 1997: 40).

This reality threatens the delivery of care, as organizations which may have survived government cutbacks, are now in an environment where

...the relationship ...between government and voluntary sector organizations has changed...this new relationship is reflective of a philosophy that introduced values associated with the private marketplace – competition, diversification, entrepreneurialism, innovation...[and]...focus on the bottom line” (Ross, 2003: 8).

This has created serious challenges to organizations' ability to fulfil their missions (Ibid.).

The resultant need for constant fundraising has deeper implications. Paid staff are increasingly subjected to pressure to participate in ongoing fundraising in order to make service delivery possible, contributing to overwork and burnout (Baines, 2004a). At the same time, there are serious consequences for service users, in the construction of the services they require as contingent rather than available by virtue of citizenship. As fundraising becomes more critical, the vulnerability of service users becomes a useful marketing tool, and they are constructed as objects of charity rather than citizens utilizing entitlements. This cannot fail to have an impact on workers' perceptions of service users, and indeed on service users' perceptions of themselves.

Tsui and Cheung (2004), citing Zifcak, 1994, suggest that in addition to its impact on public policy making and business administration practice, managerialism has become a dominant ideology in human service management. They summarize its impact in eight areas: the perception of the client as customer; the manager as key; management knowledge as the dominant model of knowledge; the market as the environment; efficiency, not effectiveness as the yardstick; cost and contracts, not care and concern as



the foundation of relationships; the equation of quality with standardization; and documentation. They argue that despite the dominance of this ideology, the usefulness of these principles is limited because “human service organizations are based on values and principles that are fundamentally different than those of the market” (Tsui and Cheung, 2004: 441). Still, three of these managerial principles are evident in the current delivery of adult day programs: the market as the environment; efficiency as the yardstick, and the equation of quality with standardization and documentation.

Where the market is the environment, not society, Tsui and Cheung suggest that the important elements are supply, demand and price, rather than support, dignity and peace (Ibid.). The shift in logics toward managing supply and demand for day programs in Ontario is signaled by the “transition” planned in 1999 involving “changes in access, funding and eligibility criteria” (Markle-Reid, et al, 1998: 1). Where providers had previously accepted referrals directly from potential service users or their families, this “transition” made day programs subject to the referral process of Community Care Access Centres, which assumed responsibility for managing waiting lists. The management of supply and demand of program spaces now takes priority over the urgency of offering support and enhancing dignity for service users.

In considering the dominance of efficiency over effectiveness, Tsui and Cheung describe efficiency as the ratio of output to input (2004: 439). Administrators of adult day programs are responsible to their provincial funders for controlling “unit costs”, the ratio of overall costs to “units of service”, in this case, the attendance of one service user at the program for a specified number of hours. Interactions which might be indicative of effectiveness or of the quality of the day care experience, such as “nurturance” (describing the staff’s efforts to care for clients) or “dignity” (balancing the amount of assistance offered to clients with respect for their autonomy) (Berry, 2004: 654) are not considered.

New Public Management is essentially “market orientation to economic efficiency in the public sector” (Box, et al, 2001: 613). The quantitative target setting associated with New Public Management (Baines, 2004b: 279) means that administrators are held accountable for units of service delivered in relation to budgets to the level of plus or minus five percent, despite the fact that attendance for this population is often beyond anyone’s control. Neither the effort and skill that has gone into planning and preparing programming that is not used, or the quality and value of the programming that it used – work that “eludes quantification” (Ibid.: 9) - is taken into account in evaluation. A unit of service delivered is the closest approximation possible to “economic efficiency”.

While managerialism places an emphasis on quality, Tsui and Cheung suggest, the standards used to define it are difficult to apply to human services and documentation is substituted, leading to time taken from direct service for paperwork (Tsui and Cheung, 2004). A long time administrator of an Ottawa day program compares receiving referral



forms of over thirty pages, and service users having “lots of forms to sign – permissions and so on” to earlier times when “there was hardly any documentation” but “there was a sweetness, an intimacy...you were one of the people” (Personal communication, 2006).

### **The Social Position of Older Adults – Essentialism, Embodiment and Social Exclusion**

In the context of immigration discourse, Li (2001) defines cultural essentialism as “the belief that cultural differences are fundamental and unbridgeable” (3), and explains that the “potential tension between the concepts ‘diversity’ and ‘integration’ is resolved...by adopting a language that either dismisses or marginalizes diversity” (Ibid.). He argues that by accentuating cultural essentialism and then restricting diversity, a monolithic version of integration is constructed such that in actuality, difference is in no way accepted or accommodated. Similarly, the concept of essentialism is evident in gerontology and in services for seniors. The older body becomes the basis of classification into the group “senior”. As Chappell, et al (2003) point out, there is “no logical reason why age 65 years is now considered to mark the commencement of old age”, yet the classification of everyone over age 65 as an older adult “homogenizes the aged” (3). While program planners have begun to address this by taking into consideration the categorization, developed by Neugarten, of “young-old”, “middle-old”, “old-old”, and “frail-old” (Ibid.), planners may overlook difference of race, gender, sexual orientation, and so forth. As with immigration discourse, the differences between older adults and the rest of the adult population is perceived as fundamental. At the same time, differences between older adults and the rest of the population may be minimized (“you don’t look your age”; “you’re only as old as you feel”) while differences within the older population are ignored.

Aging is a process that shapes and marks the body, differentiating older adults from others, from the “mainstream”. It does not automatically follow that this difference matters; what matters is the way it is constructed within society. As Gingrich (2003) states, “it is important to note that difference in and of itself does not constitute exclusion, and not all difference counts...the fundamental mechanism...is the transformation of difference into opposite—in every way—from and to the classifying group, erecting a steeply hierarchical binary relationship” (11). This is evident in the language used: “older adult” contrasts sharply with “adult”.

Despite the focus in social gerontology and in the larger society on “positive aging”, the “negativities that lie at the core of some at least of the experience of aging” remain (Twigg, 2000: 7). While the differences in older adults’ bodies may or may not be accompanied by changes to those bodies’ abilities, they are constructed to result in withdrawal from the workforce (Novak and Campbell, 2005: 178) and associated with the idea of decline. This socially constructed difference can be a source of social exclusion for older adults, an exclusion that is most pronounced for those who are oldest and most likely to be frail or physically vulnerable.

Because of its rootedness in the body, this difference is inescapable in social relations. In considering the phenomenology of racial embodiment, Alcoff (2001) argues that the lived experience of racialization illustrates that race is “constitutive of bodily experience, subjectivity, judgment, and epistemic relationships”, and thus creates “everyday embodied existence and social interaction” (171). Further, she states that “there is a visual registry operating in social relations which is socially constructed, historically evolving, and culturally variegated but nevertheless powerfully determinant over individual experience” (281). Age is (generally) as visible as race or gender. Regardless of the perspective of the older individual, for others, that individual “embodies” age. Building on earlier models, adult day program goals tend to emphasize physical health, maintenance and rehabilitation, socialization and family respite (Weiler, 1987: 8). Thus, the bodies that are eligible to benefit from the services provided by adult day programs are those which are marked by physical or mental decline.

Gingrich (2003) adds to our understanding of social exclusion by reviewing various processes through which social exclusion is accomplished in our globalized world. These include, for example, exclusion as abandonment and exclusion as co-optation (12-13). She suggests that as social relations shift, value, entitlement, and legitimacy are differently interpreted within social services in ways that exclude various groups in order to support the global market (12). Exclusion as abandonment, for Gingrich, takes the form of the withdrawal of the neo-liberal welfare state from financial and social support for domestic concerns, which requires the disentanglement of some groups in place of social action, as in the example she cites of cutbacks and workfare rather than action against poverty. This withdrawal is evident as well in the long-term care sector of which adult day care is a part:

The marginalization of such limited forms of community care is deepened by neoliberal conceptions of citizenship that prize self-sufficiency and independence, disparage need and dependence, and thus permit receding state intervention and greater privatization of care” (Aronson and Neysmith, 2001: 153).

