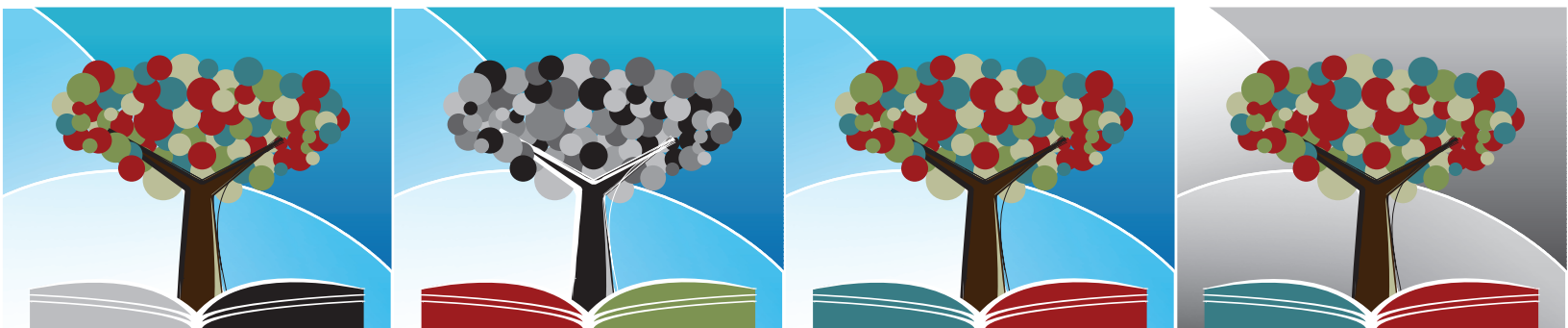


K N O W L E D G E   D E V E L O P M E N T   C E N T R E



# Engaging People with Early Stage Alzheimer's Disease In the Work of the Alzheimer Society

A Research Report

Alzheimer Society of Canada

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The logo for Canada, featuring the word "Canada" in a serif font with a small maple leaf icon above the letter "a".

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## The Alzheimer Society of Canada

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Founded in 1978, we are a nationwide, nonprofit organization dedicated to helping people affected by Alzheimer's disease and related dementias (ADRD) (Alzheimer Society of Canada, 2005d). There are 10 provincial organizations and more than 140 local groups across Canada.

Our mission is to alleviate the personal and social consequences of Alzheimer's disease and related dementias, and promote the search for a cure. We are a leading source of funds for Alzheimer research in Canada, and we provide information, referrals, support, and education to people diagnosed with the disease and their caregivers. We support our 10 provincial organizations in achieving this mission.

The Alzheimer Society is a founding member of Alzheimer's Disease International (ADI), a global organization including more than 75 member countries. Within this organization, we are recognized as a leader in engaging people with early-stage ADRD. In the ADI April 2003 fact sheet *How to Include People with Dementia in the activities of Alzheimer Associations*, we were one of three national Alzheimer organizations listed as providing information on involving people with dementia (Alzheimer's Disease International, 2003).

Historically, the Alzheimer Society and our member organizations focused on support and education programs for caregivers who needed information and guidance in caring for people in the mid-to-late stages of the disease. It was, and is, a commonly held view that people with the disease cannot speak for themselves or make their own decisions. In fact, the current public image of someone with ADRD is often based on the later stages of the disease (Alzheimer Society of Canada, 2005c).

Today, thanks to increased public awareness, people are recognizing ADRD symptoms earlier and seeking a diagnosis. These individuals are contacting us for information and support, and to become involved in our organization.

For example, in 2003, people living with Alzheimer's disease contributed to *I have Alzheimer Disease*, a section on our website specifically for people with the disease. That same year, Marilyn Truscott, a person living with ADRD, joined our board of directors. British Columbia and Nova Scotia organizations have each appointed a person with dementia to their boards of directors. People with ADRD are also taking on volunteer activities at the local level, including public relations, advocacy work, and conference planning.

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## Alzheimer's Disease and Related Dementias (ADRD)

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Alzheimer's disease (AD) is a progressive, degenerative, and fatal brain disease, and the most common form (64%) of dementia in Canada (Alzheimer Society of Canada, 2005a). Approximately 435,000 Canadians over the age of 65 have AD or a related dementia (ADRD), with an estimated 97,000 new cases in 2006. ADRD commonly affects those over the age of 65, and prevalence rates increase with each decade – from 1 in 13 over the age of 65 to 1 in 3 over the age of 85 (Alzheimer Society of Canada, 2005a). A less common form of Alzheimer's disease affects individuals in their 40s and 50s (Alzheimer Society of Canada, 2001).

### Forms of Alzheimer's disease<sup>1</sup>

Sporadic Alzheimer's disease is the more common form of the disease and accounts for 90 to 95 per cent of all cases. The role of heredity in this form is unclear and is the subject of much research.

Familial Autosomal Dominant Alzheimer's disease is a less common form of the disease and accounts for five to 10 per cent of known cases. In certain families, this form is passed directly from one generation to another.

Alzheimer's disease eventually affects all areas of the brain, including cells that control memory, judgement, and behaviour. In the later stages, the person becomes unable to care for her/himself. The average lifespan of a person living with Alzheimer's disease is between 8 and 12 years. Neither age nor recency of diagnosis determines an individual's disease progression or level of impairment. Because there is no cure, there is no way to prevent the disease or its progression.

### Defining early stage

The term *early stage* means individuals of any age who have only mild impairment due to symptoms of Alzheimer's disease. Therefore, this is not a homogeneous group, and people will have different needs and experiences depending on the age of onset and/or age at diagnosis.

People in this stage usually retain many of their capabilities and require minimal assistance. They also have insight on changes in their abilities, and can inform us of the reality of living with a progressive, cognitive illness – even help to plan or direct their future care. Said Marilyn Truscott, a person with ADRD, *“in the early stages, with our insight still intact, we know what we need to help us and to help others.”* (Alzheimer Society of Canada, 2004)

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<sup>1</sup> Retrieved August 25, 2006 at Alzheimer Society of Canada website: <http://www.alzheimer.ca/english/disease/whatisit-intro.htm>

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# Engaging People with Early Stage Alzheimer's Disease In the Work of the Alzheimer Society

## Introduction

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People are being diagnosed with Alzheimer's disease and related dementias (ADRD) earlier in the disease (Bowen & McKechnie, 2001), and many are able to remain at a high level of functioning for long periods of time. Experience is showing us that these individuals are capable of contributing in a meaningful way to shaping our understanding of dementia, their needs, and required supports (Beattie, Daker-White, Gillard, & Means, 2004). The Alzheimer Society of Canada wants to identify strategies that promote the active participation of people with early-stage dementia in our organization and our work, particularly policy, research, and service delivery.

This report is based on research conducted in 2005. We engaged a Project Advisory Committee (Appendix A) during our research.

Drawing from related literature, the experiences of people with the disease, Alzheimer Society staff, and key informants, we considered the factors that influence individuals to volunteer and the barriers that may limit their participation. We hope our findings will be of interest to all Alzheimer organizations in Canada, and to other charitable and nonprofit organizations.

## Information gathering

We gathered information by reviewing literature on early-stage dementia, volunteerism, self-advocacy, and inclusion. This review led us to our key informants – ADRD leaders, stakeholders, and experts (Appendix B), whom we interviewed by telephone. Next, we interviewed nine experienced, active volunteers from across Canada to learn more about what motivates them as they live with ADRD. Then we organized regional focus groups with three early-stage support groups, gathering thoughts and ideas on volunteering and barriers to participation from 24 individuals. Based on these initiatives, we created a survey of staff in 81 Alzheimer Society organizations nationwide. We gathered data on the present involvement of people with ADRD, and staff insights and experiences on attracting and accommodating this emerging consumer group.

