

# Developing a guide on involving people with disability in evaluation

Australia's Disability Strategy 2021 - 2031

30 November 2022

## Introduction

Dementia Australia welcomes the opportunity to contribute to Australia's Disability Strategy and the development of a guide on how to involve people with disability in evaluation.

Firstly, Dementia Australia would like to highlight the substantial benefits meaningful consultation brings to people living with dementia, their families, and carers — who prefer, in this context, to be referred to as dementia advocates.

Dementia advocates tell us that participating in this work:

- Is rewarding, validating, and stimulating
- Helps retain cognitive function
- Fosters connection with peers and supports
- Gives meaning to their diagnosis and experience
- Inspires a sense of purpose.

Dementia Australia recently published a new resource to increase the involvement of people impacted by dementia — particularly people living with dementia – in meaningful consultation.

**Half the Story: A guide to meaningful consultation with people living with dementia, families and carers** was co-authored with dementia advocates across Australia with years of collective experience in consumer representation and research.

We believe **Half the Story** can inform the development of the Evaluation Guides and addresses dementia-accessible co-design and collaboration in step-by-step detail.

**Half the Story** can be [downloaded for free](#) or available in hard copy by request.

As well as adhering to accessibility principles and policies, Dementia Australia urges everyone to challenge and expand their understanding of dementia by:

- Becoming a **Dementia Friend**
- Learning about the different types of dementia
- Speaking with people living with dementia, their families, and carers.

Dementia Australia supports the development of the Evaluation Guide with the following recommendations.

## **Principles of best practice for involving people with disability in evaluation**

Overall, Dementia Australia approves of the proposed best practice principles. However, we believe the principles could be strengthened to ensure the safe and accessible involvement of people living with dementia.

When talking with dementia advocates about their past experiences, a common criticism is that the advocate felt that their contribution was not meaningful or did not influence the outcome. Dementia Australia believes that all consultation with advocates must meet the definition of meaningful involvement and would like to see meaningful involvement included in the best practice principles.

Dementia can be a stigmatising illness, and people living with the condition regularly experience paternalism and discrimination. People living with dementia can be vulnerable to abuse due to increased reliance on external support. Fear of judgement or reprisal (such as withdrawal of services) is a known barrier to incident reporting and participating in service evaluation activities.

It is vital that the best practice principles uphold the right to safe and free expression, with evaluators being able to demonstrate how they will ensure this will occur.

Similarly, it is important that the best practice principles demonstrate a strong commitment to confidentiality and privacy to protect advocates from having their dementia status and other personal information disclosed without consent.

## **Actively involving people with disability across the evaluation cycle**

Dementia is an umbrella term used to describe over 100 neurodegenerative conditions that significantly impact a person's ability to perform activities of daily living.

The most prevalent form of dementia is Alzheimer's Disease, of which the hallmark symptom is impaired short-term memory. However, dementia is more than memory loss.

Depending on the area of the brain affected, dementia can impact:

- Mood regulation and executive function
- Vision and depth perception
- Orientation
- Language, speech or reading
- Filtering distractions
- Ability to navigate unfamiliar spaces.

In developing the Evaluation Guide, it is important to consider the broader impacts of dementia and how they might influence a person's ability to participate.

Dementia Australia suggests that the Evaluation Guide contains advice on the following areas:

- Selecting a venue or site that meets dementia-enabling design principles.
- Including the needs of people living with dementia in readability and accessibility standards for printed and electronic documents.
- Implementing consent processes that are appropriate for people living with dementia — dynamic enough to accommodate fluctuations in capacity, changes in ability, and change of mind.
- Strategies to overcome known barriers to recruitment and participation.
- Appropriate referral pathways for advocates or participants who require further information or support.

Dementia Australia appreciates every opportunity to provide advice and information about dementia-accessibility and inclusion. We extend an offer to the Department of Social Services to facilitate further engagement with people living with dementia, their families, and carers.