It is pronounced in adult day programs in Ontario. The path of admission has been altered so that participants now must be assessed by a case manager from their Community Care Access Centre for “eligibility and suitability” ([www.myhamilton.ca](http://www.myhamilton.ca)) before being admitted to an adult day program, an assessment<sup>2</sup> that apparently fills over thirty pages. In practice, shifts in emphasis appear to have resulted in a greater focus on programming for those with a diagnosis of dementia – and fewer services for those who are “merely” frail.

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<sup>2</sup> The RAI-HC (RAI) or Resident Assessment Instrument – Home Care, “a standardized, multi-dimensional assessment instrument intended for adults requiring comprehensive assessment...designed to predict a client’s ability to live independently in the community with support” ([www.health.gov.on.ca](http://www.health.gov.on.ca)).

The imposed scarcity of resources, Gingrich suggests, leads to exclusion as co-optation, with resources allocated in a neo-colonial fashion to some group members in order to control the majority (2003: 12-13). Citing Murphy, (2000), she notes that the trend toward partnerships of charitable agencies, governments and corporations situates workers as obedient servants of these partners placed in relation to “inferior, dependent and disempowered clients” (13). The impact of this reality on users of adult day services is likely to increase as the non-profit voluntary agencies which are largely responsible for providing the programs become more dependent on these partnerships for their very survival (Ross, 2003).

### **The Gendered Nature of Care Work**

As care shifts from institutional to community settings, services previously provided by skilled workers being “downloaded” onto families, primarily women (Anderson and Parent, 1999). O’Connor (1999), drawing on her research with spouses of those requiring care, described a “contestatory discourse” that challenged general understandings of caregiving by reframing responsibility for care as the responsibility of society and seeing caring activities of family members as “social contributions”. As productive members of society, caregivers are entitled to recognition of their efforts and assistance with them. However, she found that this perspective was undermined not only by the dominant discourse but also by the inadequacy and inflexibility of the services available (O’Connor, 1999: 79 - 80). At the same time, a person receiving care may experience a socially constructed dependence created by the dynamics of the caregiving situation, along with the physical dependence caused by reliance on others for things previously done independently. “The devaluation of caring, coupled with its invisibility, places those who are cared for, whether as family members or clients of service organizations, in a precarious position of socially created dependence” (Baines, et al, 1998: 8).

The work of providing adult day care is both physical and emotional. The emotional component is appropriate to the work being done in adult day care. As with much care work, it is a major source of meaning and job satisfaction for workers (Baines, Evans and Neysmith, 1998). At the same time, it is highly gendered work involving sophisticated skills, knowledge and creativity (Ibid.) particularly in sometimes-sensitive interpersonal interactions with service users and with caregivers who are often under substantial stress. However, care work is often assumed to be a natural extension of women’s role and ascribed a low status (Ibid.). As Armstrong, et al, note “women workers in particular tend to be lower in the provider hierarchy within the system, and in addition, bear the brunt of providing unpaid care outside of the system” (2001: 3).

In examining paid care work by women through the example of nursing auxiliary work, Lee-Treweek (1997) draws attention to women’s work that has been ignored in the past in favour of “defining labour in factory terms” (Armstrong, 2001: ix). She exposes the reality that this work can be “hard labour for a wage” despite societal assumptions

about women and care, based on ideas of women's 'natural role' as emotionally supportive, sympathetic, and able to deal easily with bodily substances, making the distinction between *caring* and *work* evident (Lee-Treweek, 1997: 47).

This paradox is troublesome. Emotional work is important, yet while undervalued by the wider society, it can contribute to the obscuring of, and devaluing of, other demands of care work. Care work is "saturated with the ideology of women's care as self-sacrificing, elastic, and dependable regardless of working conditions or safety" (Baines, 2004b: 1). As neo-liberal agendas are implemented, the emotional component is ignored, precisely because it is not quantifiable. As with the workers studied by Lee-Treweek, outcomes can come to be about process and order, with the routine taking precedence over the needs of either the worker or the service user (Lee-Treweek, 1997) – a corruption of care (Wardaugh and Wilding, 1993). Alternatively, workers can choose to go beyond the acknowledged limits of their jobs, contributing to their own exploitation but allowing themselves to operate "with a sense of integrity and moral conviction" (Baines, 2004a: 286).

Against this challenging political, social and economic backdrop, it is important that assumptions and practices which may further marginalize frail older citizens who receive care and obscure the labour of those who seek to sustain them be brought to light. Adult day programs are therefore an important setting to explore.

## **REVIEW OF THE LITERATURE**

Adult day programs may also be known as “adult day services” (see definition above), “adult day care centres” in the United States (Jennings-Saunders, 1999) or “adult day groups” in Australia (Tse & Howie, 2005). Tester (2001) offers a broad definition:

“A day care service offers communal care, with paid or voluntary care givers present, in a setting outside the user’s own home. Individuals come or are brought to use the services, which are available for at least four hours during the day, and return home on the same day” (Tester, 2001: 20).

While there are a range of models of adult day programs, the literature tells us that these have evolved from two basic models, medical and social:

The *medical* model includes service offered by an array of professionals who administer care to adult day care clients; these may include on-site registered nurses, speech therapists, occupational therapists, physical therapists, social workers, and registered dietitians. The *social* model stresses social activities, maintenance of client function, nutrition, and recreation for adult day care clients. Some adult day care centers use the medical model and others use the social model or a combination of both models (Jennings-Sanders, 2004).

When provided in the community, both medical and social models continue to exist, with medical models of care placing emphasis on physical health, maintenance and rehabilitation and social models emphasizing socialization and family respite (Weiler, 1987: 8). Some literature suggests that outcomes are largely the same with either model (Leitsch, et al, 2001).

Vulnerability and the need for care and supervision are major components. Day programs:

“...provide a supervised environment for the elderly who are unable to remain alone...[most] require regular attendance...typically...[programs]... provide some type of programming for their participants...Individual plans are drawn up for participants...based upon medical, social and functional assessments. Staff is available to assist day care participants with special needs, such as ambulation, taking medications, or toileting (Schneider, et al, 2001: 178).

Novak and Campbell (2005), citing studies by Baumgarten, et al, 2002; Chappell, 1983; and Chappell and Blandford, 1987, suggest that research has not revealed conclusive improvement for participants or reduction in use of other services due to use

of adult day care or the more rehabilitative adult day hospitals. At the same time, they note that participants may experience increased well being and reduced anxiety and loneliness, and that improved health for participants' spouses (i.e. caregivers) may also be a result (Ibid.).

These themes are borne out in a brief review of other recent literature. Gaugler and Zarit (2001) note the diversity of the literature but find tentatively that there is evidence of client satisfaction, some improvements in psychosocial functions, and benefit to caregivers. However, they also note that day programs supplement informal assistance rather than substituting for institutional care and that there is little effect on clients' functional status. In a longitudinal study, Zank and Schacke (2002) found that clients experienced significant positive effects on well being and dementia symptoms, as well as maintenance of health status.

Stress reduction for caregivers as a result of their family member's participation in adult day programs has also been explored in the literature. Zarit, et al, found "lower levels of caregiving-related stress and better psychological well-being" (Zarit, et al, 1998: 10). In a later study, Schacke and Zank find that day programs alleviate caregiving stress in terms of "a better compatibility of family, job and caregiving responsibility and [enhancement] of the caregiver's opportunity to take part in social and recreational activities" (Schacke and Zank, 2006: 78). In contrast, the experiences of staff providing adult day care are barely reflected in the literature. Hasselkus (1997) considers ethical behaviour by those providing care, but in the context of the need for control in order to ensure safety.