## About this report

Our report begins with findings from our literature review and the observations of our key informants. In Part 2, we summarize the insights of our volunteer and focus group interviews. In Part 3, we highlight the results of our Alzheimer Society staff survey. Finally, in Part 4, we reflect on key themes, observations, and findings, with suggestions on how our member organizations can enhance their efforts to engage people with ADRD as volunteers.

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## PART 1: Review of literature and key informants

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This literature review is complemented by information gathered through interviews with nine key informants – researchers, clinicians, and representatives from international Alzheimer organizations.

### Learning from the support group experience

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There is little published literature on engaging people with Alzheimer's disease and related dementias (ADRD) in volunteer or advocacy activities. Most of the literature on working with people with early-stage dementia is based on the experiences of early-stage Alzheimer support groups. In Canada, the first support group was established in 1993; by 2005, there were over 85 groups nationwide. These educational, self-help groups typically average six to eight members (Alzheimer Society of Canada, 2003a).

Although these groups may vary in structure, membership, and leadership, all offer a positive, non-judgemental forum for people with ADRD and their family members to discuss concerns and connect with others who face similar challenges.

A review of available studies on early-stage support groups suggests that people want to be heard and have their opinions respected. Although a diagnosis often focuses on the person's diminishing abilities, individuals with early-stage dementia are capable, functional, and able to express their insights and concerns in a group setting.

Recruitment to early-stage support groups is challenging. The most effective source for referrals tends to be local community service providers (i.e., the psychogeriatric assessment team), the memory clinic, family members, and personal contact from Alzheimer Society staff and volunteers. Individuals who get involved require some level of structure, support, and consistency.

### Making a contribution

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Volunteering can offer people with ADRD a meaningful activity, a chance to contribute, opportunities for social interaction, and a voice in the work of the Alzheimer Society. Matching the volunteer to a role that suits her or his skills will help to ensure a positive volunteer experience.

### Benefits for people with ADRD

For people with ADRD, volunteering can be an important coping strategy. It can increase self-esteem by allowing them to use their skills and experiences in an environment where the disease is understood (Beard, 2004; L. Snyder, personal communication, September 14, 2005). It also gives people an opportunity to influence policies and programs aimed at improving their quality of life, and that of others with ADRD (L. Jackson, personal communication, September 19, 2005; H. Regan, personal communication, September 12, 2005). People may also choose to contribute to research aimed at prevention, management, or cure of the condition. Through these contributions, people with ADRD will be heard and respected as valuable members of



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the decision-making process (K. Whitfield, personal communication, September 21, 2005).

*“We can educate our peers...so many are hiding, and not getting the diagnosis...if they see strong people with ADRD, more of them will come forward.”*

Active volunteer with ADRD

Whitfield and Wismer (in press) looked at people with ADRD who were involved in Ontario’s provincial Alzheimer organizations. They found that these volunteers felt positive about their involvement; they felt connected to others, nurtured, and some perceived an improvement in their health.

*“My work is still of value. I can still educate people...I can still play a valued part.”*

Active volunteer with ADRD

## Benefits for the Alzheimer Society

Increased involvement will lead to a better understanding about how to meet the needs of people affected by Alzheimer’s disease (L. Jackson, personal communication, September 19, 2005), particularly individuals in the early stages. Their input will help us clarify and strengthen the delivery of services for all consumers, keeping us and our member organizations focused and credible (K. Whitfield, personal communication, September 21, 2005). It could also help us to create a broader vision for our organization, leading to lobbying for increased government support (A. Phinney, personal communication, October 5, 2005; Regan, 2005, July).

## Challenges and issues for people with ADRD

Some experts are concerned that people with dementia might risk feeling belittled or developing increased levels of stress if they are misunderstood or frustrated in their attempts to communicate as volunteers (Whitfield & Wismer, in press).

Consultations with our key informants raised the notion of *tokenism*, but people with dementia represent a wide variety of skill levels, experiences, abilities, and interests. (A. Phinney, personal communication, October 5, 2005).

There are also practical barriers that may prevent individuals with ADRD from volunteering, such as transportation costs and other financial issues, health factors that may affect performance [such as fatigue], and the amount of reading involved.

## Challenges and issues for the Alzheimer Society

Including people with early-stage dementia also poses challenges for our organization. There are challenges in supporting people with diminishing cognitive abilities, and in facilitating active and meaningful involvement while supporting their needs. And there are barriers to developing strategies and offering opportunities to individuals who may be unable to communicate verbally or give informed consent (A. Phinney, personal communication, October 5, 2005).

There are also less obvious challenges for our staff and volunteers. Experts such as Beard and Jackson see the potential for attitudinal barriers both in society (Beard, 2004) and among staff members (L. Jackson, personal communication, September 19, 2005). And some fear that using relatively well-spoken people will prompt the public to see ADRD as less threatening and less worthy of their charity dollars.

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Some experts in the Whitfield and Wismer study caution that consumer inclusion might not adequately fulfill the needs of people with ADRD and thereby open us to criticism, or may result in a shift of power, making it difficult for organizations to meet the needs of other stakeholders (e.g., caregivers). Factors such as these could pose barriers to further inclusion of people with ADRD.

## Organizational inclusion of consumers

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Current literature reflects the relationship between good governance in an organization and inclusion of consumers (Whitfield & Wismer, in press).

In order to actively encourage and engage participation of consumers, charitable and nonprofit organizations must be accommodating and inclusive (Goldsilver & Gruneir, 2001; Prior, Stewart & Walsh, 1995; Whitfield & Wismer, in press). This means effective representation of the interests of stakeholders and a strong value base. Ideals of democracy, social responsibility, and public good are crucial for developing effective goals and policy. Other essentials for an inclusive organization are:

- accountable service providers and decision makers,
- involved consumers,
- accessible information,
- accessible services,
- client-directed needs assessments,
- some identified way of responding to complaints,
- ongoing monitoring and consumer feedback, and
- consumer involvement in service planning and evaluation.

## Consumer inclusion in other voluntary organizations

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Existing literature reflects a number of strategies for effectively including people with illnesses or disabilities in advocacy organizations (McColl & Boyce, 2003). In some cases, this means involvement through governing boards (Weaver, 2002); in others, consultation through working or focus groups proved successful (McCallion & McCarron, 2004).

A deliberative dialogue guide for inclusion and diversity has been developed (Buchanan & O'Neill, 2001) that details common approaches to achieving inclusion and diversity in organizations. Deliberative dialogue is reflective, exploratory, and open to all options; the overall goal is to understand the interests and values of consumers and the association. A moderator guides the process, helping participants share opinions and beliefs so they can make decisions that work for the organization as a whole.

Clare and Cox (2003) found that organizations enjoy several benefits by including their consumers, particularly a better understanding of the people they serve. Charitable and nonprofit organizations that do not include consumers will not draw upon a full range of available skills and support, and are unlikely to succeed effectively in meeting the needs of their consumers.

Some groups have more experience including consumers in governance and planning. The Center for Medicare Education in Washington, D.C., explored ways to recruit and retain consumers with mental health issues on boards (Weaver, 2002). They suggest that an organization recruit people who have experienced the impact of that organization's

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policies and practises. The ideal candidate would be someone who speaks up, yet understands the need to cooperate, compromise, and collaborate. Also, it is helpful to bring more than one consumer on as a board member at a time. Two or more consumers can support each other, and there is more chance that one can attend meetings if the other becomes ill. Current board members should be informed of additions well in advance and discuss the introduction of consumers to facilitate the process.

Literature by Heller et al. on involvement of individuals with mental retardation brings potential barriers to light (Heller, Pederson, & Miller, 1996). They include difficulty in understanding content, socio-economic and self respect issues, logistical difficulties like transportation, and personal support difficulties.

