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Designing for Everyone: Can the principles of dementia friendly design inform design for neurodiversity in healthcare settings?

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Abstract

Purpose: There is increasing interest in the UK in developing environments that support people who are neurodiverse. This paper reports on a project to develop a cognitively supportive environmental assessment tool to improve the design of health centres, where the majority of NHS consultations take place, for all users including people living with dementia and those who are neurodiverse.

Methodology: A three stage process was used: a literature review; the development of a matrix of key design features for people living with dementia, autism and other neurodiverse conditions; and the development of an environmental assessment tool and guide for users which included easy read versions to maximise service user involvement.

Findings: The overarching concepts of dementia friendly design can be adapted to create design for everyone including those who are neurodiverse.

Originality: This project has confirmed that the principles of dementia friendly design are applicable, with modifications, to a wider group of neurodiverse people. Critically, each person's response to sensory stimuli is individual rather than determined by their condition.

Practical implications: The tools are available free to download. With adaptation, they have potential applicability across health and care settings.

Research implications: There is a paucity of research in environmental design for primary care from the patient's perspective, and more generally further research on design for adults with learning disabilities and autism is needed.

Keywords: Dementia, older people, primary care, neurodiversity, cognitively inclusive, environmental design, assessment tools

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Background

There is increasing interest in the United Kingdom (UK) in creating physical environments that support people living with a range of neurodivergent and neurodegenerative conditions. Such conditions include dementia, autism, attention deficit disorders, dyslexia, complex needs and mental health conditions that can affect sensory and cognitive processing. These neurodivergent and neurodegenerative conditions are captured under the umbrella term 'neurodiversity'.

Dementia, learning disabilities and autism

It is estimated that there are over 55 million people living with dementia worldwide and 900,000 people in the UK (Alzheimer's Disease International, 2021; Alzheimer's Society, 2022). Over 950,000 adults aged 18 or over have a learning disability in the UK (Public Health England, 2023), while there are around 700,000 people with autism spectrum disorder in the UK (Beyond Autism, 2023). While there is likely to be some overlap between these groups, there will also be people with undiagnosed conditions, indicating the scale of the need for supportive environments. Indeed, recent estimates indicate that up to 20% of the population is either neurodivergent, meaning that their brains function, learn and process information differently, or have a neurodegenerative condition that causes sensory processing difficulties over time (British Standards Institution, 2022).

People with a learning disability are living longer and those aged over 60 are two to three times more likely than the rest of the population to develop dementia (Healthcare Improvement Scotland, 2022). For example, it is estimated that 50% of people over 60 who are living with Down's syndrome will also experience Alzheimer's disease. The prevalence and incidence of dementia in people with autism is less well known, but it has been estimated that those with autism spectrum disorder under the age of 65 are approximately 2.6 times more likely to be diagnosed with dementia than the general population (Vivanti, 2021). As the UK population ages, the numbers of people with learning disabilities and autism who develop dementia is expected to increase.

There is therefore a need to consider what, if any, part dementia friendly design can play in creating health care environments that are supportive to individuals with neurodivergent and neurodegenerative conditions throughout their lives.

Design for dementia and neurodiversity

For people living with dementia there is a growing body of evidence to suggest that appropriate design of the environment can promote inclusion, independence and quality of life (Bowes and Dawson, 2019). In the UK, following the publication of the Department of Health's National Dementia Strategy for England (2009; 2015), advice, guidance and environmental assessment tools are widely available for health and care settings (Department of Health, 2009; Department of Health 2015; Evans *et al.,* 2022; Waller *et al.*, 2017). These include the Enhancing the Healing Environment (EHE) dementia friendly environmental assessment tools (The King's Fund/University of Worcester, 2020) which were updated in 2020 in the light of the latest evidence, guidance and the enhanced recognition of family carers and the sensory challenges that can affect people living with dementia (Evans *et al.,* 2022).