Concerns for safety and security appear to dominate understandings of how day program service is delivered. For example, Hasselkus (1997) cites an earlier study of her own regarding "the need to keep people together in a group as a strategy to prevent harm" and "the overriding concern for safety ... evident in the constant vigilance over the day care participants" (641). Further, in a study considering the "hidden program of place", Diaz-Moore concludes that while place can be described as "the socially shared aspects of experience" (2004: 300), the physical setting of the adult day centre studied was "utilized so as ...to maximize staff control" (Ibid.: 304).

The main focus of the literature related to day programs appears to be on outcomes - the benefits to participants and caregivers - with little attention paid to the costs and to rates of institutionalization, and no attention to individuals' experiences. Tse and Howie, 2005, suggest that there is in fact "a lack of research into day centres...and, in particular, participants' experiences of attending this programming". One goal of this thesis is to address this gap in the literature, and to broaden these understandings by exploring the perceptions of caregivers and of those who deliver the service as well.



## METHODOLOGY

### Epistemology

The theoretical concepts of “health and well being”, “support for caregivers”, and “safety and security” are evident in the literature and in the text used here as the “official account” of adult day programs. However, a conscious decision was made not to develop these concepts further prior to the interview process. This decision is based on Glasser and Strauss (1967):

an effective strategy is, at first, literally to ignore the literature of theory and fact in the area under study, in order to assure that the emergence of categories will not be contaminated by concepts more suited to different areas.

This decision is supported by Campbell and Gregor (2002) who state that it is important not to import concepts from the dominant discourse that could colour the researcher’s understanding of individual respondents’ experiences.

One goal of this research is to bring forward the voices of those involved with adult day programs. Aspects of an interpretive approach, as described by Neuman (1997) were used, focusing on what is meaningful to the people being studied, allowing for multiple realities, and fostering the construction of meaning and creation of interpretation through social interaction. Further, the data gathered were considered within a framework of values, attempts were made to acknowledge the researcher’s perspective, and the knowledge sought is seen as power to be given back to participants to help them improve their lives (Ibid.). The methods used – close analysis of texts and transcripts – are described by Neuman as appropriate for supporting this approach.

However, because the goal of this research is to understand experiences in relation to underlying structures, a critical approach was also used. An analysis of gender is also important, since the majority of those involved in adult day programs, from all of the perspectives to be considered, are women. Therefore, a feminist approach, as described by Neysmith (1995), is appropriate because it acknowledges that those who live the experience of being involved with adult day programs are expert, it acknowledges the influence of the researcher, it looks at the social context for individual experience, it includes an analysis of gender, and it seeks to add knowledge that may inform change.

The specific approach used here is that of institutional ethnography, developed by Smith (1987). Smith emphasizes knowing through individual experiences: “if we begin where people are actually located in that independently existing world outside texts, we

begin in the particularity of an actual everyday world” (Smith, 1987:109). At the same time, “she [recognizes] that knowing differently [is] the basis for changing the condition of women’s lives. To begin to undermine oppression, one must be able to identify and challenge the prevailing problems in otherwise unquestioned, taken-for-granted, prevailing ways of knowing and acting” (Campbell, 2003: 8).

## **Methods**

In order to explore the perceptions and experiences of those involved with adult day programs, and compare them with official accounts, a qualitative approach was used. A purposive sample was sought through two agencies that offer adult day programs, as well as through the local Community Care Access Centre. A purposive sample, also called a judgment sample, allows the researcher to choose the sample based on her own knowledge of the population, its elements, and the nature of the research aims (Rubin and Babbie, 1989: 229). Recognizing that the experience of adult day programs is constructed by participants, the goal of selecting participants in this fashion was to balance the voices of those who receive services in adult day programs with those who deliver it.

All potential participants were given a letter of information about the study. (The same letter was used for all participants – see Appendix 1.) To ensure that they did not feel coerced to participate, they were invited to express their interest by leaving their name and telephone numbers with a staff member at McMaster University. A presentation was made to a group of seven day program clients, and individuals who indicated an interest in participating were given a copy to take home to consider. Copies were mailed to 430 caregivers. 30 copies were distributed to staff of the programs and 6 copies to volunteers. Copies were also distributed to 5 Case Managers at the Community Care Access Centre. This process yielded key informant interviews with two clients, two caregivers, one agency staff member, one agency volunteer, and one case manager.

Interviews were conducted with these participants, each of whom have experienced this programming from specific perspectives. These in-depth interviews each lasted approximately one hour each. Separate interview guides were used with clients and caregivers and with service providers and referring agents (see Appendices 2 and 3). Open ended questions explored individuals’ experiences with day programs (their stories), and their understandings of when day programs are needed by individuals, of how they are structured, and of what relationships are important in this context.

Interviews were tape-recorded and transcribed with participants’ consent. In order to increase participants’ control over the process and confidence in the protection of their privacy, interviews took place at locations chosen by the participants – some were at program sites, while others were at the individuals’ homes. In addition, a “vulnerable persons” police check was done on the researcher prior to arranging interviews so that respondents would have extra assurances if they chose the latter option. The researcher shared her “insider” position as a past provider of adult day services in order to build trust



with participants. As much as possible, techniques such as checking accuracy and meaning by paraphrasing and rephrasing during the interview were used to increase the trustworthiness of the data.

The information collected from participants was compared with the “official account”, the service definition for adult day programs provided by the Ontario Community Support Association ([www.ocsa.on.ca](http://www.ocsa.on.ca)). This document can also be considered a sample (Strauss and Corbin, 1998). The process used to choose these samples, discriminate sampling, is appropriate because it allows the researcher to choose “the sites, person and documents that maximize opportunities for comparative analysis” (Strauss and Corbin, 1998: 212.)

### **Ethical considerations**

A significant ethical issue is that of informed consent. Kayser-Jones and Keonig (1994) state that informed consent includes the following: having and understanding information about the research, voluntary participation, and freedom to withdraw. It was important that the issue of informed consent be addressed with particular sensitivity with day program clients, who may face cognitive challenges. Kayser-Jones and Koenig note that while cognitive difficulty does not preclude an individual from making decisions about whether to participate in research, decisional capacity, defined as “the ability to comprehend information relevant to the decision...the ability to deliberate about choices according to one’s personal values and goals, and...the ability to communicate with others verbally or nonverbally” (Ibid.: 20) must be assessed before informed consent is possible in this circumstance. This judgement was made by the researcher on the basis of observations made during conversation with individuals and with the larger group.

The researcher spoke to clients as a group about the research, describing the research goals and process, and the possible risks and benefits. Those who expressed an interest in participating were given a letter of information, which could then be taken home and considered carefully by themselves and by their family members. Individuals and their family members were assured that their participation/ non-participation would have no impact on the services they receive at their day program. To avoid any disappointment due to the small sample size sought, potential participants were informed in advance that only a few names would be “drawn” from those who have volunteered. At the time of each interview, the information was reviewed, and participants were asked to sign a consent form.

The issue of consent was also addressed with staff and volunteers who were potential participants. The information described above was shared on an individual basis. The sponsoring agencies undertook that there would be no repercussions to staff or volunteers as a result of their participation; data specific to the participants was not shared with the agency. Reassurance of this was given as part of the process of seeking informed consent. At the time of the interview, the information was reviewed, and participants were asked to sign a consent form. A similar process was followed in seeking

an interview with a case manager with responsibility for referring individuals to day programs. Management was not told which case managers had responded to the request for participants.

Informed consent also involves consideration of the potential risks to participants, so that individuals are aware of these risks at the time of consent. As suggested by Schnieder, et al (2000: 122) particular care was taken to ensure that older participants are not “overtired or discomforted by the process”. As they recommend, the researcher was prepared to assess participants’ state during debriefing, and inform responsible persons such as family members or care providers if there is a concern. In addition, because of the possibility that the information shared would focus attention on their challenges, and that this would be distressing, care was taken to attend to any evidence of distress.

