

LETTER

Engaging individuals living with dementia as stakeholders

INTRODUCTION

Since its founding in 1980, the Alzheimer's Association (Association) has been at the forefront of breakthroughs in research, advocacy, and support surrounding Alzheimer's and dementia. A critical component of these advancements has been the Association's thoughtful inclusion of individuals living with dementia as key stakeholders in the work. The Association has been leading and convening individuals living with dementia as stakeholders for nearly 2 decades. Their input and guidance help to ensure that the priorities and work of the Association are aligned with the true needs of those living with the disease and their caregivers. This article outlines the evolution and growth of the Association's stakeholder engagement and the impact and influence this engagement has had on dementia care, practice, policy, and research across the country. Special emphasis is placed on the Association's highly successful Early Stage Advisory Group, including its details, contributions, and the Association's lessons learned. Finally, we discuss how including the voices of persons living with dementia in research is a growing movement and describe the exciting future directions of the Association with regard to increasing the influence and profile of these key stakeholders.

HISTORY OF THE ALZHEIMER'S ASSOCIATION'S STAKEHOLDER ENGAGEMENT

Recognizing the changing demographics of our aging population and science advancements on the horizon, in January 2006 the Alzheimer's Association launched an Early Stage Initiative to gather information about current early-stage programs and to explore the best ways to provide services to the emerging early-stage population. For the purposes of program design and planning in this initiative, "Early Stage" refers to people, irrespective of age, who are diagnosed with Alzheimer's disease or related disorders and are in the beginning stages of their disease. In this stage, individuals retain the ability to participate in daily activities and participate in a give-and-take dialogue. This includes, but is not limited to, persons with "younger onset" who develop dementia under age 65 and who are still in the early stages.

Between 2007 and 2008, and in support of this initiative, the Association conducted a series of nationwide town hall meetings. Intended

to gain further insights and perspectives, this series represented the first-ever nationwide discussion of Alzheimer's disease by individuals living with the disease. Of the approximately 800 participants, 301 were living with early-stage Alzheimer's or dementia. A broad range of topics were covered, including: diagnosis, available treatments and medicines, participation in research, loss of independence/coping with changes in function, changes in roles and relationships (personal and professional), safety issues (driving, wandering, home safety), care and support services, meaningful activities/social opportunities, and advocacy efforts. The thoughtful, open discussions arising from these historic town hall meetings provided profound insights on how to better empower individuals living with the disease, reduce stigma, and support independence.

EARLY STAGE ADVISORY GROUP

In the decades since the founding of the Early Stage Initiative and the nationwide town hall series, the Association has led the way in incorporating the voices of those living with dementia by including them across all facets of the organization. For the past decade and a half, one of the most important components of this effort has been the Association's National Early Stage Advisory Group (ESAG).

The ESAG is composed of 8–12 individuals from across the country who are living with early-stage Alzheimer's or other dementias, or mild cognitive impairment (MCI). The mission of the ESAG is to offer their unique perspectives and experiences related to living with the disease and to help raise awareness of Alzheimer's disease, advocate for funding and research, and provide invaluable input and advice on the development of programs and services designed for people living with the disease and caregivers. Participation in the program requires a letter confirming the diagnosis of dementia. In addition, nominees must be willing and able to share their stories publicly and travel to events as needed (with a required travel companion). ESAG members commit to a 1-year term, monthly conference calls, and two in-person meetings. An Institutional Review Board review is not required and individuals can discontinue their participation at any time.

A multi-step process is used to select each year's set of ESAG members. Interested persons are invited to apply through the Association's nationwide network of chapters, the Association website (alz.org), and

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via word of mouth (especially through past and current members of the group). Applications are done online, following which an interview by phone or virtual call is conducted covering their background, diagnosis, relationships, day-to-day challenges, and reasons for wanting to join. Next, an internal review committee (composed of representatives from public relations, medical and scientific relations, public policy, diversity, equity and inclusion, and communications) meets for 1 h, during which they receive a high-level overview of each nominee. These committee members are then given a detailed summary of each nominee to review on their own (including the information gathered during the interviews), and are asked to submit the names of 10 to 12 individuals they feel would make the best ESAG participants. Once the votes are tallied, the preliminary finalists are reviewed by the committee to ensure that the group is representative of the population of persons living with dementia. If the composition of the group lacks sufficient diversity in terms of age, race/ethnicity, socioeconomic status, diagnosis, or professional status, the review committee is reconvened and recommendations are provided and discussed, leading to the final group selections. Since its inception, 177 individuals living with dementia or MCI have participated in the program.

