

Executive summary

Disability, loneliness and relationships: A thematic report

This report explores the lived experiences of disabled people regarding relationships, loneliness, and connectedness in the UK. Building on the findings from systematic literature review conducted by the University of Leeds Centre for Disability Studies and Disability Rights UK, the aim of this qualitative literature review was to:

- identify disabled people's preferences in forming social networks and relationships
- understand any barriers they may face and the impact of them
- review any improvements to schemes, designs, adaptations and services

Methodology

There were 158 sources from the wider evidence base that covered themes of families and the private sphere. These sources were quality assessed to ensure they:

- used a qualitative methodology

- used participant samples that consisted of disabled adults as defined under the Equality Act (2010)
- must explore the experiences of loneliness, including its risk factors, barriers and impacts or connectedness, including its facilitators of disabled adults

Exclusion criteria for studies followed the principle of the social model which is “nothing about us without us”. Articles or reports were excluded if they:

- only included the voices of parents, carers or advocates of disabled adults
- lacked lived experience of disabled adults or based on statistical analysis
- were review articles, methodological articles, commentaries book chapters or case studies
- were written in a foreign language

From the 158 articles or reports, 58 were excluded, leaving 100 articles or reports to analyse. This evidence formed the basis of the thematic review on disability, loneliness, and relationships for this report.

Summary of findings

Across 10 themes, we identified that disabled people experience a variety of barriers. These can make it hard to establish and maintain relationships, and can lead to social

isolation and loneliness. However, the review focuses on lived experience research, and limitations include small sample sizes and limited peer review. Lived experience research gives us a better, but far from complete, understanding of the issues faced by disabled people and people with health conditions in relation to relationships with family and friends.

The findings highlight that disabled people:

- often have smaller networks than non-disabled people and are more dependent on these networks, which can lead to alternate definitions of friendship
- face an increasing dependency on their network – outside of family and service workers, these networks often include relationships with people similar to themselves
- are regularly made to feel as an 'other' by social perceptions and therefore do not feel they fit in – as a result, disabled people can internalise negative societal perceptions and self-isolate
- experience disparities in perceptions, such as for people who acquired their impairment compared with other disabled people
- navigate additional barriers in relationships regarding roles, often balancing 'traditional' non-disabled roles with aspects of caregiving and increased dependency, especially for partner and parent/child relationships

- value sexual identity as much as their non-disabled peers, but face stigma about their sexual expression – they can face heightened stigma if they identify as LGBTQ+ and therefore, due to their dependency on their smaller networks, are not able to explore their sexuality or gender identity in the same ways as non-disabled people
- seek greater independence and autonomy within their lives, and significantly face the assumption of incompetence by non-disabled people, to the detriment of all relationships
- are not afforded the same access to education and information on sexual health, sexual wellbeing, family planning and relationships

Suggested improvements regularly included:

- training and support for caregivers and service professionals to give a greater understanding of disabled people's lives
- initiatives to break down social perceptions and stigma
- significant changes to existing services to improve access to education, information, social opportunities, and other communities

Overall, the findings suggest that while legislative protections and conventions promote the rights of disabled people, the lived realities are overwhelmingly different. For example, a

disabled person's preference for socialising is less of a factor than whether they can access the opportunities to socialise in the first place. The qualitative research landscape also disproportionately uses participants from institutional, clinical, and service-orientated settings, and does not fully reflect the diversity of the disabled community.