Support strategies that they found helpful include:

- having a support person sit with the consumer at meetings;
- sending meeting materials in advance so there is time for the consumer to go over things and ask questions;
- taking time at meetings to allow for understanding and response; and
- using smaller steps in assigning tasks or giving instruction.

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## Inclusion of people with early stage dementia

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As early diagnosis is a relatively recent phenomenon, literature on this topic is scarce. In 2003, we reviewed available early-stage dementia literature and shared a discussion paper on our findings with our provincial societies (Alzheimer Society of Canada, 2003a). One challenge identified at that time was how we can reach and include people recently diagnosed with early-stage dementia.

Most of the progress on this issue is exemplified in literature from Australia, New Zealand, and the United Kingdom. Australia has a well-developed consumer consultation system; each state has an advisory council in place (Eayrs, personal communication, October 4, 2005), and a report on consumer inclusion is a standing item on the agenda of each council.

The New Zealand People with Dementia Terms of Reference Group is a consumer-based consultation group that provides opinion and advice to Alzheimer's New Zealand on policies, priorities, and strategic direction. Research conducted by the Alzheimer's Society of the United Kingdom on its Learning to Live with Dementia Project has also been essential (Robson & Locke, 2002). This project provided consumers with support and encouragement to become involved in the Society and have more say in their care. An evaluation of the project revealed that people with dementia were more visible and influential compared to their status two years prior to the project launch.

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The project also looked at the Society's attitudes and structures in light of encouraging involvement. Traditionally, involvement has mainly been through support groups rather than contributing to service or policy; most consumers influence staff through caregivers and by informal contact with staff and professionals.

Organizational changes as a result of this project include the fact that the Society's Council of Management has made involving people with dementia a strategic priority. The project has also become part of the core activities and budget of the Society. And it has helped to create conditions for staff to provide enhanced service to people with ADRD.

## Funding issues

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Until recently, the focus of our funding has been to support caregivers (Whitfield & Wismer, in press), which makes it difficult to develop strong partnerships with people with ADRD. We will need to convince funders that we require more funding to maintain a balance between our current programs and our efforts to include more people with ADRD. With government cutbacks and demands for services increasing, many Alzheimer Society organizations are already struggling to maintain their present services.

*"Being focused on one's own existence and stability makes it difficult to be innovative."*

Alzheimer staff member, 2006

## Issues of capacity and loss

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With diseases such as ADRD, there are fluctuations in abilities that affect peoples' capacity over the long and short term. We should take advantage of the fact that people can still communicate and contribute until the later stages of the disease.

Regardless, there will be an eventual loss of competence and individuals will have problems completing tasks. This can have a negative impact on the mission and credibility of this organization (Alzheimer's Disease International, 2003).

Preparations must be made to address this issue in an acceptable manner for both our organization and volunteers. Addressing these concerns at the beginning of the volunteer relationship can help. For example, we can tell a volunteer that she or he can make the decision to eventually move on based on her or his unique situation, or offer volunteer roles to people for a set period of time. We can also suggest alternate ways to remain involved such as other Alzheimer Society or community programs (L. Snyder, personal communication, September 14, 2005).

Practical considerations for governance include:

- Making constitutional and additional arrangements as dementia-friendly as possible to ensure that people with dementia can make a useful contribution. Examples include setting length of term, using sub-committees to handle routine business, providing a calendar of board meetings, reducing ad hoc or changed arrangements, and using e-mail or online conferencing for some business.

- Exploring other ways that people with ADRD can be involved in decision-making if the board is not an appropriate mechanism. Examples include consumer advisory boards or involvement through working groups and sub-committees.

## Strategies to promote inclusion

Suggestions for promoting inclusion (Alzheimer's Disease International, 2003; Alzheimer Society of Canada, 2003; Eayrs, 2002) include:

- holding regular consultation groups when developing new services and information packages;
- surveying individuals about services/programs to determine whether their needs are being met and if changes are recommended;
- inviting them to share their experiences to help develop policy;
- including their perspective in awareness campaigns;
- inviting them to speak at events, conferences, or training sessions;
- involving them in planning and implementing fundraising campaigns;
- involving them as peer supporters for people with a recent diagnosis.

## Establishing inclusion as a priority of the Alzheimer Society

Giving people with ADRD a stronger voice in the Alzheimer Society will involve some changes in our attitudes, systems, and structures. It is the responsibility of our leadership to foster open communication and use a participatory style of working. Participation requires an organization-wide effort that is supported with regulations and

policies (Whitfield & Wismer, in press). Boards and management need to demonstrate that they value openness, trust, and support, and that they are committed to drawing out the capabilities of individuals with ADRD.

As with other volunteers, inclusion is most successful when volunteers and tasks are appropriately matched. We must therefore develop the capacity to involve people with ADRD based on their skills and experiences. Volunteers should also be encouraged to be involved to the extent that they are willing and able. (L. Jackson, personal communication, September 19, 2005; L. Snyder, personal communication, September 14, 2005).

Alzheimer's Australia provides a number of concrete suggestions for organizations to facilitate inclusion (Eayrs, 2002), such as:

- clearly stating in their values and vision their commitment to involve people with dementia;
- endorsing the consumer's right to participate in the activities of an association as far as she or he is willing and able;
- acknowledging the value of current and future contributions by consumers;
- reviewing the strategic plan to strengthen opportunities for consultation and participation;
- identifying mechanisms to strengthen the volunteer at other levels of the association;
- looking for further opportunities for consumers to be involved;
- keeping consumer focus as a standing item on agendas to provide a standard for monitoring progress and to encourage the sharing of ideas; and
- networking with other similarly minded organizations to strengthen capacity.

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Some researchers such as Whitfield (K. Whitfield, personal communication, September 21, 2005) have identified a number of organizational factors that must be taken into account when planning for inclusion:

- organizational characteristics, such as inclusive leadership, an inclusive vision and structure for the organization, organizational readiness, and a collaborative culture within the association;
- considerations at the planning level, for instance, an assessment of the prior professional capacity and leadership experience of the person with dementia, and the requirements of individuals who are facilitating inclusion;
- using various strategies designed to facilitate inclusion (e.g., face-to-face meetings on relevant issues for people with dementia who are involved as board or committee members), and the use of certain criteria when evaluating inclusion efforts.

Whitfield also identifies constraints that may hinder inclusion, such as a lack of resources, fragmentation in services, a historical focus on caregivers, and both the progressive nature and stigma associated with the disease.

The structure of Alzheimer associations in the United Kingdom exemplifies how organizational changes may prove difficult. Individual chapters in the UK are quite variable in terms of quality, priorities, and activities. Each one is autonomous, and few, if any, regulations apply to all organizations. Effecting change in situations such as these can be difficult (P. Robson, personal communication, September 20, 2005).

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## Attracting volunteers

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The Australian report (Eayrs, 2002), recognizes that support groups can be essential in recruitment, but stresses that information on volunteer opportunities should be offered without obligation to group members.

The literature on recruitment of volunteers among other advocacy organizations translates well to our field. Staff must recognize and address a potential volunteer's socio-economic and self-confidence issues, and logistical difficulties related to transportation or personal support.

Research into recruiting baby boomers also offers us some useful strategies. This generation is reaching the age where ADRD is more common, so it is likely that a person with ADRD will be similar in characteristics and experiences to others in her or his generation (Bowen & McKechnie, 2001).

As Dawn Lindblom states,

*“This generation will be seeking volunteer opportunities in which they can make a meaningful contribution, in a shorter amount of time. This reflects the urgency for organizations to reflect on the potential for short term opportunities that exist and determine if there is a role for senior volunteers to contribute.”*

(Bowen and McKechnie, 2001:20)

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In the case of baby boomers with ADRD, this statement is doubly significant. They may be motivated to make a contribution to our understanding of the dementia process and leave a legacy of improved services. Designing ways that they can do this in short, focused stages will be crucial for recruitment, retention, and recognition.