Onboarding of new members begins with a request for a few documents (e.g., a signed volunteer agreement and a letter from their physician confirming their diagnosis) and the distribution of the ESAG Participant Handbook. The Handbook provides a general overview of the ESAG, member's role and responsibilities, the types of engagements members may participate in, and the type of support they will receive throughout their term. A full-day, an in-person business meeting is held at the Association's Home Office at the beginning of their term. During the meeting, the care and support, public policy, and public relations teams provide an overview of their work and how they engage and support the ESAG. This meeting and a related celebratory dinner act as a catalyst for forming relationships and developing cohesion among the new group members.

KEY CONTRIBUTIONS OF THE ESAG

For over a decade and a half, ESAG members have used their unique and personal experience with dementia to help ensure that government, media, and other entities better serve individuals living with Alzheimer's and dementia and their caregivers. A sampling of their most tangible contributions to public policy, board and committee appointments, programming and resources, medical and scientific advancements, and public awareness are described below.

Public policy

ESAG members living with younger-onset Alzheimer's disease (YOAD) spoke at a hearing with the Social Security Administration, advocating for the inclusion of YOAD and other dementias as part of the Compassionate Allowance Initiative. As a result, individuals living with YOAD became eligible to receive social security benefits more quickly. Members' comments were also incorporated into the Behavioral Risk

Factor Surveillance System (BRFSS), the Centers for Disease Control and Prevention's (CDC) nationwide health-related telephone survey that collects state data about US residents regarding their health-related risk behaviors, chronic health conditions, and use of preventive services.

Board and committee appointments

ESAG members have held appointments on a number of the nation- and worldwide committees. These include the Advisory Council on Alzheimer's Research, Care, and Services for the National Alzheimer's Project Act (NAPA), which discusses the efficacy of US government programs targeting the needs of individuals and caregivers coping with the consequences of Alzheimer's disease and related dementias (AD/ADRD). ESAG members have also served on the Food and Drug Administration's (FDA) flagship Patient Representative Program, which offers patients and caregivers the opportunity to provide critical advice to the agency as it regulates medical products, including drugs, biologics, and devices. Most recently, the World Dementia Council welcomed the first African American and former ESAG member to be one of only 24 council members working across six continents. Council members are global leaders who work in research, academia, industry, and civil society. They attend meetings, vote on key issues, and participate in the organization's work. Last, since 2006, the Association has had ESAG members on its National Board of Directors, which is responsible for defining the organization's mission and purpose, setting policy, developing long-term goals and strategic planning, monitoring general operations, and approving organizational outcomes and resource allocations. These and other appointments are a testimony to the dedication of ESAG members, the skills they develop via their ESAG membership, and the ESAG program as a whole.

Programming and resources

ESAG input was the impetus for the development of a number of early-stage programs and resources offered by the Association. The LiveWell online tools are interactive and focus on helping newly diagnosed individuals move toward acceptance. The "I Have Alzheimer's" webpages are an online resource for information and strategies to help those with the disease lead their best lives for as long as possible. Both of these are critical nationwide resources for individuals living with dementia. In 2021 alone, the Live Well pages received nearly 60,000 views. The ESAG continues to provide feedback to strengthen and best target these efforts while offering guidance in the development of future important resources.

Medical and scientific advancements

Several organizations and government agencies have sought ESAG input. For example, in 2021, ESAG members and their caregivers participated in a virtual listening session with FDA officials to share their

personal perspectives on living with Alzheimer's disease and what access to a disease-modifying treatment would mean to them and their families. Input from those who would directly benefit was among the top reasons cited by the FDA in its statement announcing the conditional accelerated approval of aducanumab (Aduhelm) as the treatment. ESAG members also provided input on a Shared Decision-Making Tool developed by the American Academy of Neurology (AAN). This tool helps the person living with dementia and their doctor discuss options and make decisions about their healthcare goals together. The input was also provided to the American Psychiatric Association's (APA) Practice Guidelines on the Use of Antipsychotics to Treat Agitation & Psychosis in Patients with Dementia. These guidelines help patients and families begin the discussion with their physician in order to make an informed decision about appropriate treatment. ESAG members are particularly eager to offer their expertise in relation to medical and scientific advancements, and they welcome future opportunities to do so.

