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# An Intergenerational Approach to Dementia Friendly Communities

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## Abstract

There are many initiatives encouraging community engagement with people with dementia, one such being Dementia Friendly Communities. However, these initiatives can sometimes be limiting for people with dementia, confining their community engagement only to 'dementia friendly' venues and activities. There are many untapped community resources which can be used to expand community engagement, awareness, and receptivity of dementia such as primary schools, but these may require technologies to support interactions between the two groups. Designing these technologies together can help ensure they respond sensitively and empathetically to children's and PwD's needs, but the process of co-design between the two groups presents many challenges in itself.

## Author Keywords

Dementia; technology; intergenerational; communication; digital civics

## ACM Classification Keywords

H.5.m [Information interfaces and presentation (e.g., HCI)]: Miscellaneous

## Introduction

Developments in psychosocial dementia care have long encouraged people to live well with dementia in their homes

where they can remain a part of their community, but in doing so shifts the responsibility of care from health services to friends and family. Carers and communities are often ill-equipped to deal with the responsibility of in-home care, leading to the withdrawal from communities by both people with dementia (PwD) and their primary carers, causing experiences of loneliness and social isolation [2]. Causing further complications for PwD and family carers is the greatly increased risk of depression from social isolation and loneliness [10], both further challenging prospects of engaging with local communities and support structures. This issue extends into institutional settings, seeing the majority of residents experiencing loneliness [8], highlighting the ubiquity of loneliness across dementia care circles. For some this could mean a loss of agency, where they may be unable to resume typical elderly roles in the community, such as: sharing knowledge with younger members of the community, interacting with peers, or visiting family. For many this loss of social roles can negatively impact a sense of social identity and citizenship, as social roles can no longer be used to orientate themselves in the community [12].

### **Related Work**

Recent *'Dementia Friendly'* initiatives such as Dementia Friendly Communities (DFCs) are regarded as a positive intervention for PwD, helping to increase a community's understanding, awareness, and receptivity of dementia [3]. DFCs have attempted to reintegrate PwD back into their local communities through working with local establishments, increasing the accessibility of community venues and events for PwD. Current literature suggests perspectives and lived experiences of PwD are integral to forming successful DFCs and informing establishments on how to be dementia friendly, but the perspectives of PwD are often overlooked [3]. Consequently, DFCs can sometimes have a negative social impact on PwD, where only being

able to participate in coffee mornings specifically for PwD can reinforce labels and stigmatisms [7]. These feelings of stigmatisation can cause a sense of detachment from the community, rather than the DFCs overall goal of increasing connectivity; highlighted in a workshop by Morrissey et al. *"You wouldn't want to go past a restaurant or something and on the door it says, 'We welcome people who have dementia.' You know? And it doesn't make the person feel that they are part of the community if there's something there saying, 'We know you're different, but you're welcome.'"* [7, p. 10:2167]. Swaffer highlights the saliency and impact of this stigma from the perspective of someone with dementia, noting how this stigma reduces early diagnosis and engagement with the community from a fear of being othered [11].

Previous literature in exploring community engagement with PwD shows school children have been powerful advocates for community change. O'Shea et al. [9], describes children as a strong catalyst for creating a DFC, further demonstrated by Gawande with the positive effect relationships with local school children plays on identity [1]. Yet typically PwD may lack access to younger generations in their community as they move into residential care. For some this may reduce the opportunity to take on traditional elderly social roles, such as sharing experiences and advice to younger community members, further reinforcing this perceived loss of citizenship. Furthermore, communicative difficulties exist between younger people and PwD, where younger people may lack a knowledge of an older person's past, often making reciprocal conversations challenging [6]. However, using technology to support these intergenerational interactions can boost PwD's agency across their social settings, and simultaneously boosting connectivity between different generations [13]. Supportive communicative technologies can meaningfully connect the youngest

and oldest generations, helping to expand existing DFCs through reaffirming a sense of social identity and citizenship in PwD.