Family volunteering also gives an individual with ADRD the opportunity to do something meaningful while spending time with a family member (Bowen & McKechnie, 2001). For the individual and her or his family, volunteering together can promote

the development of working as a team, with family members providing direct support and allowing the person with ADRD to complete as much of the task as possible. For family members, this provides an opportunity to help and interact with the person with ADRD. For both parties, volunteering offers the support of others in similar situations.

Volunteer Canada has also published a discussion paper on family volunteering that may be useful for our member organizations in promoting this approach (Volunteer Canada, n.d)

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## PART 2: The consumer view

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We spoke with two groups of people with Alzheimer's disease and related dementias (ADRD) – the first included individuals who are active and experienced volunteers with the Alzheimer Society; the second included members of early-stage support groups who are not currently volunteers.

Both groups were asked questions in order to highlight similarities and differences in knowledge about our services, as well as perceived benefits, challenges, and supports needed to encourage inclusion.

Overall, active volunteers demonstrated a better understanding of the types of services we provide and the best ways they could make contributions as volunteers. They also identified a broader range of barriers to volunteering, such as staff attitudes.

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### The active volunteers

Six men and three women made up this group: 2 from Western Canada, 5 from Ontario, 1 from Quebec and 1 from Eastern Canada. Two discussion sessions were held – a face-to-face session with five people and a teleconference with a group of four. Informed consent was received from all participants. Discussions were audio taped. The following section reports on the findings.

#### How did you come into contact with the Alzheimer Society?

Most active volunteers say they first became involved as a member of an early-stage support group, and were invited by an Alzheimer Society staff member to become more active in the organization.

#### What do you do as a volunteer for the Alzheimer Society?

Most volunteers are involved in education about ADRD and its impact. They speak to local service clubs, to college students, at Alzheimer Society open houses, and to the media. Several have participated in events designed to raise the profile of ADRD and break associated stigmas or have made presentations at national and international conferences. Four volunteers were board members of either a local office or the national Alzheimer Society. Two were involved in government advocacy efforts. Several have been involved in public policy or program development committee work. One volunteer is the editor of a newsletter for and by people with ADRD and co-facilitates an early-stage support group. Another offers personal support to newly diagnosed people.

#### Do you think people with early-stage dementia would benefit from becoming involved in the work of the Alzheimer Society?

Volunteers are very enthusiastic about their involvement and they highly recommend volunteering to others with the disease. They say they are motivated by their desire to educate [the public] and others with the disease. Other benefits include improved levels of self-esteem and the pleasure of providing “a voice” for people with the disease.

Volunteers say involvement with the Society provides opportunities to learn from and share with others, and makes them feel good about what they do. They see that their work is of value, and that they are respected and appreciated. So they believe being involved and



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doing something useful may help an individual to deal with the depression that often comes with the diagnosis.

### **Do you think the Alzheimer Society would benefit from people with early-stage dementia being involved in its work?**

Volunteers believe they have several benefits to offer the Alzheimer Society, such as providing insight into living with ADRD and assisting the Society in its education and advocacy work.

### **What, if any, challenges or barriers did you face as you began your volunteer involvement?**

Active volunteers say personal barriers (e.g., the time it takes to absorb the shock of diagnosis and gather the courage to step forward), making transportation arrangements, and finances were challenges to volunteering.

Volunteers also say that some staff still see *“the disease more than they see the person.”* Members of staff were overly concerned about putting them in positions given that their ability to fill that role will eventually deteriorate. Yet, organizations have policies or ask “regular” people to leave board and other positions when they lose capability due to advanced age, illness, or other situations.

### **What kinds of practical help do people with Alzheimer’s disease need to be able to volunteer with the Alzheimer Society?**

Volunteers say staff support is important. They suggest a number of ways that staff could help volunteers, such as handling all public speaking and media requests, and helping volunteers prepare related presentations. Overall, volunteers acknowledge the extra work involved for staff but feel that their contributions outweigh the assistance required.

### **Support group participants**

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Three group discussions were held with members of existing early-stage dementia support groups. Twenty-four people participated (16 men, 8 women) in the Western Canada, Ontario, and Quebec groups. A fourth discussion group representing the Eastern Region could not be convened.

Facilitators for each early-stage support group conducted the group sessions. They received a thorough orientation on content and procedure. The group discussions were audio taped. The following sections reports on the findings.

### **How did you come in contact with the Alzheimer Society?**

Most participants say caregivers had made initial contact and inquiries on their behalf. A few participants were referred by their physicians following diagnosis, but most contacted the Alzheimer Society themselves after receiving information through the media.

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## How is the Alzheimer Society helping you right now?

Participants say being involved in a support group is helpful. They enjoy making friends and having an open forum to share experiences, thoughts, and feelings. Sharing helps members to understand the nature of their illness, cope with anxiety, and have hope for the future. Many say that it gives them a place to go for encouragement and positive feedback.

*“[The group] helps me keep active and see that my life is not over since my diagnosis and gives me hope for the future.”*

A few participants say they have also attended Alzheimer Society information sessions, which help them stay current with issues and resources. Participants say these programs also benefit health care staff, who need to recognize and be aware of the disease.

*“[The] best thing is that they don’t leave us out as clients or consumers [and] get us involved as much as they can, that’s really important.”*

## What else do you think the Alzheimer Society does?

A number of participants are not aware of other Alzheimer Society activities. Some knew about our commitments to fundraising, education, and supporting medical and research advances.

## Do you think people with early-stage dementia would benefit from becoming involved in the work of the Alzheimer Society?

Many agree that being involved is beneficial, allowing them to give back to the Society. They say it would also be informative for them and their caregivers, helping them to become more aware and appreciative of the Society’s work. This knowledge could help them reach out and communicate with others with the disease as well as the general public.

*“[Being involved] helps relieve the anxiety and tension that the individual experiences with the disease...you would know that ‘you are not alone’...the future seems a little less frightening.”*

## Do you think the Alzheimer Society would benefit from people with early-stage dementia being involved in their work?

Echoing points raised by experienced volunteers, many participants say the Alzheimer Society would benefit from the skills, talents, and insights of people with early-stage dementia.

## From your perspective, what would a person with early-stage dementia need to become involved in the work of the Alzheimer society?

Many say access to information on volunteer opportunities is important, allowing them to make decisions based on comfort level and interest. Some say it would have been helpful to have one-to-one contact with a staff member following diagnosis, such as an in-home visit and discussion on their needs, to get them involved. Participants recognize, however, the financial implications of providing this kind of personalized support.

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## PART 3: The Alzheimer Society staff survey results

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In interpreting the survey results, it is important to understand the different organizational models of our members across Canada.

In Western Canada, the Alzheimer Society is organized as a central provincial agency; a provincial board serves each province through local offices. In Ontario and Quebec, cities and regions have developed independent chapter offices with individual boards. They work in collaboration with the provincial boards. In Eastern Canada, New Brunswick and Newfoundland and Labrador's provincial offices serve each province through local offices. In Prince Edward Island and Nova Scotia, the provincial office serves the entire province.

### Our methodology

We gave provincial associations the choice as to how they would like to participate. British Columbia, Saskatchewan, New Brunswick, and Newfoundland and Labrador requested that the survey be sent to the provincial office only. Alberta, Manitoba, Ontario, and Quebec chose to have surveys sent to both provincial and local offices.

Our survey gathered data on the present involvement of people with Alzheimer's disease and related dementias (ADRD), staff insight and experience related to recruitment and accommodation, and efforts to promote inclusion.

We e-mailed 81 surveys and received 50 completed surveys – a response rate of 62% (Table 1, p.14). The national office responded, as did every provincial office (100% response rate). Out of 70 local offices, 39 (56%) responded.