Public awareness

From movies and media to the government, ESAG members are active in efforts to increase awareness surrounding Alzheimer's and dementia. ESAG members served as consultants for actress Julianne Moore as she prepared to play a woman living with young onset Alzheimer's disease (YOAD) in the film, *Still Alice*. ESAG members' stories and experiences have garnered more than 452 million media impressions in national outlets, including *The New York Times* and NBC Nightly News. They have continued to bring awareness to the disease and the unique challenges they face through engagement and awareness initiatives offered by the Office of Minority Health, the Society for Nuclear Medicine & Neuroimaging, and the American Society of Neuroradiology.

The contributions listed above showcase just a small sample of the wide range of activities ESAG members have engaged in over the past decade and a half. Their willingness to share their stories, experiences and insights have supported advances in the Alzheimer's and dementia field, reduced stigma, and improved understanding and acceptance of this disease.

LESSONS LEARNED

The foregoing makes clear just how essential and beneficial it is to ensure that the lived experience of having dementia is included at the Association level and beyond. We highly recommend that approaches such as the ESAG (or other ways of including people living with dementia) be used more broadly. To that end, and based on the Association's recognized leadership in this type of engagement work, we offer lessons learned and tips for maximizing the impact of this type of group in terms of group size, group governance, technological support, in-person engagement, engaging care partners, preparing for and supporting member engagement, representation and recruitment, and limitations in generalizing to persons later in the disease progression.

Group size

The ESAG group size of 8–12 individuals seems ideal for creating sustained and meaningful engagement. This size group is large enough to offer representation from diverse backgrounds and experiences while remaining small enough to guarantee that all individuals are engaged and have enough work to feel relevant and successful. This size group is also ideal for creating meetings that are content-rich without being overwhelming for members and staff. Finally, 10–12 members mirror a typical support group size, offering a sense of familiarity and encouraging peer support, learning, and engagement.

Group governance

The ESAG is overseen by two staff members of the Association who manage all aspects of the ESAG, including the nomination process, nominee interviews, coordinating the review committee, the onboarding process, and day-to-day communication and support for members as they participate in various national engagements. We have found that having just one to two main points of contact for members facilitates rapport and relationship building. Members know exactly who to reach out to if they have questions or concerns and they feel comfortable doing so.

Technological support

Because ESAG members are located across the country, the Association communicates via Zoom, email, and at times, text messaging. All potential members are informed of the technical requirements during the initial interview process. This ensures that they are comfortable using these systems and gives them the opportunity to consider whether this may pose any barriers to their full participation. Email is the primary mode of communication for sending out content and reminders. Zoom is used on a monthly basis for group conference calls. The Participant Handbook offers detailed instructions on using Zoom, including labeled screenshots of how to access the platform and its capabilities. Having at least two staff members on all virtual calls is recommended, as it allows the meeting to continue should one or more members require staff help with technological issues. ESAG members' care partners are also briefed on the mechanics of the virtual conference calls, and they are encouraged to assist in setting up and using required technologies as needed.

In-person engagement

Although in-person engagement has proven more difficult in recent years due to the COVID-19 pandemic, this is a critical component of successful engagement. At the beginning of each ESAG yearly term, all members are invited to an in-person meeting at the Association's national headquarters in Chicago. This gives the group the opportunity to get acquainted with one another and receive onboarding

information. Meeting in-person versus virtually enables stronger connections and rapport-building, which ultimately leads to increased comfort levels and trust, essential ingredients to open sharing of sometimes highly personal stories and opinions.

Engaging care partners

Although the role of ESAG is specifically designed to highlight individuals living with dementia, care partners play a key role in members' success as they act as the primary support person during his or her term. During the initial ESAG in-person meeting, care partners are encouraged to attend their own onboarding meeting where they learn more about the mission of the ESAG, member expectations, their role as the member's primary support person, how the Association will support members, and the amount and types of communications the care partner can expect to receive during the member's term. Information on Association programs and caregiver resources is also provided. During the term, care partners are copied on all communications related to ESAG meetings, engagements, and conference calls so that they may assist as needed with calendars, travel arrangements, reminders, and other necessary support.

Because the mission of the ESAG is to highlight the voice of the person living with dementia, care partners are discouraged from attending monthly meetings meant only for ESAG members or from speaking on behalf of an ESAG member during the preparation for, or engagement in, an ESAG activity. However, there are often opportunities for speaking engagements that include the care partner. If a care partner is interested in participating in one of these engagements either alone or alongside the member they are supporting, Association staff provide support regarding preparation, messaging, logistics, and travel.