### **Supporting Community Engagement**

DFCs already encourage community engagement and care for PwD, but there are opportunities to further expand engagement through technology and existing community resources. One avenue of fostering community engagement is encouraging collaboration between primary schools and care homes, giving younger children opportunities to learn more about dementia, but also helping PwD to configure their own interactions with their community. Children and PwD can participate together in co-design activities, aiming to design technologies which support their interactions together and with their wider communities. Using practices such as experience-centred design [5] in these co-designs sessions can help create technologies that not only respond sensitively and empathically to the PwD's needs, but also those in the community looking to support PwD.

Involving PwD in younger peoples education around the condition and later life can give PwD a chance to reposition themselves within the social spheres of their communities. This would present opportunities to show younger people that people living with dementia can still contribute to the community, and can act as a valuable community resource, especially in sharing and teaching about the local area's history and people. Using care homes as settings for co-design activities can help increase the permeability of these spaces, whilst PwD's engagement with the community can then grow beyond the venues and events ran as part of DFCs. Further engagement with the community can present the community and opportunity to reconfigure their interactions with PwD - in such that PwD can play an active role in educating younger people sharing their lived

experiences of the local area.

### **Challenges for Growing Community Engagement**

The method outlined assumes equality between children and PwD in the co-design process, expecting both will have an expert knowledge of the problem space; the barriers preventing them from communicating with each other and sharing their experiences. In practice relationships between designers and children may be difficult to configure so that both are equal actors and are effectively co-designing [14], potentially further complicated when PwD are also a part of these relationships. One of the bigger challenges will be how to configure design processes that recognises both children and PwD's voices equally, without infantilising PwD or makes the children feel comfortable in the process.

Varying methods of communication present a significant challenge when co-designing with children and PwD. There may be situations where children may be unable to effectively articulate and vocalise their needs during the design process, and their needs may be outweighed by a more outspoken person with dementia. Inversely PwD, especially those communicating non-verbally, may be outspoken by the children - resulting in designs which account more for the childrens needs and experience. Children and designers may be unable to effectively understand sometimes nuanced forms of non-verbal communication, which would negatively affect a person with dementia's agency in the design process. This imbalance may have further reaching consequences, where the ongoing reconfiguration of PwDs' social roles could place them as a group of people with a more diminished agency if the children learn thier needs hold more weight than PwD.

Abstract thought and vocalisation holds a privileged role in co-design, but PwD may increasingly lose this ability as

the design process continues. A new design language is needed to help level the communicative playing field. Killick and Craig explore artistic mediums as a way to give voice to PwD, helping to express identity and self through artwork [4]. Using materials such as: paint, fabrics, and cardboard, to mediate communication between: children, designers, and PwD may help level the playing field, redistributing agency within co-design sessions. This can present children with other methods of understanding non-verbal communication as they are both encouraged to communicate through the same medium. This mediums need to be carefully selected with respect to the abilities of the group as using physical mediums to mediate communication may either infantilise PwD, as they engage in activities such as painting with children, or inversely highlight the affects of dementia if the activities are beyond their physical ability.

Creating a space for children and PwD to co-design technologies together is unlikely to happen in isolation, instead there will be a large number of stakeholders - ranging from teachers to care home staff. This presents a challenge when configuring design sessions, especially from the designers perspective when deciding how much weight these stakeholders should hold. For a collaboration like this to be effective it requires support from care home staff, teachers, parents, and primary caregivers, but should these stakeholders be able to influence the design process and resulting technologies?

There are clear questions that need addressing for collaborations like these to be successful - present in all co-design projects with PwD, but much more clearly highlighted when children become equal actors.

- How do we conduct co-design between children and PwD, should this process reflect one group may have

more complex needs, or do both groups have an equal stake in the process?

- How can creative mediums be used such as paints and materials be used to remove biases of abstract thought and verbalisation and create a level communicative playing field.
- How do we identify and acknowledge stakeholders without unduly influencing the design process or outcome?

These questions must be sensitively addressed during the co-design process as configuring sessions in such a manner that removes agency from PwD may unduly influence children's understanding of dementia.

## Conclusion

There are currently many positive interventions to increase community engagement with dementia, such as DFCs, but these can sometimes increase stigma and reduce a sense of connectivity to the community overall. Children have been shown to be an excellent catalyst for community change, presenting an opportunity to further increase community engagement with dementia through collaboration between schools and care homes. Whilst this can be a powerful method for PwD to shape their engagement with the community it also presents many difficult challenges for design and participation.

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