For any research participant, there is a risk to privacy. Participants may not wish attention drawn to their participation in a study. As noted above, participants were given the option of having interviews conducted at the day program site, at their homes, or at another neutral location of their choice. For all participants, it was stressed that they retained the option to withdraw from the study at any time.

## **Analysis**

Using an ethnographic approach, data analysis compared the themes that emerged from the interviews with those evident in the extant texts. The concept of social organization helps us “to recognize that people’s actions are coordinated and concerted by something beyond their own motivations and intentions” (Campbell and Gregor, 2002: 30). Using this concept allows us to see the “relations of ruling” which organize society. As these are exposed, one can then see and examine the relational processes that lie underneath. Assumptions about the connection between social organization, the relations of ruling, and the meaning of texts within the approach of institutional ethnography described by Gustafson (2000) were borrowed here for use in analyzing the chosen text. First, “analysis...does not treat [the text] as an independent document whose meaning is located solely in the words...printed on the page. Instead [it is seen as] a single component in a complex set of documentary practices that mobilize...activities...in an actual social and historical location” (Gustafson, 2000: 179). Second, the analysis attends to “the way social relations are organized by and in relation to [the text]” (Ibid.: 180). Third, it is understood that the activities captured by the text are institutionally organized by the text and by bureaucratic practices internal and external to the organization, so that the bureaucratic activities can only be understood in that larger context. Fourth, activities generate texts that make up the institutional record – a “documented account of reality” which overrides subjective experience (Ibid: 180).

The process for analyzing the data gathered from interviews included first reading the transcripts of each interview through in its entirety, while listening to the interview on audio tape to more fully capture the meaning behind the words. Next, a line-by-line

analysis of the transcripts was done, noting key words or phrases. Concepts were developed from these key words, then developed further into categories, and the categories further refined. As information emerged, analysis centred on “the idea of social relations at the heart of [the] research interest” (Campbell and Gregor, 2002: 85), that is, on what day programs *mean* to those most involved. The goal of comparing the two texts is to attempt to understand participants’ experiences in the context of the dominant discourse about day programs.

## **FINDINGS**

### **Voices**

Underlying the approach of institutional ethnography is the concept of “embodied knowing” (Campbell and Gregor, 2002: 24). Those who live an experience best understand and are best placed to describe what they know about that experience. Thus, it is logical to begin with “the particularity of an actual everyday world” (Smith, 1987: 109), by hearing the voices of specific individuals involved with adult day programs. Each of the individuals who participated in this study can be seen as having a defined position or role within the long-term care system. They are clients, caregivers, a staff person, a volunteer, and a referring agent. Their accounts are based not only on these roles, but also on their own individual experiences. Together they represent the day program community, but their experiences remain their own.

Both of the clients interviewed are regular users of day programs, who volunteered to be interviewed after hearing about this research. Each has attended for a significant period of time. Each attends once each week, although Client A also attends another program for two additional days. Both describe their experience of day programs in very positive terms, seeing the program as an opportunity to interact with others. Both speak positively of the activities they participate in, of enjoying the other people present, and of their enjoyment in being there:

it's a great place to come when you haven't got... you know... for a program out... and you get to learn a lot of things if you want to do, participate in things like I got myself in the art and music and trivia, I like that stuff. It's a nice day out... (Client A)

and “What you need to know is that people have fun here”. (Client B).

Interestingly, both also recognize the dual function of day programs in supporting both clients and their families. Client A suggests that, while he does not have a caregiver, for others,

...probably the people that are looking after them, a family member or whatever... they like to have a rest so they, that's why I think a lot of them are sent out you know so they have some time to themselves, the person has got time for themselves too the patient has got time for themselves. The health care aid or whatever that helps them, they get some time off. It kind of gives them a break...

while client B notes: “she [her sister] doesn’t have to look after me [when I’m at] the day program”.

While they are not connected to the clients interviewed, the caregivers in the study are experienced with providing care and with the day program context. While caregiver A brings her mother to a day program several days a week, caregiver B feels that one day of service from the day program is well balanced by the other services she receives. Both are enthusiastic about the value of the service to them and to their family member. For one, the day program is clearly an alternative that allows her to avoid placing her mother in a long term care facility, while the other describes the day program as having been critical to having her mother live with her when she was still working. Again, the dual focus of day programs quickly emerges: “that program is important for both of us” (Caregiver B) and “I mean it just all around benefits both of us totally” (Caregiver A).

The day program staff member interviewed provides a thorough description of the planned program components:

Programming, sort of structured programming begins at 10 and that’s morning social discussion, it can be reality based orientation you know its today’s May 29th, it’s spring, it’s sunny, you know it’s going to be hot today. We do physical activity at least once throughout the day so then there might be an exercise program or an active game, uh, followed by some form of cognitive stim appropriate to the group. Then we serve a hot lunch.

Interviewer: What would be cognitive stim?

Cognitive stim would be like a word game, uh, some sort of a quiz, something to stimulate them cognitively as opposed to physically. Uh then they, you know we break as well sometime in there to help people in the washroom ... we have sort of set times for that for people that need cueing and assistance but then if people are able to independently use the washroom they can go whenever they want obviously. Uh, then there would be, lunch would be served followed by afternoon activities and they would be varied from you know crafts to baking, independent programming, art, things like that. So and then people leave between anywhere between 3 and 5.

With a decade of experience, she also offers insight into her own motivation for choosing to work in this field: “I think I maybe want to say it takes a special kind of person to work in a day program in that you need to be compassionate, you need to be, have a love for people... and it’s wonderful to be a part of this environment.”

The volunteer interviewed sees being an older adult herself as helpful in making clients comfortable: “I’m their same age group”. At the same time, she laughs “I guess I

see myself, I see one of these days I might be here. I always say I'm preparing a place for myself". She volunteers once a week, and describes herself as "a jack of all trades...I water the plants. I help set the tables, help feed, help with the programs, do the one to one, help with the laundry... you know this, it's a variety, there's no monotony about it". Her own introduction to the program came through helping a friend: "well the first time I came here was because I had a very dear friend with Alzheimer's whose daughter was trying to keep her at home and she came here the first day it opened and I used to pick her up".

Case managers with Community Care Access Centres are responsible for making the referrals that are the first step to attending adult day programs. The case manager interviewed describes what the process is like for her:

Uh I think, you know you always get these, the visits where they really don't know what's available so you sort of feel like you're providing all of this, this information and I think you know for those clients that are truly lonely and socially isolated and really want to be more socially involved and you can say "well have you heard about these programs?" And they haven't. I find that the most satisfying the ones that are "oh that's great" "oh sign me up". I mean you don't always get that response you know a lot of times uh people will say "oh you know I've never been a very social person and that's not really for me". But I think that's the most satisfying when they haven't heard of the program and it's something they'd be really well suited to. Or again in the caregiver relief situation sometimes just knowing that even though there's a wait list that there's sort of a light at the end of the tunnel and that's very satisfying too... [day programs are] sort of an added, an added little bonus that you can offer people... usually people are quite fine with having to wait and they understand that you know it's a program that's in demand and they're usually quite fine with that... I think maybe because they're not anticipating being able to access something like that through me so they're looking at that as "oh, oh you do that too" so they're in that frame of mind so it's not disturbing to them that they have to wait. In most cases, I mean certainly the crisis cases where they're really desperate for caregiver relief, but there's only so much I can do then...the waits are troublesome but in most cases they're just willing to wait.