Preparing for and supporting engagements

ESAG members are asked to participate in a variety of engagements, including giving speeches, taking part on panels at conferences, writing blogs, and providing expert reviews. The Association's main goal is to ensure that the member feels successful in each engagement from beginning to end. Given the progressive nature of Alzheimer's disease and other dementias, discussions with members throughout the engagement prep are crucial. In addition to gauging member readiness, they allow Association staff to make adjustments to the member's scope of work in order to meet their current strengths and comfort level.

Engagement requests, whether originating from the Association or an outside organization, are first directed to the Association staff overseeing the ESAG. Before soliciting the interest of the ESAG in the activity, staff holds an information-gathering call with the requesting party to ascertain whether the opportunity is appropriate for the group. Staff then work with members to provide them with as much information as possible about the engagement before they decide whether they would like to participate. Key details include when and

where the engagement takes place, the general audience size, whether it will be live or recorded, and the topic. Ideally, engagement requests are presented to ESAG members no more than 3 months in advance to account for any changes that may take place between the initial request and the event. If at any time leading up to the engagement the member experiences disease progress or feels uncomfortable with any aspect of the engagement, staff will work with the requesting party to adjust the engagement to ensure the member feels comfortable and successful in how they are participating. This can entail eliminating open Q&A sessions or shifting the format from live and in-person to virtual or pre-recorded.

If a member agrees to participate in an activity, staff will schedule preparation meetings that include both the travel companion and representatives of the requesting party to go over details such as: when, where, and to whom it is being delivered; the goal or message to be delivered through the engagement; the structure of the event or meeting; any pertinent details related to travel, dress, props, or technology; and a timeline and next steps. Written details and a recording of the call are emailed after the meeting.

In instances where a prepared speech is part of the engagement, ESAG members will outline a first draft of what they would like to share. Association staff will then work with them to review and provide feedback and edits related to the presentation's overall structure, messaging, disease-related accuracy, and time management. All of this is done with the goal of retaining the member's voice and experience.

If the engagement requires the ESAG member to present in person, the Association staff will handle all planning, purchasing, and coordination related to travel, including flights, ground transportation, and hotel accommodations. Ideally, all flights will be direct, but if that is not possible, flights without short layovers are chosen, as these can be stressful and increase the risk of mid-travel transportation changes. Staff creates and distribute (in both electronic and hard copy format) a detailed travel itinerary that includes specific information on where they need to be, when, how they will get there, dress codes, on-site contacts, and emergency contact information. This is provided in both electronic and hard copy formats.

Due to the progressive nature of many cognitive impairments and the complexities and stress of travel, all ESAG members are required to designate a travel companion for each event requiring travel, even if they live independently and/or do not have a care partner. Travel companions act as the primary support person throughout the engagement. They can be anyone the member chooses, provided they are over the age of 18n. The travel companion must be able to remain with the member from the time they depart their home airport or begin their drive by car until they return home at the end of the trip.

Representation and recruitment

One of the primary goals of the ESAG is to convene a group of diverse individuals living with the disease to lend their unique perspective to the work of the Association and beyond. Achieving this goal, therefore, requires attracting and recruiting people from

historically underrepresented groups, including Black/African Americans, Hispanic/Latino Americans, Asian/ Pacific Islanders, Native Americans/Alaskans, sex/gender minority populations, persons with co-morbid disabilities, and individuals from varying socioeconomic backgrounds. Historically, a majority of ESAG members have been white, middle-class, and younger (under age 65), which can lead to a more homogenized perspective not fully reflective of the actual population living with the disease. To address this, the ESAG staff continues to collaborate with the Association's Diversity, Equity & Inclusion team and their partnerships with national organizations to raise awareness of the ESAG among people from diverse backgrounds who may be interested in joining.

Disease progression

Due to the progressive nature of the disease, only individuals who are early in the disease progression and who can successfully articulate their experiences are included in the group. However, those in the early stage of the disease represent just a proportion of those living with Alzheimer's disease and dementia. Because of this, we are limited with regard to the perspectives of those living in the later stages of the disease.

A GROWING MOVEMENT WITHIN SCIENCE

The Association is highly gratified to see the ways in which the research community has recognized the importance of including the voices of persons living with dementia in their work. Obtaining such input has in some ways become nearly standard practice for studies involving dementia, and it would not be possible to detail them all in this paper. However, we would like to touch on several projects of particular importance that are centering on the voices of persons living with dementia.