Tables 2 (p.15) and 3 (p.15) present the number of full and part-time staff working for provincial and local Alzheimer Society organizations. As Eastern Canadian respondents gave a single response for each provincial office, we have no information on staff numbers in local offices.

Fifty-nine percent (59%) of these offices operated with five or fewer full-time staff, and 8% had only part-time staff.

Volunteers have a significant role in the work of Alzheimer Society organizations, as reflected in Table 4 (p.16).

As noted previously, participation in early-stage support groups is often the first point of contact that people with ADRD have with the Alzheimer Society, and this appears to be integral in recruitment. Figure 1, p.16 presents the percentage of organizations that have early-stage support groups.

As shown in Figure 1 (p.16), the percentage of organizations in Quebec that offered support groups was somewhat lower than in other regions. Nearly half of Quebec respondents (43%) wrote elsewhere in the survey that they recognized the need for support groups.

**Table 1: Survey response by region and province**

Region	Province	Sent (81)	Received (50)
<b>Western Canada</b>	British Columbia	1 provincial	1 provincial
	Alberta and the Northwest Territories	1 provincial 4 local	1 provincial
	Saskatchewan	1 provincial	1 provincial
	Manitoba	1 provincial 5 local	1 provincial 2 local
<b>Ontario</b>	Ontario	1 provincial 40 local	1 provincial 24 local
<b>Quebec</b>	Quebec	1 provincial 23 local	1 provincial 13 local
<b>Eastern Canada</b>	New Brunswick	1 provincial	1 provincial
	Nova Scotia	1 provincial	1 provincial
	Prince Edward Island	1 provincial	1 provincial
	Newfoundland and Labrador	1 provincial	1 provincial
<b>National</b>		1 national	1 national

Participation in early-stage support groups varies across regions. In the last fiscal year, 57% of respondents served 10-35 people in support groups, and 29% served nine or fewer. This contrasted with the 15% of respondents who served between 40 and 150 people with ADRD.

Support group participation is growing. Eighty percent (80%) of respondents reported 10 or more new members in the past year. In contrast, 88% of respondents said that fewer than five people had left the group during the past year.

**Table 2: Full and part-time staff in provincial Alzheimer Society offices**

No. of Staff	Number of provincial offices (n) in sample							
	Western Canada (n=4)		Ontario (n=1)		Quebec (n=1)		Eastern Canada (n=4)	
	Full-time	Part-time	Full-time	Part-time	Full-time	Part-time	Full-time	Part-time
1 – 2	0	2	0	1	0	1	1	1
3 – 5	0	1	0	0	1	0	2	3
6 – 9	1	0	0	0	0	0	1	0
10 – 15	1	1	0	0	0	0	0	0
Over 15	2	0	1	0	0	0	0	0

\* Note: Each column shows the number of offices per region and the number of staff for these offices. For example, in Western Canada, one office had 6-9 full-time paid staff members, one had 10-15, and two had over 15. Regarding part-time paid staff, two offices had 1-2, one office had 3-5, and one had 10-15.

**Table 3: Full and part-time staff in local Alzheimer Society offices**

No. of Staff	Number of local offices (n) in sample					
	Western Canada (n=4)		Ontario (n=1)		Quebec(n=1)	
	Full-time	Part-time	Full-time	Part-time	Full-time*	Part-time
1 – 2	1	1	5	13	6	5
3 – 5	0	0	8	8	4	3
6 – 9	0	0	5	1	0	4
10 – 15	0	0	4	2	1	1
Over 15	0	0	2	0	1	0

\* Data were missing from one survey.

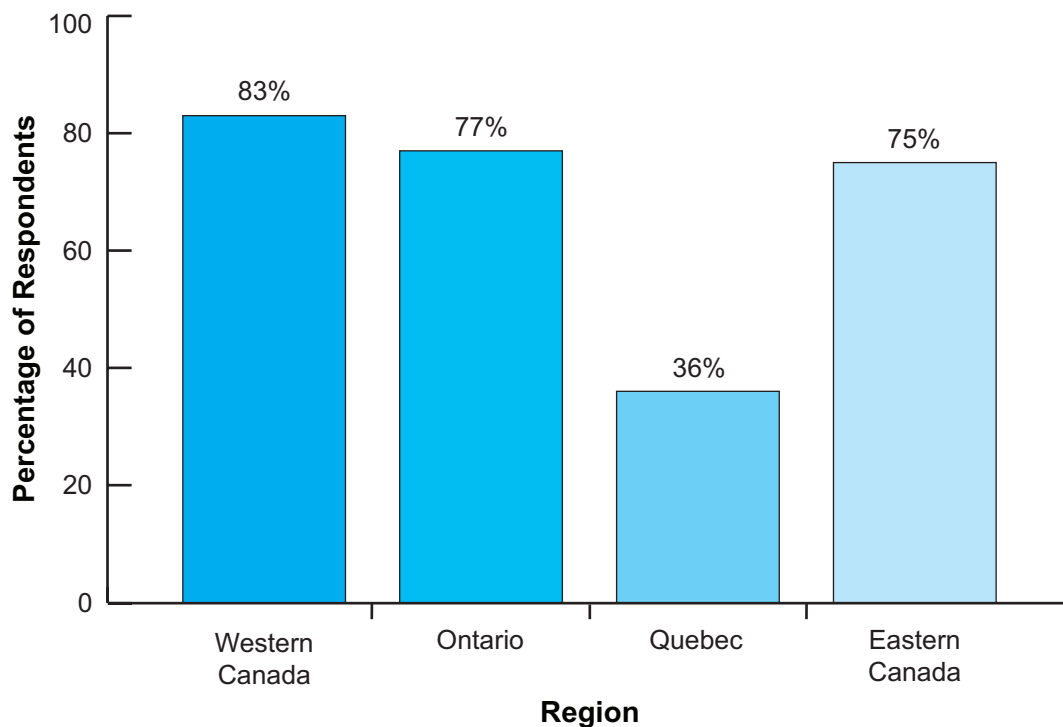
\* Note: Data from Eastern Canada were not included in this sample as we collected provincial data only.

**Table 4: Volunteers in provincial and local Alzheimer offices**

No. of Staff	Number of provincial offices (n) in sample						
	Western Canada		Ontario		Quebec		Eastern Canada
	Provincial (N=4)	Local (N=1)	Provincial (N=1)	Local (N=24)	Provincial (N=1)	Local (N=13)	Provincial (N=4)
1 – 50	0	0	1	2	0	8	0
51 – 100	0	1	0	8	1	4	0
101 – 150	0	0	0	5	0	0	0
>150	4	0	0	9	0	1	4

Note: Data from Eastern Canada’s local offices were not included in this sample.

**Figure 1: Alzheimer Society organizations offering support groups by region**



## Volunteers with ADRD and their activities

Table 5 (p.18) presents the number of organizations that have active volunteers with ADRD.

As shown in Figure 2, 8% of respondents indicated other activities, including co-facilitating early-stage support groups, accompanying staff to meetings with government officials, and conference presentations.