### **The Dominant Discourse**

*Adult Day Services: A community support service which provides supervised activities for adults to assist in achieving and maintaining their maximum level of functioning, to prevent premature and inappropriate institutionalization and to provide respite and support for caregivers. Service components may include transportation, meals, supervision, social and recreational activities, personal care, counselling and minor health care. This service is for frail older adults and adults with acquired brain injury and Alzheimer's Disease. (www.ocsa.on.ca)*

One question this study set out to explore was the extent to which participants' accounts of day programs reflected the dominant discourse about day programs' purposes. The concepts of supervision for clients and respite and support for their caregivers quickly emerged in participants' descriptions of what occurs, while the ideas of maintaining maximum levels of functioning and of preventing institutionalization were mentioned less often.

The concept of *supervision* was mentioned both explicitly, and less directly in terms of safety, security, and of someone "taking responsibility" for clients who were vulnerable. In one sense, supervision is a response to the inability to manage on one's own:

...when I describe to I guess for example to friends or family...what I do... I would say that we're a social recreation program for seniors living in the community who are no longer appropriate or accepted or able to uh participate, that's a better way of saying it, in social programs or activities in the community. So they need support, they need supervision, they need cueing to sort of carry out their day and we provide... (Staff member)

Structured activities offer people an opportunity to participate, with assistance where needed:

And exercise is within reason because you sometimes have to sort of skivvy them to do this movement and that movement... you really have to go with the flow, you really do. If it isn't working then... move on to something else... And these girls are good at it. (Volunteer)

At the same time, supervision implies safety, in that dangerous behaviour will be monitored and the risk of harm to the client will be managed.

...for her daughter who worked, she's a teacher; it was very comforting to know that she was in a safe environment because she wasn't safe at home. For instance she thought it was cold one night so she put Sally's nightie in the oven to warm. So it's scary when you're at home with things like that happening especially if you have to leave them. And uh so it was, for Sally it was a very comforting thing to know that she had somewhere that Mabel could come and be looked after and you know be happy and, and know that ... she just wasn't very safe left at home by herself... (Volunteer).

As for my mother it gives her a social interaction, she has a place to come, she feels happy here, she feels secure here, uh she is well looked after here, she is given the food according to her [needs] you know she has health problems so she can only eat certain types of foods so she's, that is provided for... She used to like



to nibble cheese but she's allergic to milk products... and they sort of, I think they put the cheese plates away also because she would you know behind their back go and sneak something and then I'd have a problem at home. (Caregiver A)

There is a lot of responsibility, you have to... and you have to take that responsibility. You also have to realize you know, you also maintain the same kind of confidentiality as you do in a hospital. (Volunteer)

...So I started looking for somewhere to take her uh that would be responsible, that would be fun and that wouldn't be a warehouse where people drop people off to be forgotten for the day. (Caregiver B)

As noted above, day programs are consistently seen as important for both the client and the caregiver. *Respite and support for caregivers* were mentioned frequently, with a noticeable emphasis on the importance of respite:

... part of our criteria is that they have a caregiver cause we're also filling the respite component of the need ...(Staff member)

... I mean certainly its very very valuable in terms of caregiver relief 'cause we just do not have the hours to give people in terms of caregiver relief hours, our monthly maximum hours are 60 hours a month and we have pretty tight caregiver relief criteria um so you know those days or day that somebody can count on every week is really really valuable. (Case manager)

I would describe it as a means of, first of all for a caregiver, is a means of a break because you are given a certain amount of time to do what you need to do, to rest or to recuperate or you have friendship or to have an activity or to go to the doctor's or you know... it's countless what it allows you to do uh you know, physical exercise whatever it is, it gives you that opportunity. (Caregiver A)

Descriptions of support for caregivers took several forms. Day programs were seen by caregivers as a resource for practical information and training:

And if you have any problems or you can't figure things out or uh whatever you always come here and say well I have this going on what should I do about it or I don't know what to do about it. (Caregiver A)

... sometimes going in when I'm picking her [the caregiver's mother] up and hearing from a program worker something they've done, maybe giving me a new perspective on things because I'm just a person too and I don't have program training so although I've interacted with people all my life it's possible that somebody may have a better slant on things than I. And Tanya the nurse is



excellent, she's always good to call you into her office to explain something if something has happened or to check something with you. (Caregiver B)

This sharing of expertise included an emotional component, through modeling positive behaviours and offering 'moral support':

The crucial fact is in how its helped me is that by coming here I learned to deal with her [her mother] better because I was getting frazzled and angry and uh ... sort of, I wasn't hurting her or anything but I knew I was getting to a place where I might lash out and by coming here and you know they're so calm, relaxed (laugh) you know easy going and they treat everybody so well and you start looking and you start reacting the same way and you know and I sort of learned the same thing at home you know... I guess that is perhaps the most important thing is that it enabled me to uh deal with her better in a more compassionate caring way because I was sort of getting like this and I didn't need to be but I didn't know how to cope. So in a way I'm saying they taught me how to cope. (Caregiver A)

...you can talk to virtually anybody... any of the staff members if you're having a down day you can tell them anything and they try to boost your morale up. (Caregiver A)

Support for caregivers extends even beyond the program:

It's not uncommon that we get called from the day program coordinators to say you know I'm really concerned about Mister So and So his mobility seems to be deteriorating and he had a fall and you know we need to have a physiotherapist go out or you know Mrs. So and So seems more stressed can you go . . . That, that happens quite a bit. That happens quite a bit. And it's very valuable because sometimes too they have a relationship with the family because often it's the family dropping them off and so they sort of get, and they have a good feel sometimes for the caregiver's stress level...because they're chatting with them. Now that's very very common. Very common. And I think I mentioned to you earlier you know [one adult day program] in particular I have, Tracy, the coordinator will call me quite frequently and uh just sort of a back and forth about what services we're providing at home and what's happening at the day program. And certainly I've been involved in [case] conferences at the day program too (Case manager)

While mentioned less often, participation in day programs is also seen as important for clients in *achieving and maintaining their maximum level of functioning*.

...there's the social piece for the client and you know getting them out and the importance of maintaining their interactions and experiences as a person and in a

dignified manner and in a supportive manner that is going to make them feel successful and feel good. (Staff member)

...something to do that will tax their mind and possibly their body and keep everything functioning. (Caregiver B)

And it made a difference with me because I was... kind of backwards when I got in here and I thought well I've got to... It's really done me a lot of good because up to that time I wasn't really, I was kind of quiet but I've been kind of quiet through the time any way about you know being, doing such a thing like speaking you know... but I got rid of that to a point. (Client A)

Finally, *preventing premature and inappropriate institutionalization* is perhaps implicit in participants' understandings, but was mentioned only once:

... 'cause we were considering putting her in a nursing home but we, we reconsidered and I think she's happier here. (Caregiver B)

The cohesiveness of the various descriptions offered from various perspectives in the day program context is noteworthy. "According to the social organization of knowledge, individuals *enact* the world they inhabit and know about in concert with other people and of course, with the technologies that people operate." (Campbell and Gregor, 2002:23). The experience of participating in day programs is created by the participants, based on their shared understandings of what day programs are about. Through their actions, they bring the text, in this case the service definition, to life.

### **Another Discourse: A Discourse of Relationships**

Participants' shared understandings of the dominant discourse were evident in their explanations of the purpose of day programs and their descriptions of what occurs. Threaded through their responses, however, was another theme, that of the relationships they experienced or observed and the way that they felt that they and other people were treated. In their descriptions, texture was added to the service by the way it was delivered, from the translation of an assessment of social function into an understanding of individual needs, to the way individuals were treated on a daily basis. Relationships were valued. Participants described practices that fostered dignity and respect: providing individual attention, welcoming people, nurturing a sense of belonging, demonstrating concern and caring, and accepting challenging behaviours. The effort and skill involved was acknowledged, but in a much more offhand way, while the challenge and risk encountered was downplayed significantly.

