

Developing consensus-based recommendations for the delivery of dementia services for the LGBTQIA+ community in the Republic of Ireland

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This research has developed a consensus based, PPI driven, list of needs and recommendations for healthcare delivery for people with dementia from the LGBTQIA+ Community.

Background:

The number of LGBTQIA+ adults is rising and will continue to rise significantly in the coming years, in combination with the number of people who will be affected by dementia. Currently, there are no dementia-specific services for people from the LGBTQIA+ community. In general, older LGBTQIA+ people do not engage with health services until a crisis situation, and 40% do not disclose their sexuality to their care providers specifically due to the possibility of discrimination.

Aims:

- Identify the future needs of older LGBTQIA+ people and their care partners in relation to dementia care service delivery
- Develop consensus based recommendations for dementia service provision in Ireland

What work was done

Work was completed using a six stage process-

1. Development of a PPI Advisory Group

- This group oversaw review of survey questions, advising on recruitment strategies and were involved in the virtual consensus meeting.

2. Survey

- 49 participants who were members of the LGBTQIA+ community / supported someone who is / was, aged >50 years old
- Online/video call/phone call/postal survey

3. Interviews with stakeholders

- 8 interviews with older LGBTQIA+ people and their care partners

4. International review of best practice

- Review of existing literature in the area and interviews with international experts working in dementia care for LGBTQIA+ community.

5. Consensus Meeting

- Virtual meeting of PPI Group members, interview participants and representatives from voluntary and healthcare backgrounds working with people with dementia.
- As part of this meeting, the wider group discussed results to date and agreed on a list of needs and recommendations.

6. Final member checking

- Final study results were distributed for comment and agreement, allowing participants to rank items in order of importance.

What was found

- Authors identified 10 key needs and recommendations that focus specifically on dementia care in Ireland for the LGBTQIA+ community. These are appended below.
- Survey data found that many LGBTQIA+ older adults felt it necessary to conceal their gender/ sexual identity when accessing care/healthcare or stopped expressing their gender or sexual identity. This was mainly down to the discrimination they experienced in their lifetime and in the last 5 years.
- Interview data highlighted the idea of identity suppression and anticipated concerns as well as the importance of creating an LGBTQIA+ affirmative ethos and workforce. The inability to conceal gender or sexual identity was reported to leave older LGBTQIA+ people with dementia vulnerable, particularly in potentially unfriendly environments. It was also suggested that mandatory training should be provided to care workers and hiring more LGBTQIA+ care workers.

What this means

These needs and recommendations are being drawn from the LGBTQIA+ older community and their care partners. With the growing numbers of people with dementia, and therefore people with dementia from the LGBTQIA+ community, it is imperative that these recommendations and needs are considered when planning for delivery of dementia services and care.

It is essential that the LGBTQIA+ community receives rights-based dementia care. There is a clear message that respect for identity and families of choice in care decisions is integral. Safety of services was also highlighted, with avoidance of healthcare services often leading people to be admitted to residential care when it may have been preventable.

What happens next

The below needs and recommendations have been identified by the older LGBTQIA+ community as essential. It is critical that all dementia-service providers consider and implement recommendations as soon as possible.

Top 10 Recommendations

1. At first contact with services/ at diagnosis, everyone should be given a multitude of resources including information about LGBTQIA+ services.
2. LGBTQIA+ older adults should have a choice between integrated and dedicated services.
3. Integrated services with mandatory comprehensive training for staff should be available where dedicated services are unavailable.
4. LGBTQIA+ specific services for older adults and people with dementia should be introduced.
5. Services' LGBTQIA+ inclusiveness and training should be auditable by a relevant health authority.
6. Service-users should be asked who they would like to help them in their care and decision making as their dementia symptoms progress.
7. Independent advocates for people with dementia should be triggered upon diagnosis. Advocates can work with people with dementia and their close networks to give them the care they desire most.
8. Training should include understanding differences in LGBTQIA+ networks and how to incorporate an individual's network in care without making assumptions; as well as intervening with homophobic/transphobic bullying/mistreatment from family of origin/other.
9. When working with transgender people with dementia, care providers should address them as the gender they are presenting as in the current moment and not engage in any kind of coercion regarding their gender expression.
10. An explicitly LGBTQIA+ inclusive ethos message and visible displays of LGBTQIA+ acceptance should be clearly displayed in leaflets and webpages of dementia services. This must be accompanied by staff trained in LGBTQIA+ affirmative care.

Top 10 Needs Identified

1. To feel respected and for your partner to feel respected.
2. To feel safe in expressing your identity if you want to.
3. To know that you, or your partner, are entering into a safe environment.
4. To have dignity in all areas of treatment, especially end of life care.
5. Care that values your needs as individuals and as LGBTQI or A+ people.
6. To be safe from abusive families of origin (if you have an abusive family of origin).
7. In a nursing home/ residential care setting, to be safe from homophobic/transphobic bullying/mistreatment from other residents.
8. Not to feel pressured into expressing your identity if you don't want to/ or don't feel safe.
9. Provide specific trans* and intersex medical training for doctors and care staff working with older LGBTQIA+ people, to enable them to work safely with unfamiliar bodies.
10. The need to support trans* people with dementia while also recognising the reality of biology and that some supports may require a focus on sex and not gender.