Fourteen percent (14%) of respondents provided specialized volunteer training that included:

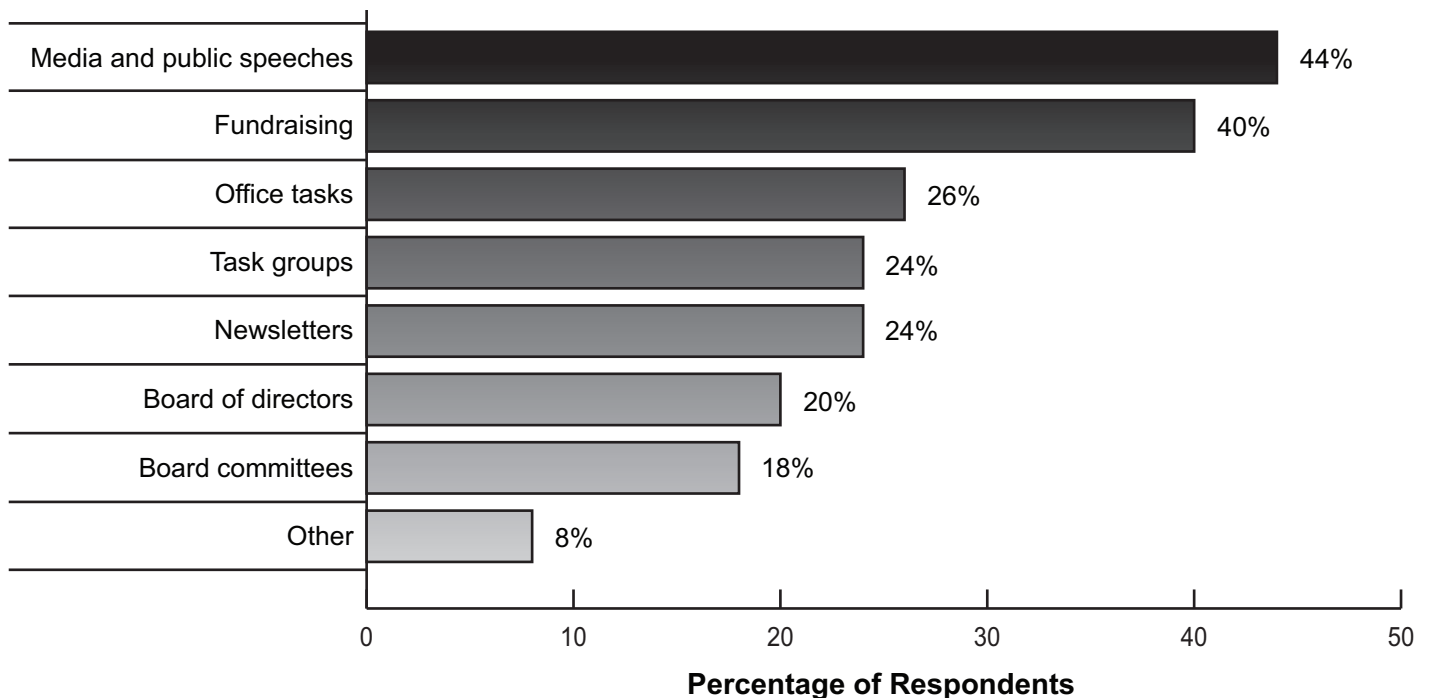
- detailed board orientation packages, with time set aside for questions and clarification,
- rehearsals for media interviews and specific information or education training sessions, and
- a five-part volunteer orientation for those on the speaker’s bureau.

Forty-two percent (42%) said they provide additional support to volunteers with ADRD. Most noted that the assistance is individualized, such as:

- preparing notes or information packages for the volunteer before a media interview or speech;
- frequent meetings with the volunteer or educational coordinator; and
- providing transportation or escort services.

Twenty percent (20%) of respondents noted the extra expense involved in supporting these volunteers due to costs for staff time and transportation.

**Figure 2: Volunteer activities for people with ADRD**



**Table 5: Active volunteers with ADRD in provincial and local Offices**

<b>Region and Number of offices in sample (n)</b>	<b>Respondents Reporting Volunteers with ADRD</b>	<b>Total Number of Active Volunteers</b>	<b>Average Number of Active Volunteers by Organization</b>	<b>Range in Number of Active Volunteers</b>
<b>Western Canada (n=4 provincial) (n=1 local)</b>	Provincial (n=2)	20	10	0 – 10
	Local (n=0)*	N/A	N/A	N/A
<b>Ontario (n=1 provincial) (n=23 local)</b>	Provincial (n=1)	1	1	N/A
	Local (n=17)	71	4	0 – 15
<b>Quebec (n=1 provincial) (n=12 local)*</b>	Provincial (n=1)	1	1	N/A
	Local (n=8)	18	4	0 – 7
<b>Eastern Canada (n=4 provincial)</b>	Provincial (n=3)	41	14	0 – 30

\* Data were missing from one survey.

\* Note: Data from Eastern Canada’s local offices were not included in this sample. Volunteers are involved in a range of activities, as reflected in Figure 2. Activities are arranged in descending order based on volunteer involvement.



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## Direct consultation with people with ADRD

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The majority of respondents (87% overall) consulted directly with people with ADRD. Reported methods of consultation are shown in Figure 3 (p.20).

Twelve percent (12%) of respondents used other methods of consultation, including specific discussions when developing new programs or services, InfoLine calls, and feedback from participants in support and education programs.

### Activities to increase inclusion

More than three quarters (77%) of respondents engaged in activities to include people with ADRD. Figure 4 (p.20) shows the list of activities. More than half were actively discussing the issue of inclusion (54%) and involving people in planning new services (50%). Approximately one quarter (24%) were working to establish specific goals and strategies to promote inclusion.

Twelve percent (12%) of respondents identified other inclusion activities, including a literature review on inclusion issues, a research project focused on inclusion, and a proposal to host an inclusive conference.

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## Attitudes and opinions

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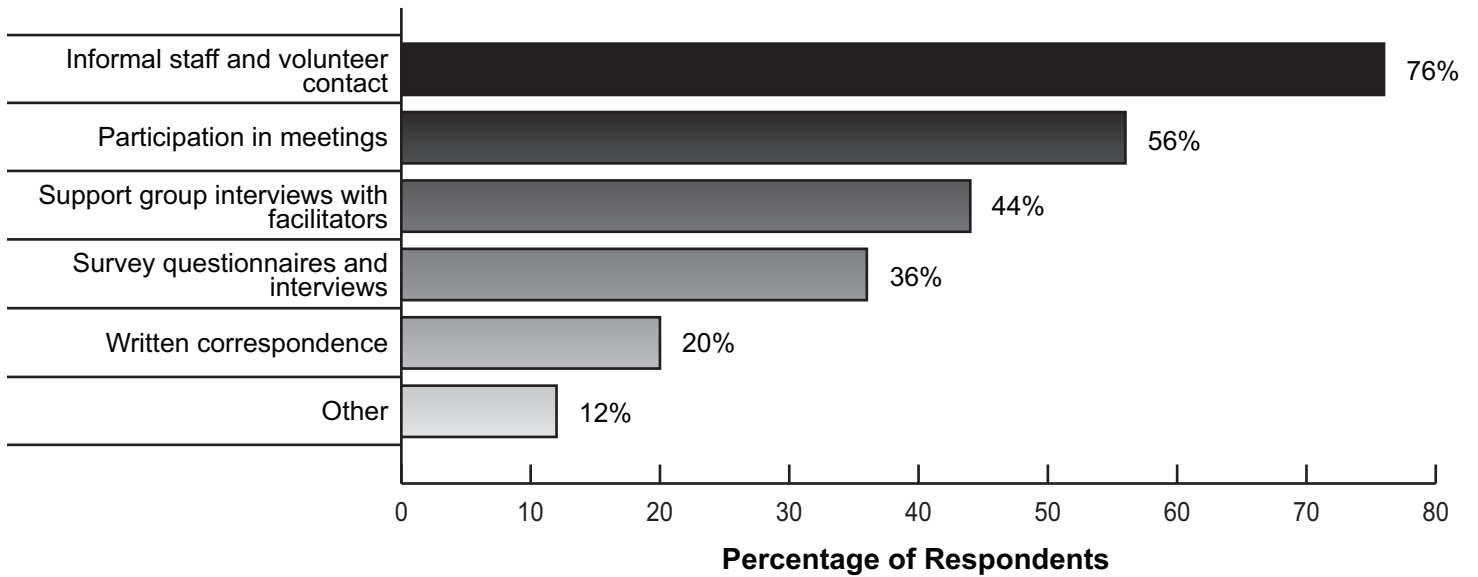
Given differing literature and expert opinions on involving people with ADRD in our work, we presented a number of statements to measure respondents' attitudes and opinions on this issue, and on the Alzheimer Society and its staff. Many of these statements were drawn from a survey related to the British Learning to Live with Dementia Project (Robson & Locke, 2002). Respondents were asked to indicate their degree of agreement for each statement, using a four-point rating scale where 1=disagree and 4=agree. The tables that follow present average scores based on all respondents' ratings.