Access to adult day programs is based on case managers' professional assessment of need:

...there is a social function section in the RAI [assessment tool used by the CCAC]... where you ask people what they like to do, what their hobbies are, you know if they have a religious affiliation, if they're a spiritual person, uh and you can really get into as much detail or as little detail as you want. I usually try and ask people what they like to do in their spare time and then often that will trigger a conversation where somebody may say "well I used to do this but I can't and I used to do this but I can't and I used to go visit my friends but I can't take the bus any more and you know my vision is deteriorating"... So that section's a big trigger and then again for the caregiver's stress issues where we're really looking at the caregiver is burning out... one gentleman that I just referred to a day program lives with the daughter, daughter has a 13 year old daughter and she said to me "I don't have any time to do grocery shopping, I don't have any time to do things with [my daughter], I can't do this, I always have to be here with my dad and I really feel like I'm short changing everybody". And I said to her "have you thought about an adult day program so that you could send him a couple days a week and have that time to yourself?" So those are kind of the two areas that tend to flag for me for adult day programs. And sometimes, I mean I did one not that long ago, one of my retirement homes, and the fellow said to me "you know all my friends are going ... and I'd like to go with them".

Once day programs receive the referral forms, this clinical assessment of a person's needs is translated into more personal terms. Although this translation may be seen as just good practice, it is more than that – it is the beginning of coming to know a person. The theme of "supervision" is still evident in the emphasis on safety, but the individual's identity is beginning to emerge:

...the case managers do the RAI assessment form and then they fax that to us and then we would review that and then we would have our own assessment as well on top of that just to kind of get into a bit more specifics...diet is big, what kind of food they would eat while they were here because several of our clients require mixed, moist, pureed, if they're a choking risk, diabetic, things like that that's very important. Toileting needs are important. Behavioural needs are important to find out. Activities they did previously. And then there's a risk assessment as well, are they a risk for wandering? Are they a risk for eating non food items? Are they a risk to send home alone? So do they need a caregiver waiting for them at the other end? Most of the times that's yes. Um that's sort of like a fact sheet where we can eyeball and see right away what that person's needs are. So it's pretty specific. And then we do that and then the caregiver meets with us as well, medications are also reviewed there and then uh there's a series of consent forms, payment agreement and ...Then once the client comes a few times we really get to know them 'cause its all kind of subjective right until you actually spend the time with them. Like this gives us those basic things that we need to know prior to coming in for, for their own, you know, safety and well being. (Staff member)

This personalized approach, *providing individual attention*, continues as someone begins to participate in day program activities. “The initial assessment that we do explores as well what they previously enjoyed so that if appropriate we can implement it into their programming for the day...” (Staff member)

Everybody’s sort of catered to individually. I’ve seen people not wanting to participate and just wandering around and the staff wander around with them because they can’t settle or they’re asleep or it just is whatever goes whatever goes for the individual I think is, that’s what they cater to. So what’s good for them basically. Uh so you know they do all sorts of things given you know the time period or the season...But this is the ideal place because everybody’s catered to individually. (Caregiver A)

At the same time, there is an attempt to balance needs: “...every single person needs something different and, and while you have to have some structure you also have to have a lot of flexibility... so that everybody gets a little bit of the pie.” (Volunteer)

Respect for the individual is illustrated most vividly by the staff member’s thoughts on providing personal care:

... these people... are so vulnerable... and personal care is a big thing for me in that I feel so privileged and honoured to help someone in such an intimate part of their life that when I’m in there I’m not uncomfortable myself I feel respect and dignity for them and how it must be for them to have a stranger, to have a young woman or you know a woman even helping them in the washroom uh so I just I have, that’s a big area for me in that I really feel uh I feel empathy for them and what it must be like to, to have that sort of taken away from them and needing assistance like it’s, it just touches me in areas that I can’t even explain... just that it’s just so . . . It’s intimate you know it’s intimate, it’s personal. And then our clients that resist care you know how do we help them with that? And then we have a caregiver saying well I don’t want them sent home wet you know and we have to find that balance and and that uh that area of not forcing them but you know keeping them... it’s huge, it’s huge. You know so we try and they resist so then we try again and again and again. Like we have client that all afternoon we all take a turn trying to get her in, you know sit her on the toilet, have her do something you know in a routine, something that’s familiar like sitting on the toilet. She’s going to think ok I might have to urinate or I might have to try and have a bowel movement and then if they are incontinent to try and dignify in a dignified way you know change their pad. It’s just, it’s huge, it’s just huge... [It’s] just that they have a lot to offer and that you know at their stage of...the disease they aren’t able to get that out in a normal way. So I like to think that I’m part of tapping into that positively and productively and meaningfully for them. (Staff member)

The respect being expressed in the statement “they have a lot to offer” stands in stark contrast to the foregoing description and the embodiment of age that could easily have been constructed in response to it. Twigg’s “negativities of aging” are both accepted, and overcome.

At a fundamental level, being treated as an individual begins with acknowledgement. The ideas of *being made welcome* and of belonging were mentioned repeatedly: “...people arrive...and they’re greeted and accepted and welcomed” (Staff member).

And they always greet her at the door and see how she’s doing and usually make a fuss over her so she settles in you know sits down, is happy and gets along with the program. (Caregiver A).

...there’s a social aspect to it, people get to know who’s coming on their day and they look for each other and welcome each other. [With the caregiver’s mother]...there’s a couple of people that she knows and I know that she does because I see her face light up when she sees them so I, I know that that’s somebody she’s happy to see. (Caregiver B)

Planning goes into *nurturing a sense of belonging*:

Um its organized because... people with dementia they need some, they need structure, they need to be able to feel like they’re a part of something. Small groups are definitely better. And just to give people a sense of belonging... (Staff member)

This sense is extended to the feeling of being “at home”:

...and I have a knowledge of what [is happening with her mother], I know everybody you know and everybody knows me and you feel quite at home that’s the other thing... (Caregiver A)

...I think we provide a very very homelike environment here, a home away from home and . . . and I think that our clients they respond to that appropriately and I think it speaks for itself the way that our clients manage when they’re here, the way they’re supported, the way their caregivers feel. You can imagine leaving, like there’s a lot of guilt that goes along with, for these caregivers dropping their loved one off, having their loved one picked up its really difficult it’s a really hard transition for them and it’s, there’s a huge trust issue, for them, to trust us and I take that very seriously. (Staff member)

A sense of *concern and caring* for clients and caregivers is fostered by involvement with them:

...everybody does everything. Everybody helps clients in the washroom, everybody assists clients... with their eating, everybody runs programs, everybody, for the most part everybody does everything. (Staff member)

They're great people in there and they're all dedicated people. I mean that's an old fashioned word, its not supposed to be used any more but its true. They really are. (Volunteer)

... There's... program workers that really you know try and make the day meaningful, the games that are played meaningful. (Caregiver B)

You know these are people who are vulnerable and who need protecting and you sort of... I think that's the real thing they're vulnerable, they need protection and they need care, need someone to... someone who likes them. (Volunteer).