Until very recently, there was a glaring lack of guidelines on how best to include individuals with cognitive impairments in research. In response, Frank et al.¹ created and led the Persons Living with Dementia Stakeholder Group (PLDSG), which included former ESAG members.¹ Formed to support the first *National Research Summit on Care, Services, and Supports for Persons with Dementia and Their Caregivers*, the PLDSG influenced the development of the content of the Summit agenda, and PLDSG members presented at the Summit. Of the final 58 recommendations that emerged from the Summit, 30 expressed ideas directly contributed by persons living with dementia, demonstrating the importance of hearing from these stakeholders.

In a related publication, Frank et al.² outlined the steps used to implement the PLDSG and offered guidance for both persons living with dementia and researchers for partnering on research conference planning and participation, including governance, convening, and providing input.² Feedback from PLDSG members revealed that some were initially unsure about participating due to concerns over their ability to contribute or the progression of their disease. However, all

members reported that participation was a positive experience. A self-evaluation conducted by PLDSG members yielded specific strategies likely to be useful when forming and implementing future partnerships between researchers and persons living with dementia. A few of these recommendations include: identifying and supporting ways to participate while considering limitations; using video conferencing tools to aid group communication and involvement offering, financial and logistical support for travel if necessary, and confirming deliverable products.

Individuals living with dementia are a key part of the Care and Support Advisory Group for LINC-AD (*Leveraging an Interdisciplinary Consortium to Improve Care and Outcomes for Persons Living with Alzheimer's and Dementia*). This 5-year, interdisciplinary consortium, convened by the Association and funded by the National Institutes of Health, brings together leading experts to identify, develop, and disseminate measurement tools to advance psychosocial research and achieve better outcomes for those facing the disease. Since 2019, the Care and Support Advisory Group has met quarterly and has contributed to discussions on the definition of person-centered care, what is important to measure, and an RFA for research on measurement.

Given the Association's leadership in the area of convening persons living with dementia as stakeholders, many organizations have sought assistance from the Association in creating their own stakeholder groups. The NIA IMPACT Collaboratory, a group formed in 2019 that aims to build the capacity to conduct pragmatic clinical trials of interventions for people living with dementia and their care partners, has engaged with the Association for help in convening a Lived Experience Panel to evaluate research proposals and provide input on the development of clinical trials. The BOLD Public Health Center of Excellence on Dementia Caregiving, funded by the CDC, has also partnered with the Association to develop a Stakeholder Engagement Advisory Group. Comprised of caregivers and individuals living with dementia and MCI, the group reviews materials and resources created by the Center, has participated in the Center's conferences and panels and provides overall recommendations for the Center's activities.

Last, the Holistic Evaluation to Advance Research in Dementia (HEARD) project, funded by the National Institutes of Health, includes individuals living with dementia as equal members of the Steering Council, which also includes researchers and caregivers. Using a human-centered approach, the goal of the HEARD project is to develop measures that are: (1) meaningful to the person with dementia; (2) focused on positive psychosocial outcomes; (3) useful for research and practice; and (4) useful for mild to moderate stages of the condition. Individuals living with dementia have been key to the formation of two new measures, *Good Day, Bad Day*, and *Living Well with Dementia*, which will move forward to the development phase.

Building off the success of the Association's continuous work and dedication to serving the needs of persons living with dementia and their care partners, the Association's next goal is to broaden engagement with people living with dementia in local communities nationwide, including diverse and underserved communities, as they are disproportionately impacted by the disease. This model would provide tools and resources to the field highlighting best practices on

how to recruit, vet, onboard, engage, and support a person living with dementia.

CONCLUSION

Stigma relating to Alzheimer's disease and other dementia has played a significant role in excluding the voice of individuals living with dementia in the work that directly impacts their well-being and that of their loved ones. As a result, information, education, and resources continue to be targeted more toward care partners. Through the ESAG and related efforts, the Association has been instrumental in demonstrating that the voice of those living with dementia can and must be engaged in efforts to positively influence important work, including ensuring that outreach, research, and supports are effective, appropriate, and informed.

The success and longevity of the Association's ESAG, and the many stakeholder groups that have been formed since are indicative of the ever-increasing importance of involving the voices of those living with dementia. However, as individuals living with dementia and their care partners are increasingly included as stakeholders in advisory groups and committees, organizers must keep the needs of individuals living with dementia at the forefront through careful selection and onboarding, and through continuous and clear monitoring and support. The Association will continue to provide help and advice toward these efforts as we also work to expand this work within our own organization at the nationwide chapter level.

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CONFLICT OF INTEREST

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SUPPORTING INFORMATION

Additional supporting information can be found online in the Supporting Information section at the end of this article.