### People with early stage dementia: Skills, abilities, benefits and challenges

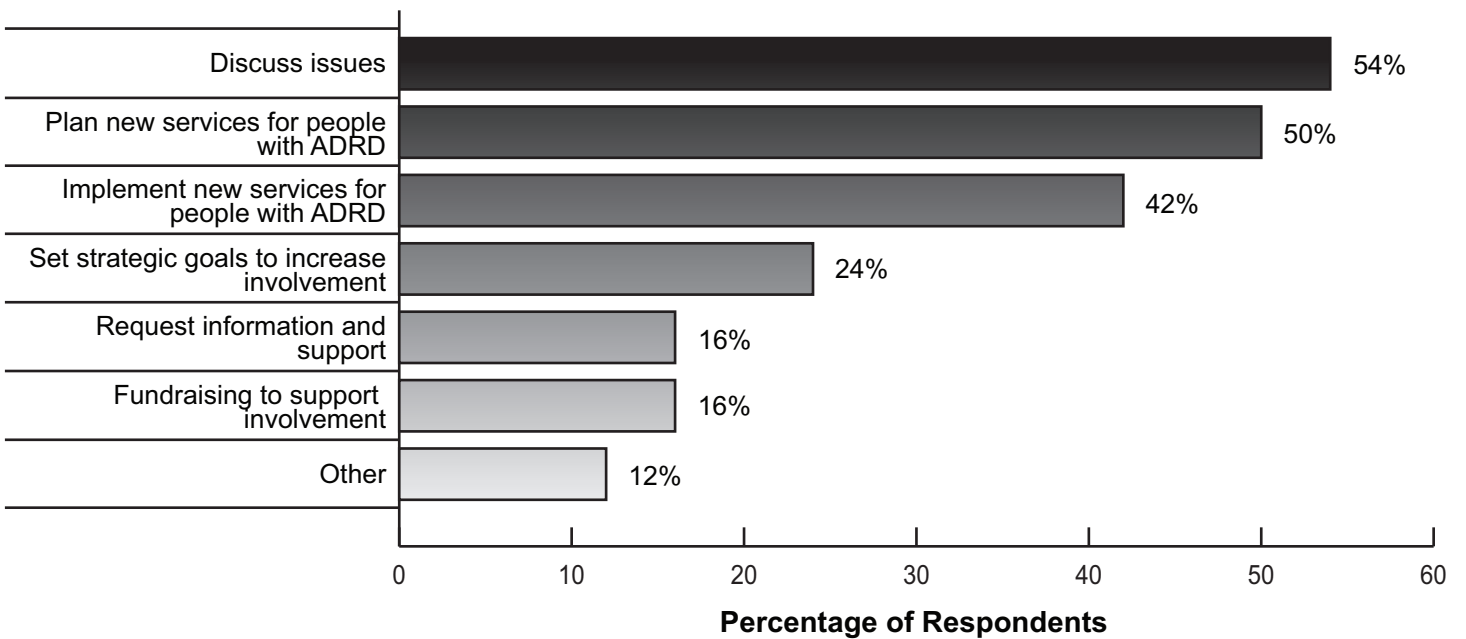
Respondents considered statements about the skills and abilities of people with ADRD, and perceived benefits or challenges related to involvement. To reduce response bias, three items were reversed, so that disagreement with the item (i.e., a 1.0 response) would indicate a more positive attitude or opinion. For all other statements, values closer to 4.0 indicate positive attitudes. Statements are listed in Table 6 (p.21), with the reversed items indicated. In addition to the table, the accompanying text outlines respondents' answers in percentages.

Virtually all respondents (98%) agreed (*Agree* and *Somewhat Agree* responses) that people with early-stage dementia have the same right to be heard as anyone. Most agreed that people with early-stage dementia are able to help plan programs (98%) and educate staff or other volunteers (92%).

**Figure 3: Direct consultation methods between Alzheimer Society offices and people with ADRD**



**Figure 4: Organizational activities to facilitate inclusion**



**Table 6: Attitudes and opinions about people with ADRD**

<b><i>People with early-stage dementia...</i></b>	<b>Average Rating</b>
have the same right to be heard as other citizens.	4.0
can help plan programs.	3.8
can help educate staff and volunteers at the Alzheimer Society.	3.7
find working on committees too frustrating or stressful because of their limitations. (reversed)	2.0
can be involved in research as study participants, but not in any other aspect. (reversed)	1.5
lack the skills necessary to work with us by the time they are diagnosed.(reversed)	1.4
<b><i>Volunteering with the Society can provide a way for people with ADRD to...</i></b>	<b>Average Rating</b>
develop new relationships.	3.9
increase their self-confidence.	3.9
use their skills and experience.	3.9
make a meaningful contribution.	3.9
influence policy and programs that directly impact their lives.	3.8
develop new skills.	3.5

In answering the reversed questions, most respondents indicated that people with early-stage dementia retain the necessary skills to work with the Alzheimer Society after diagnosis (88%), and that they can be involved in all aspects of research, not just as study participants (82%).

There was a lack of consensus on the statement that people with early-stage dementia find working on committees too frustrating or stressful (58% disagreed; 34% agreed and 8% did not provide a response).

Almost all respondents (95%) agreed that people with ADRD would benefit from volunteering by developing new relationships, increasing their self-confidence, using their skills and experience, and making a meaningful contribution. Most (84%) also agreed that people with ADRD could develop new skills, although responses to this statement ranged widely.

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## Alzheimer Society: Skills, abilities, benefits and challenges

Using a series of statements, we explored attitudes and opinions on the perceived skills and abilities of the staff of the Alzheimer Society, and the related benefits or challenges of increased inclusion. These statements are presented in Table 7 (p.23). Several statements (indicated by an asterisk) were designed to determine whether staff share the anxieties about inclusion that we found in the literature. The remainder aimed to identify potential strategies to promote inclusion.

Virtually all respondents (98%) agreed that people with ADRD should have a voice in the Alzheimer Society. Ninety-six percent (96%) agreed that involving volunteers with ADRD will help eliminate the stigma of the disease, give hope to others, and encourage individuals to seek early diagnosis (96%). Most respondents further agreed that the Alzheimer Society has a strong understanding of what caregivers (94%) and people with ADRD need (96%). The majority also agreed that we should set an example by including people with ADRD in all aspects of our work.

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## Challenges to the Alzheimer Society

Most staff respondents (88%) were not concerned that including volunteers with ADRD as spokespeople could bias public perceptions regarding the severity of the disease and hamper fundraising efforts. Most also agreed that increasing the number of people with ADRD in program planning would not divert funds from caregiver services (88%). Respondents recognized that extra staff time is required to support volunteers with ADRD, but 98% of respondents reported that it is worth the cost.

There are some areas where respondents said we could assist them in increasing inclusion. As Table 7 (p.23) shows, most want to see a clear policy statement on the role of people with ADRD in the work of the organization. Roughly half (48%) agreed that specific training would help them work directly with people with ADRD. Almost half (46%) were concerned about what would be done when volunteers with ADRD could no longer perform their roles. Two-thirds (66%) were concerned that increasing the number of people with ADRD in program planning could make caregivers feel uncomfortable about voicing their own needs.