Well it's a lot of caring... I think these people care about the clients as people not as Alzheimer's, as a person. This is William he isn't Alzheimer's he's William, he has a personality of his own. He's different but he's William. And this is another one who you have to watch she doesn't get too near the men but you know that's fine she's a person and she has her own characteristics and you just located them. (Volunteer)

...if a client has a bad day and that you know they've been at the door a lot and we aren't able to reassure them and make them feel safe and comfortable and they go home you know agitated I don't feel great about that because I know I'm sending them home to the caregiver who's going to have to ultimately deal with that at the other end. (Staff member)

Finally, along with this involvement came *acceptance of challenging behaviours*:

...we get a lot of agitation. And it's catching...It's very contagious and if you have somebody that's agitated and it spreads and then you have a job calming everybody, that's a bad day. And it is very contagious if you have one who's [agitated] so usually we try and contain them and take them away. Like we had a... lady who was very vocal and very loud and very you know and so we tried to keep her out and away from the rest of them. (Volunteer)

I guess you could call it violence I don't know. I've had my share of violence here, I've been picked up and thrown... (laugh)... across the floor... This was a lady we had she was very tall (laugh)... she was very tall and very, really nice lady but very agitated and a couple of occasions I can remember, I remember one time I was in the bathroom I heard this voice say Helen, Helen, Helen... I came, Wanda who was also very tall was in the washroom, and [the client] had

her hands around Wanda's throat. (laugh) Carefully we managed to take her away and... and it was the same lady who... I guess I got on the wrong side of her where to seat her for lunch so she just (laugh) picked me up and threw me across the floor... (Volunteer)

you have to see past that [some behaviours] and sort of know that some of them are having personal problems and you just have to give them a hug and tell them whether it was going to be ok or what. (Volunteer)

Again, it was significant that the descriptions provided by people in different positions overlapped and repeated so often. What is known about the relationships within day programs may not be part of the official account, but understandings are shared among insiders.



## **DISCUSSION**

This study proved to be a valuable opportunity to examine both the ways in which services are organized by the text and the relational practices that underlie service delivery. By uncovering these relational practices, normally hidden or overlooked, it is possible to see that day programs do more than help people function as well as possible, but in fact add meaning to people's lives. Individuals are seen as people, not "objects of work", and they are treated with dignity and respect. It also becomes clear that a significant amount of both mental and physical work is required to sustain this, work which goes unnoticed and unacknowledged. In using the approach of institutional ethnography, researchers "have a responsibility to those to whom we write" (Smith, 1987: 224). It is hoped that this research has met that responsibility by bringing attention to the unique perspectives of the services users and providers of adult day programs who so generously shared their thoughts and experiences.

There are some methodological qualifications to consider. As a graduate level thesis, the size of the sample and the range of questions were necessarily limited by the scope of the research. A larger study population would have enhanced the validity of the study by allowing the analysis of the findings to reach saturation, the point where no new themes are found (Strauss and Corbin, 1998: 214). In addition, the research was done through two agencies providing adult day care to clients living primarily in urban areas, who were described by staff members as a largely homogenous population, with little variation in cultural or ethnic background. This did not allow for the opportunity to explore, for example, issues of access in rural areas or variations in needs and service provision.

However, as a small exploratory study, this research does not seek to produce findings that can be widely generalized. It focuses instead on the particular experiences of those who were interviewed, in a particular historical time and place. The transferability of these findings to another setting is dependent on the richness of the description provided for the use of another researcher (Lincoln and Guba, 1985: 217). They are offered as a basis for conceptually extending understandings of organization and delivery of adult day programs that other researchers may find useful.

### **The Text-in-Action**

The meanings in the "service definition" text are not located only in the printed words, but have been taken up by service providers and service users alike. Workers in a given agency may plan and implement programs according to the text, but the text, as Gustafson (2000) observes, is only one part of a more complex system. The textual sample used here was taken from the web page of the association of service providers. It



represents agreement among service providers about what this service consists of, and the message that is made available to anyone accessing the web page. At the same time, with minimal differences in the wording, the text forms the basis for each agency's "service agreement", its contract with the state, represented by the Ministry of Health and Long Term Care, to provide service to eligible Ontario citizens. In return for the funding which makes the service possible, the agency agrees that the service they provide will follow the shape and form of this definition. When the definition is applied consistently, it means that services will be roughly equivalent in any region of the province. At the same time, the definition communicates what agencies are offering to other parts of the long-term care system and links to their services, as with the assessment of "social function" done by the CCAC using the RAI-HC.

"Social relations are organized by and in relation to [the text]" (Ibid.: 180). As the text is being used for different purposes in different contexts, it impacts on interactions in different ways. For example, the "supervision" (by agency staff and volunteers) of activities participated in by older adults is noted in the text and is dominant in accounts of the service. It is clear that this "taking responsibility" is important to caregivers – for example, the volunteer interviewed noted that caregivers need someone "to be responsible" while the second caregiver searched for a program "that would be fun, that would be responsible". There is a level of trust required, as noted in the staff member interview, for the caregiver to feel that his or her family member will be treated well while being kept safe. At the same time, this understanding of the text by caregivers and agencies is much more than an understanding of social or moral responsibility. In the context of agencies' contracts to provide service, "supervision" implies a legal responsibility toward clients and potential liability if things go awry.

Gustafson also points out that the activities captured by the text are institutionally organized by the text and by bureaucratic practices internal and external to organizations – thus bureaucratic activities can only be understood in the larger context (Ibid.). For example, before taking on the responsibility of providing "supervised activities" there are both external and internal assessment processes to be followed, including the assessment for which the CCAC assumes responsibility and the internal assessment that gives day program staff a clearer picture of the person. The assessment done by the CCAC helps the external long term care system quantify someone's "social functioning" in relation to his or her physical state ("being frail" or having the diagnosis of dementia or acquired brain injury). The internal process helps the agency plan the details of the "supervised activities" they will be able to offer an individual and helps to organize the terms under which the services will be offered, i.e., through the consent forms and payment agreement.

Finally, Gustafson notes that activities generate texts that make up the institutional record – a "documented account of reality" which trumps subjective experience (Ibid.: 180). The documented account becomes more important than individual experience. The official reality of day programs is thus supervision, respite,

optimum functioning and institutionalization avoided; the more subjective relational aspects disappear from view.

### **Relational practices**

To return to the starting point of this study, are there other ways in which these services can be understood? The data presented here show quite clearly that day programs fulfil their official purposes. At the same time, they make visible “relational practices” that give meaning to the day program experience, consistent with the interactions between persons with dementia and staff observed by Berry (2004) in a similar setting.

Looking *beneath* the accomplishment of the purposes of day programs allows us to see the caring work involved in “*providing individual attention*” “*welcoming*” “*nurturing a sense of belonging*” “*offering care and concern*” and “*accepting challenging behaviours*”. This work is difficult to perceive. As Devault (1991) states “...public discourse only hints at the complex character of caring work, and the effort and skill it requires. The ‘workful’ character of this activity is often unrecognized even by those who do it” (228). These data illustrate that “workful character”. Planning goes into organizing care when an individual’s specific needs are considered and programs are designed for small groups to nurture a sense of belonging. Judgement is needed to adapt programming to participants’ changing situations: “If it isn’t working then . . . move on to something else”. There is responsibility for clients’ safety, and risk to oneself: “I’ve been thrown...across the floor”. There is skill involved in managing agitation and in reassuring someone who is agitated and making them feel “safe and comfortable”. There is physical effort in feeding and toileting, especially when someone resists your help. It becomes clear that a significant amount of both mental and physical work is required, work which is known to the insiders who are familiar with day programs (“these girls are good at it”), but rarely acknowledged elsewhere.

Within the dominant discourse, the focus of day programs is on care for clients, which constructs the clients as “objects of work”. They must be supervised for their own safety, and assisted to optimum functioning; the work of the program provides respite to caregivers (a helpful substitute within the system for caregiver relief hours) and helps to avoid institutionalization. These data show that there is another narrative, one which may be much more consistent with individuals’ perception of themselves<sup>3</sup>. Rather than being seen as objects of work, individuals using adult day programs are treated as people. Their preferences are taken into account when planning programming. They are made to feel welcome and comfortable. They are treated with respect and dignity in intimate contexts. The volunteer interviewed for this study expresses this best: “I think these people care

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<sup>3</sup> Hurst Rojiani (1994) uses “identity management” to describe the way that individuals share and socially create their identities over time through relationships, including those between professional and client. The relationships described in this narrative clearly enhance individuals’ identities.

about the clients as people not as Alzheimer's, as a person. This is William he isn't Alzheimer's, he's William, he has a personality of his own."

