Understanding and using experiences of social care to guide service improvements: translating a co-design approach from health to social care

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Scientific summary

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Scientific summary

Background

Local authorities need to find new ways of collecting and using data on social care users' experiences to improve service design and quality. Our study has drawn on and adapted as appropriate an approach, accelerated experience-based co-design (AEBCD), from the healthcare improvement field to address this need using loneliness as a focus. Loneliness can have a well-documented and significant negative impact on health and quality of life. While many and varied preventative activities are instigated in the community, there is little evidence about their effects.

Aim

To assess whether an effective and efficient co-design approach, AEBCD, can be translated from health to social care.

Objectives

1. To understand how loneliness is (1) characterised and experienced by people who are in receipt of social care in England and (2) characterised by social care staff and the voluntary sector.
2. To identify how services might be changed to help tackle the problem of loneliness experienced by users of social care.
3. To explore, with one local authority, whether an approach to service improvement, known to be effective in health care, could be adapted for use in social care.
4. To disseminate all study outputs and publish resources on a newly established Socialcaretalk.org platform for public, family carers, service users, voluntary organisations, researchers, teachers, policy-makers and providers.

Methods

Discovery phase

In-depth interviews were conducted online or by telephone with a diverse, national sample of 37 adults who experience loneliness, and 20 social care staff who provide support or manage these services with a remit to tackle loneliness from local authorities and private/voluntary sectors. Data were analysed thematically. A catalyst film was co-produced capturing touch points (good practice points or examples where services could be improved) from the data.

Co-design phase

Doncaster was the site for exploring the AEBCD approach, which involved staff (paid and volunteers) and users of loneliness support in a two-stage process. Stage 1 involved a set of three workshops in which staff and support users worked together, first separately, and then jointly in the third workshop, to share experiences of local loneliness support and agree improvement priorities. In stage 2, these priorities were furthered by staff and support users together in smaller co-design groups. Evaluation of this approach adopted methods used successfully in the evaluation of AEBCD in health settings, including interviews, ethnographic observation, attending planning meetings and co-design groups. Our focus included the acceptability of the approach to staff and support users, and what adaptations are needed for future use of AEBCD in social care.

Findings

Discovery phase

The findings suggest that loneliness is complicated and may stem from unfulfilled interpersonal social needs but also from a wider undermining and invalidation of people's social identity. Unmet care and support needs meant participants felt unheard, in turn perpetuating feelings of abandonment and social alienation. Furthermore, the stigmatisation of loneliness meant many participants endured the phenomenon in silence. These findings should be considered when developing interventions that aim to ameliorate loneliness.

Co-design phase

We found AEBCD has considerable potential for transfer from the healthcare improvement field to social care. The adapted process was largely acceptable to co-design participants, who reported a range of benefits and enjoyed the work. The two co-design groups identified various loneliness support improvements, some of which had more easily defined routes to implementation than others. Learning from the evaluation pointed both to some common aspects of using AEBCD in health care and in loneliness support and to some differences requiring attention to improve the fit of AEBCD for use in social care settings which are preventative, community-based and involve multiple providers.

Dissemination

The catalyst film and a new section containing summaries of key themes, video, audio and text extracts from the discovery phase interviews are published on Socialcaretalk.org. The findings will be further disseminated via academic publications and conference presentations.

Limitations

The project was disrupted by the COVID-19 pandemic and associated lockdown restrictions. The discovery phase fieldwork was moved online, which may have hindered participation. The capacity of the project partner, Doncaster Council, to participate in the co-design phase was temporarily affected by overriding priorities.

Conclusions

The strengths of using AEBCD within social care are very apparent, and it was possible to identify user, group, social and political values. There was strong articulation by co-design group members of feelings of empowerment and the importance of being listened to. The development of active citizenship and political value was apparent in the way working group members discussed how they would take learning from the project to other settings, and their determination to continue with this work. Adaptations are necessary for a social care context; however, some of these are more a question of degree or nuance than a departure from the previously evaluated model.

Research recommendations

Recommendations for transferring accelerated experience-based co-design to social care

- Identify people or organisations who potentially could have responsibility for implementing improvements, including finding relevant funding.
- Identify an appropriate sample of staff and people with lived experience (PWLE), taking time to fill gaps in representation of provision, knowledge and people's characteristics, and consider whether staff and PWLE have distinct or shared experiences and how to build on these.

- Time is needed for coalition-building, developing trusted relationships and understanding different perspectives.
- Consider whether PWLE and staff participants have pre-existing relationships or should be selected on account of these, and the impact of having or not having such relationships.
- Consider opportunities for co-design group members to continue contributing their expertise.

General recommendations

Many of the general recommendations echo wider research on the conditions for successful organisational change:

- Ensure good facilitation of the workshops and the co-design group work and establish ground rules for both.
- Ensure paid staff involved in the co-design process – whether as participants or supporting the process itself – have protected time for the work involved.
- Be clear about processes, aims, expectations and roles from the outset and think about endings.
- Ensure that groups are large enough to represent all relevant parties and absorb inevitable uneven meeting attendance.
- Consider aspects of the process which may exclude some people and what adaptations may accommodate these.
- Ensure co-design group participants know that they can seek outside views and bring in external experts as necessary.

Areas for future research include the costs and opportunity costs of the approach compared to more 'top-down' initiatives; the purpose and focus of the catalyst film; the impact of AEBCD as an intervention for people who use social care services – what this might mean to participants, and the potential of the approach to generate service improvements; the adaptation of the approach to enable greater inclusion and accessibility; and exploring whether using AEBCD in a more clearly defined area avoids some of the challenges identified in this study. Finally, there is scope to explore using AEBCD in multisector improvement efforts, for example in mental health care, learning disabilities and frailty in old age.

Trial registration

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