Finally, more than two-thirds (68%) agreed that the Alzheimer Society would only need to make minor changes to involve people with ADRD as active volunteers.

**Table 7: Attitudes and opinions about the Alzheimer Society**

<b><i>Our Alzheimer Society...</i></b>	<b>Average Rating</b>
should give people with ADRD a voice in their organization.	3.9
has a high degree of understanding of what caregivers need.	3.9
can adapt volunteer tasks so that people with ADRD can make a contribution.	3.8
has a high degree of understanding of what people with ADRD need.	3.6
needs a clear policy statement on the role of people with ADRD in the work of the organization.	3.5
should set an example by including people with ADRD in all aspects of our work.	3.5
will only have to make minor changes to our ways of doing things to include people with ADRD as volunteers.	3.1
needs to provide me with specific training if I am expected to work directly with people with ADRD.	2.4
will have to make significant changes to our ways of doing things to include people with ADRD as volunteers.	1.8
<b><i>If people with ADRD work on committees or volunteer...</i></b>	<b>Average Rating</b>
it is worth the extra time to support them because our Society will benefit from their knowledge.	3.8
it takes extra staff time to support them.	3.2
I will worry about what to do when they can no longer do their job successfully.*	2.4
<b><i>Increasing the number of people with ADRD in program planning...</i></b>	<b>Average Rating</b>
will make caregivers feel uncomfortable speaking out about their needs.*	1.8
will divert funds away from caregiver services.*	1.3
<b><i>Having people with early-stage dementia act as spokespeople for our Society will...</i></b>	<b>Average Rating</b>
help break down the stigma of ADRD.	4.0
give hope to others with ADRD.	4.0
encourage others to seek an early diagnosis.	3.9
negatively impact fundraising effort because people will think ADRD isn't so bad.*	1.3

\* Statements that explore whether staff share the anxieties about inclusion that we found in the literature.

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## PART 4: Findings and recommendations

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Findings from this project show that there is an international trend toward inclusion, and Canada has helped to lead the way. People living with Alzheimer's disease and related dementias (ADRD) are volunteering with the Alzheimer Society, and many others see the benefit of becoming involved. Our findings also indicate that both people with ADRD and Alzheimer Society staff are willing to overcome whatever challenges are involved to increase this involvement.

Based on these findings, we have identified the following five priorities:

### **1) Develop a strategic direction, policy statements and goals for consumer inclusion**

The Alzheimer Society of Canada is about to begin a federation-wide strategic planning process that will reflect our core values and guiding principles, specifically to *make the people we serve the primary focus in all decisions*. Developing a clear federation-wide strategic direction that addresses the need and importance of inclusion is consistent with this commitment.

Although virtually all staff surveyed (98%) agreed that people with ADRD should have a voice in the Alzheimer Society, most (88%) indicated the need for a clear policy statement on the role they will play. A federation-wide policy would encourage consistency and allow our member organizations to work together to better engage people with ADRD. The policy must be accompanied by both achievable goals and a series of tactics that local organizations

can easily implement. These goals and tactics should be evaluated frequently, especially during the early stages of development. Alzheimer's Australia, for example, has found it helpful to review reports of inclusion activities from each state association at national board meetings to monitor activities and developments.

### **2) Pursue enhanced funding**

For inclusion efforts to be effective, staff will require more time and funding to accommodate these new volunteers and their logistical needs (e.g., transportation). Alzheimer Society organizations are small; more than half operate with four or fewer full-time staff, and 8% with only part-time staff. Funding is uncertain, and available funds are stretched to provide current services. Although survey results indicate that organizations are willing to increase involvement, additional financial assistance is needed from government, by partnering with local health care organizations, or through fundraising.

### **3) Provide support and training for staff and volunteers**

Most professional literature on ADRD highlights the importance of staff training to increase inclusion, a sentiment echoed by our key informants and staff survey respondents.

Survey respondents identified several areas where education and support would be helpful, such as guidance and training on how to serve and support

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consumers while balancing caregivers' needs. Some (30%) expressed concern that caregivers may not feel as comfortable speaking out if people with ADRD were more involved in planning programs.

More than half of the respondents said they would not know what to do when volunteers' abilities deteriorated and they could no longer perform their roles successfully. Staff could benefit from guidance on how to address this issue at the time of recruitment. For example, they could state during recruitment that all jobs have a limited term. Ongoing communication and possible modification of tasks must occur to ensure that the work of the organization is being done and that the volunteer is not overwhelmed by responsibility or guilt. Scripts could be developed for staff on how to handle such situations. Staff also suggested that education for board members and volunteers would prepare them to communicate clearly and include new volunteers in a meaningful way.

Staff members also need ongoing support in adapting programs and services to increase the inclusion of people with ADRD. Networking through computer bulletin boards, professional issues meetings, teleconferences, or other creative means will help frontline staff share experiences and provide support across the country.

#### **4) Provide information and support for consumers**

Focus groups and active volunteers suggested several ways to improve involvement. Most want initial one-to-one contact with staff, access to information about volunteer opportunities, and a personal invitation to get involved.

They also need practical supports such as transportation and financial aid. Support and encouragement from staff and caregivers throughout the volunteer experience are particularly important.

Some focus group participants and staff (34%) agreed that working on committees might be too stressful for people with ADRD. This attitude could result in a standard response of exclusion. The issue can be addressed by acknowledging it with the volunteer when they are recruited, encouraging open communication, and offering assistance or job modification as necessary. Most staff indicated that although supporting people with ADRD as volunteers takes more staff time, it is worth it because of what these volunteers have to offer.

#### **5) Enhanced advocacy efforts and inclusion**

Further work is required, both in terms of lobbying the government for funding for more specialists and in partnering with physicians and universities for increased education for present and future physicians. People with ADRD could help in this advocacy process by educating government and medical personnel, and adding their eloquent voices to the arguments of the Alzheimer Society.

Involving people with ADRD in the advocacy process will ensure that we are meeting their needs and acknowledging their priorities. As Jim Jackson from Alzheimer Scotland stated in personal correspondence, *"We have greater legitimacy to do this because we can now say that we speak on behalf of people with dementia after we have involved and consulted them."*

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Having people with ADRD involved can help us and our member organizations stay focused on our mandate.

*“We have an office volunteer who comes in twice a week to do office tasks...Every time she comes, she reminds us why we are here...As we see her steadily decline, it is an opportunity for us to see first hand how this disease affects people directly...She is a strong advocate not only for herself, but for people with ADRD...She remains positive...The effect of her coming in twice a week appears to have been positive for her as well.”*

Staff survey respondent

## Conclusion

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The purpose of this project was to identify strategies that promote the active participation of people with early-stage dementia in the work of the Alzheimer Society.

Through a wide range of information gathering, interviews, and surveys, we've learned the valuable contributions that people with ADRD can and are making to the Society. We have also been reminded of the meaningful role that volunteering can offer people with Alzheimer's disease and related dementias, and the benefits they enjoy from having their voices and opinions heard. In short, we have reinforced much of what we already believed to be true, and learned a great deal about how we can move forward in our efforts to be more inclusive.

With the creation of a clear strategic direction and policy statements, we will continue to create opportunities for people to become full, active participants in our organization. Although we understand the challenges that will accompany this new path, the Alzheimer Society is dedicated to finding the necessary solutions.

Furthermore, it is our hope that the findings and observations of this report will be useful to other charitable and nonprofit organizations that are concerned with advocacy, inclusion, and empowerment, and would like to see their consumers become active self advocates, not just passive recipients of care and support.



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## APPENDIX A: The project advisory group members

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## APPENDIX B: The key informants

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# NOTES

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