The work involved in providing day programs is under-recognized for another reason. Day programs as a community support service are situated within the long-term care sector, but with a social rather than a medical focus. As Twigg has pointed out, the setting for this kind of care work is significant. "The relation between the medical and the social is not an equal one...the medical is the defining sector and the social a residual category, representing 'all the rest'" (Twigg, 2000, 112-113). With the introduction of LIHN's (Local Integrated Health Networks) into Ontario's health system, the corporate permanent reconstruction continues, while acute care needs continue to dominate. Within long term care, adult day programs are at the margins of a marginalized sector's concerns and resources. Thus it is unsurprising that the case manager in this study would see day programs as "an added little bonus".

### **Looking Forward**

The results of this study reveal that the values of adult day programs support programming that is person-centred and relational. Day programs function to meet participants' "thick needs" as described by Fraser (1989)<sup>4</sup> bringing meaning to people's lives in addition to meeting the official purposes described in the service definition. This alternate discourse of relationships that bring meaning is undermined by the position of day programs within the long term care system and by ongoing changes occurring more broadly in health care. Despite this, within the non-profit settings where adult day programs are delivered, workers are likely to retain their "strong identification...with the social caring mandates of the agencies in which they are employed" and their "gendered and racialized sense of moral and political obligation to provide care for individuals and communities" (Baines, forthcoming: 1). In the words of the volunteer interviewed for the study: "they're great people in there and they're all dedicated people. I mean that's an old fashioned word, its not supposed to be used any more but its true. They really are."

It will be crucial that these values be upheld, while the pitfalls within the trend toward managerialism are recognized, and its appeal resisted (Tsui and Cheung, 2004: 441). Going beyond this, "strategies for resistance need to expand and improve social care...[when faced with] the endless organizational change...of New Public Management" (Baines, 2004c: 24). The shift from "needs-led" provision of service to "budget-led" provision, and the de facto rationing that results when allocations are exhausted (Dominelli and Hoogvelt, 1996: 58) is a serious threat to these values. The "needs-led" provision in existence in Canada prior to the mid-1980's (Lightman, 2002)

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<sup>4</sup> "Thin needs" describe minimum or basic needs, for example, the need to maintain functioning in order to continue to live in the community, while "thick needs" encompass much more complex concepts, such as retaining one's identity as member of the community, participating in social activities, and having the experience of being known to others through one's relationships with service providers and other participants.

remains an ideal, one which must be upheld despite the unresponsiveness of neo-liberal governments. In the case of long term care and adult day programs in particular, it will be important that workers, professional groups, concerned citizens and advocates work in alliance and press for the restoration of broader criteria for service and ultimately for the restoration of guaranteed access to service on the basis of need. By bringing to light the meaning and value of adult day programs, this study aims to contribute to this endeavour.

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## **Appendix 1**

### **Research Project: “The Meaning of Adult Day Programs for Older Adults”**

#### **Letter of Information**

I am a graduate student in the School of Social Work at McMaster University. As part of the requirements of the Masters in Social Work Program, I am conducting a research project. Dr. Jane Aronson has agreed to supervise my work.

Within our larger health care system, Adult Day Programs are provided as part of community support, or long term care in the community. As our population ages, demand for programs such as these can be expected to grow. The purpose of this research is to gain an understanding of what Adult Day Programs mean to those who are involved in them, including participants and their family members, staff and volunteers, administrators, and case managers who refer individuals to programs.

While day programs are designed to help individuals maintain independence, they are not widely studied or well understood. The goal of this study is to gather information from those most directly involved that will add depth to our understanding of day programs. You can provide a unique perspective based on where you are located in this wider system. Sharing your stories and examples of your own experiences with day programs can provide valuable information that will deepen our understanding.

**I am seeking to interview individuals who have experience of day programs, preferably of at least one year. Participants are asked to meet with me for approximately one hour. Interviews will be conducted at your convenience during May and June, 2006.**

Your participation in this research is voluntary and confidential. If you wish to be considered for this study, please call and leave your name and phone number with Darlene at the School of Social Work, **905-525-9149 Ext. 24596**, and I will contact you privately. Every care will be taken to respect your privacy throughout the study. No identifying information or identifying quotes will be included in any of the written reports generated from this study. You are welcome to withdraw from the study at any time.

This project has been reviewed and approved by the McMaster Research Ethics Board. Should you have any questions or concerns regarding your participation in the study, you may contact:

McMaster Research Ethics Board Secretariat  
c/o The Office of Research Ethics  
1280 Main Street West, GH-306  
Hamilton, ON L8S 4L9

905-525-9140 Ext. 23142  
E-mail: [ethicsoffice@mcmaster.ca](mailto:ethicsoffice@mcmaster.ca)  
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Phone: 905-525-9140 Ext. 23783

Thank you in advance for your assistance!

## **Appendix 2**

### **Research Project: “The Meaning of Adult Day Programs for Older Adults”**

#### **Interview Guide: Service Users and Caregivers**

The guide that follows will structure areas of questioning for the interviews with service users and caregivers in this study.

Within our larger health care system, Adult Day Programs are provided as part of community support, or long term care in the community. As our population ages, demand for programs such as these can be expected to grow.

While day programs are designed to help individuals maintain independence, they are not widely studied or well understood. The goal of this study is to gather information from those most directly involved that will add depth to our understanding of day programs. You can provide a unique perspective based on where you are located in this wider system. Sharing your stories and examples of your own experiences with day programs can provide valuable information that will deepen our understanding.

As a user of day program services, whether you attend the program or whether you are a caregiver, it is especially important that your voice is heard. Thank you in advance for your help!

- 1) How would you describe day programs to someone who might need the services?
  - What happens there? What are the main activities of the day? Why do you think they organize the day in that way?
- 2) Please tell me about your own experience as a user of day program services.
  - How do you describe coming here – for example, “on Wednesday, I’m [you’re] going to .....”?
  - What was happening in your life that led to you [your relative] beginning to attend the day program?
  - What made you decide to attend [that it might be good for your relative to attend]?
  - Could you please describe an especially good or bad day at the program for you [your relative]?
- 3) Is attending the program [having your family member attend] helpful to the family member you rely on most [to you in helping your relative]?
  - If yes, in what way is it helpful?
  - Does it make a difference?
  - What do you like about it?
- 4) Who are the most important people you see here?
  - Please tell me more about that.
- 5) Again, thank you for your help! Is there anything I haven’t asked about that it is important for me to know?

### **Appendix 3**

#### **Research Project: “The Meaning of Adult Day Programs for Older Adults”**

##### **Interview Guide: Service Providers and Referring Agents**

The guide that follows will structure areas of questioning for the interviews with service providers (staff and volunteer) and referring agents in this study.

Within our larger health care system, Adult Day Programs are provided as part of community support, or long term care in the community. As our population ages, demand for programs such as these can be expected to grow.

While day programs are designed to help individuals maintain independence, they are not widely studied or well understood. The goal of this study is to gather information from those most directly involved that will add depth to our understanding of day programs. You can provide a unique perspective based on where you are located in this wider system. Sharing your stories and examples of your own experiences with day programs can provide valuable information that will deepen our understanding.

Thank you in advance for your help!

- 1) How would you describe day programs to someone who might need the services?
  - What happens there? What are the main activities of the day? Why is the day organized as it is?
- 2) Please tell me about your own experience as a provider of day program services [or in referring people to the programs].
  - How do you describe the work that is done here to others?
  - Could you describe an especially good or bad day in doing your work?
- 3) How do you see day program attendance as being helpful to service users and their caregivers?
  - Typically, what might be happening in someone’s life that might lead you to suggest that they begin attending a day program?
  - What else would lead you to believe that this type of program would be appropriate for someone?
- 4) For yourself, what do you value about the work you do in this area?
  - Please tell me more about that.
- 5) Again, thank you for your help! Is there anything I haven’t asked about that it is important for me to know?