A Position Paper by

LAUNEX LTD

Title

When "the dementia community" becomes a label: how collective clustering can seed stigma — and what a rights-based, person-led alternative looks like

Abstract

Public awareness has increased, yet stigma and discrimination experienced by people living with dementia remain persistent. This paper explores a specific mechanism that often sits unnoticed at the very beginning of stigma: **collective labelling**, particularly when people are clustered into an abstract group identity (for example, "the dementia community") that is spoken about rather than spoken *with*. Drawing on stigma theory, disability rights framing, and evidence on language and public attitudes, we argue that well-intended grouping can inadvertently create "othering," reduce individuality, and legitimise paternalistic practices. We propose a practical, improvement-focused alternative: a rights-based, person-led approach that centres lived experience, safeguards autonomy, and changes everyday communication habits across families, services, policy messaging, and public discourse.

Keywords

Dementia; stigma; discrimination; labelling; language; rights-based approach; person-led care; autonomy; epistemic injustice; social model of disability.

1. Introduction

Across dementia care systems and public narratives, we often see a familiar pattern: people living with dementia are referred to as a collective "community" or "group," and then the collective is described in ways that unintentionally flatten individuality. This is not usually malicious. It frequently stems from attempts to raise awareness, campaign for services, or show solidarity. Yet, the lived experience reported by many advocates is that stigma persists precisely because everyday narratives still position "people with dementia" as a separate category of human experience — one defined primarily by loss, risk, burden, or tragedy. Kate Swaffer's rights-based framing highlights how stigma and discrimination can be reinforced by cultural assumptions and institutional habits, even inside well-meaning awareness efforts.

This paper examines how collective clustering can become the **starting point** of stigma, and how we can improve our practice without resorting to blame. The goal is constructive: to offer a usable framework for families, professionals, organisations, and communicators who want to reduce stigma rather than accidentally reproduce it.

2. Why language and clustering matter

Language does more than describe; it shapes expectations and behaviour. When people are routinely framed as a homogenous “dementia community,” the label can do three things at once:

First, it can subtly imply that “they” are not “us” — a classic condition for othering. Second, it can shift attention away from the individual’s personhood (values, preferences, identity, goals) and toward the diagnostic category. Third, it can normalise speaking *about* people living with dementia rather than designing support *with* them.

This is consistent with evidence that stigma remains widespread and is linked to delayed help-seeking, social withdrawal, and reduced quality of life. A major international report on attitudes to dementia documents persistent stigma and fear-based beliefs, even where public awareness has increased.

Language choices are increasingly recognised as part of improving the social environment around dementia. For example, the Alzheimer’s Society explicitly encourages avoiding stigmatising terminology (such as “sufferer”) and promotes respectful person-first alternatives.

3. Conceptual framework: how “community” becomes stigma

This paper uses three linked lenses to explain the pathway from clustering to stigma.

3.1 Stigma as social marking and status loss

Stigma is not only a feeling; it is a social process where a label becomes a mark that changes how others treat the labelled person. When “dementia” becomes the dominant identity, it can influence how risk is assessed, how competence is assumed, and how autonomy is granted.

3.2 The “benevolent” pathway: compassion that still removes agency

A common mechanism in dementia discourse is benevolent paternalism: “we mean well, therefore we decide.” This is not always experienced as care by the person receiving it. It can function as discrimination dressed as kindness, especially when communication defaults to protection rather than partnership. Swaffer’s rights-based critique draws attention to how this happens culturally and structurally, not only individually.

3.3 Epistemic injustice: when the person’s voice is treated as less credible

Clustering can enable a quiet form of silencing: the person is treated as a member of a category rather than a credible knower of their own experience. Recent work on dementia and epistemic injustice explores how people living with dementia can be systematically discredited or excluded from meaning-making, even when they are communicating clearly in ways that differ from typical norms.

4. The “clustering → stigma” chain in everyday practice

In real-world settings, the chain often looks like this:

A public post, service description, or policy document refers to “the dementia community” and then describes “what they need.” The narrative tends to emphasise vulnerability, risk, decline, or burden. The public absorbs a simplified story: dementia equals incapacity. That story becomes “common sense,” shaping how family members, professionals, and institutions interpret behaviour and make decisions.

The consequence is not merely emotional harm; it affects practical outcomes. Stigma can contribute to late presentation for assessment, avoidance of support, and increased social isolation. A recent Lancet Neurology Commission on dementia stigma and discrimination underscores that stigma remains a significant barrier with measurable harms.

5. A rights-based, person-led alternative

A rights-based approach does not require attacking "the system." It requires upgrading the assumptions that guide decisions and communications.

