RIA Schlegel-UW Research Institute for Aging

Enhancing Life

The Imperative for Meaningful Engagement of People Living with Dementia and Care Partners

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The Imperative for Meaningful Engagement

Executive Summary

1. Meaningful engagement is imperative to recognizing the rights of people living with dementia.
2. Meaningful engagement ensures that investments are directed to initiatives that meet the needs and priorities of people living with dementia and care partners.
3. Resources and time must be invested to ensure meaningful engagement in directing policy and funded initiatives.

Maximizing Impact of Investments Through Rights-based Engagement

Lived experiences of dementia **must** inform dementia-related policy, research, programs and services. People living with dementia and care partners have long advocated for this right. The United Nations Convention on the Rights of Persons with Disabilities and the Accessible Canada Act reinforce this call. The latter states that people with disabilities (including people living with dementia) "*must be involved in the development and design of laws, policies, programs, services, and structures*" (Accessible Canada Act, 2019).

Collaboration is a foundational pillar of Canada's National Dementia Strategy. This means that people living with dementia and care partners are indispensable partners in the strategy's implementation. Meaningful engagement is an effective way to collaborate. This approach ensures the voices of people living with dementia and care partners have equal value and impact in decision-making. For meaningful engagement to work, it must be implemented to recognize the rights of people living with dementia and care partners and improve the relevance and impact of initiatives. For policymakers, specifically, this means meaningfully engaging people living with dementia and care partners to guide all dementia-related policy and funded initiatives.

Meaningful engagement of people living with dementia and care partners involves four simple steps:

1. **Identifying and engaging the target audience:** Engage the people living with dementia and/or care partners who will be impacted by the policy or initiative. Consider their diverse characteristics and identities (e.g., geography, language, ethno-racial background, socioeconomic status, type of dementia, stage of dementia, gender and sexual identity).
2. **Creating an accessible engagement process**: Accommodate different cognitive, sensory and physical needs as well as competing demands.
3. **Understanding perspectives of people with lived experience:** Invite people living with dementia and care partners to share their experiences, ideas and feedback on the policies, research, programs or services that you are proposing or developing.

4. **Acting on what you hear:** Apply the insights you collect in decision-making. Engagement without action wastes time and resources, and may further perpetuate stigma and exclusion rather than supporting the rights of people living with dementia and care partners.

The Risks of Inaction: Failing to meaningfully engage people living with dementia and care partners risks investment in initiatives that do not meet their needs or priorities. This wastes time and resources.

Ensure Appropriate Resourcing for Meaningful Engagement

Policymakers must require and resource meaningful engagement within policy-making and funded initiatives. This includes fully resourced, actionable plans for engagement. People living with dementia and care partners must be provided with necessary supports (e.g., clear communication, accessible spaces, transportation, expense reimbursement, respite care). Their time, contributions and expertise should also be recognized through wages, honoraria or stipends.

Calls for Action

In support of the Canadian National Dementia Strategy, the following calls will empower people living with dementia and care partners to direct policies and initiatives, ensuring investments align with their needs and priorities and, therefore, reduce wasted time and resources:

1. Require policy-making processes and funded initiatives to include actionable strategies for meaningfully engaging people living with dementia and/or care partners in governance and decision-making.
2. Integrate meaningful engagement of people living with dementia and care partners as a formal metric in all funding applications and reporting and evaluation frameworks.

By embedding people living with dementia and care partners into the systemic decision-making pipeline, the government can mitigate the risk of misaligned resources, improve service delivery, and ensure policy outcomes directly match needs.

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