5.1 Core principle: from "doing for" to "working with"

Person-led care begins with the premise that the person's values and preferences remain central, and that support should be designed around *their* definition of a good life, not only around organisational convenience or risk frameworks.

5.2 Replacing "dementia community" with "people living with dementia" (and naming the person whenever possible)

This is not cosmetic. It returns the subject of the sentence to the person and reduces identity capture by diagnosis. It also creates space to ask: "Which people? What are their different contexts? What do they say they need?"

5.3 Autonomy as practical scaffolding, not a slogan

Autonomy is not "all or nothing." A rights-based model treats autonomy as something we protect through supports: accessible communication, time, predictable routines chosen collaboratively, and shared decision-making that adapts as abilities change.

6. Practical recommendations (improvement-focused)

To keep this usable, the recommendations below are designed to be implementable without major funding.

6.1 Communication standards (families and professionals)

Use identity-preserving language: "a person living with dementia," "a person who uses support," and avoid terms that imply helplessness or inevitability. Follow the person's own preferred wording where possible.

6.2 Content standards (organisations, charities, training providers, media)

When describing needs, include lived experience quotes and co-authored statements. Avoid speaking for people as a homogenous group. Make visible the diversity of dementia experiences and the continuing capacity for preferences, relationships, humour, meaning, and contribution.

6.3 Decision-making standards (services and providers)

Shift from default paternalism to "supported autonomy": ask what matters, offer options, document preferences, and review them. Treat the person as a partner in risk planning, not an object of it.

6.4 Measurement standards (what "good" looks like)

Success should include autonomy indicators: felt respect, participation in decisions, continuity of identity, and meaningful daily choice — not only incident reduction or task completion.

7. Implications for LAUNEX LTD

LAUNEX LTD can operationalise this approach by making one promise visible across all public communications: **we do not teach families or professionals to manage a "dementia community"; we teach them to understand and respond to a person.** That distinction is the anti-stigma stance in practice.

This paper can also anchor a LAUNEX LTD's "language standard" for external posts, course materials, and partner communications, showing that LAUNEX LTD takes an evidence-informed position before making public claims.

8. Conclusion

Clustering people into a single labelled group can unintentionally trigger the very stigma awareness campaigns aim to reduce. A rights-based, person-led approach offers a practical upgrade: it preserves individuality, restores credibility to lived experience, and replaces protective paternalism with supported autonomy. The result is not only kinder language — it is better care, better outcomes, and a more humane public narrative.

References

All references were selected to reflect contemporary evidence on stigma, language, personhood, and rights-based approaches to dementia, with particular emphasis on lived experience and practical application.

Alzheimer's Society. (2023). *Dementia, language and stigma*. https://www.alzheimers.org.uk/about-dementia/dementia-friendly-communities/language

Batsch, N. L., & Mittelman, M. S. (2012). *World Alzheimer Report 2012: Overcoming the stigma of dementia*. Alzheimer's Disease International. https://www.alzint.org/resource/world-alzheimer-report-2012/

Goffman, E. (1963). *Stigma: Notes on the management of spoiled identity*. Prentice-Hall.
— foundational theory underpinning modern stigma research.

Kong, E. H., Kim, H., & Kim, H. (2022). Nursing home staff's perceptions of barriers and needs in implementing person-centred care for people living with dementia: A qualitative study. *Journal of Clinical Nursing*, 31(13–14), 1896–1906.
https://doi.org/10.1111/jocn.16039

Livingston, G., et al. (2020). Dementia prevention, intervention, and care: 2020 report of the Lancet Commission. *The Lancet*, 396(10248), 413–446.
https://doi.org/10.1016/S0140-6736(20)30367-6
— includes evidence on stigma, delayed diagnosis, and social harms.

Livingston, G., et al. (2024). Dementia prevention, intervention, and care: 2024 update of the Lancet Commission. *The Lancet*.
— highlights persistent stigma and discrimination despite awareness efforts.

Sabat, S. R. (2001). *The experience of Alzheimer's disease: Life through a tangled veil*. Blackwell. — seminal work on personhood and identity beyond diagnosis.

Swaffer, K. (2014). Dementia: Stigma, language, and dementia-friendly. *Dementia*, 13(6), 709–716.
https://doi.org/10.1177/1471301214548143

Swaffer, K. (2026). *Dementia stigma and discrimination: A rights-based perspective*.
https://kateswaffer.com/2026/01/07/dementia-stigma-and-discrimination-a-rights-based-perspective/

United Nations. (2006). *Convention on the Rights of Persons with Disabilities (CRPD)*.
https://www.un.org/development/desa/disabilities/convention-on-the-rights-of-persons-with-disabilities.html

Williamson, T. (2018). *The importance of language in dementia care*. Dementia Engagement and Empowerment Project (DEEP).
https://dementiavoices.org.uk/