Despite this focus on dementia friendly design and an increasing recognition that good design can benefit everyone irrespective of age, health or condition, until relatively recently less attention has been given to the possibility of developing supportive design for people who are neurodivergent or have a neurodegenerative condition that causes sensory processing difficulties (BSI, 2022; HM Government, 2019)

The term 'neurodiversity' is predominantly used in relation to people with autism who can experience a range of sensory challenges including sensitivities to noise, light, smell, taste and texture, all of which are known to also be important to people living with dementia. People who are neurodiverse may also experience challenges with sociability, learning, attention, mood and other mental functions. 'Neurodiverse' describes individuals rather than a specific condition and there are a wide range of neurodivergent and neurodegenerative conditions, as well as people with complex needs and mental health conditions, that can affect sensory and cognitive processing. There is a move away from a medical definition of autism to a social model which emphasises that external barriers, rather than individual differences, are the problem (RCN, 2022). However, currently there is no standard definition of

either the neurodegenerative or neurodivergent conditions that should be included in the umbrella term neurodiversity.

Research into design for autism, a lifelong condition, has focused on design for schools and residential settings for young people (Beaver, 2011; Humphreys, 2008; Mostafa, 2014). Although it is estimated that half of those with autism may have a learning disability, there is a paucity of research on good design for this group. Employers are recognising the particular problem-solving skills and creativity that neurodiverse people can bring to the workplace and the critical part that the physical environment can play in supporting them (BBC, 2022; Chartered Institute of Personnel and Development, 2018; HOK Group, 2019).

In 2022 the British Standards Institute (BSI) published 'Design for the mind' – Neurodiversity and the built environment' (BSI, PAS 6463, 2022). The introduction makes it clear that the Publicly Available Specification (PAS) is not about one condition, difficulty or difference, but recognises the diversity of human brains and that each is unique.

This paper reports on a project undertaken to inform the development of a suite of cognitively supportive environmental assessment tools intended to inform both the design of new builds and the assessment of current health centres, premises where the majority of interactions with the NHS take place, but where there is a paucity of dementia friendly design research.

The project

The authors have considerable experience in the development of dementia friendly environmental assessment tools (Ref x 2 removed for anonymity). In 2020 they were approached to design a bespoke assessment tool by Assura plc, a leading British-based property company that designs, builds and manages over 600 health centres serving over six million patients each year across the UK. To gain a better understanding of the lived experience of patients who use their buildings, the company had commissioned reports from national patient organisations (Dimensions, 2020; The Patients Association, 2019). These confirmed the critical importance of the built environment to the patient experience and the delivery of high-quality primary care services. They concluded that health centres needed to be

welcoming, calm and comfortable whilst being supportive of patients' independence, privacy and dignity and affording them choice and control. There were clear indications in both reports that a poor environment, lack of privacy and inadequate toilet facilities could lead to increased significant stress for patients and in some cases missed appointments.

The company therefore wished to reflect the needs of all patients regardless of cognitive ability, and to build on best practice in dementia friendly design by commissioning the development of an environmental assessment tool that reflected the design features known to be important to all those who are neurodiverse.

The design of primary care environments

With the benefit of funding from Assura plc, the project focused on the environmental design of health centres (GP surgeries, primary care premises) which are the gateway to wider NHS services and where, in normal circumstances, over 300 million patient consultations take place annually (NHS England, 2017). Many of these premises are relatively old and known to be far from ideal, particularly for an ageing and increasingly diverse population, yet there is little freely available advice specifically on good design for people living with dementia in this setting other than the EHE assessment tools and a guide for creating dementia friendly GP surgeries (iSPACE, 2015; The King's Fund/University of Worcester, 2020).

Methods

A three-stage process was used to develop the suite of cognitively supportive environmental assessment tools.

Stage 1 – literature review

A scoping review methodology was employed (Arksey and O'Malley, 2005) focusing on design for dementia, autism and neurodiverse conditions. This type of literature review considers the extent of knowledge but does not address the quality of studies included.

The following key search terms were identified:

'design' and/or 'environment' *(to be searched in title/abstract/ keywords)*

AND dementia OR Alzheimer's OR cognitive impairment OR autism OR neurodiversity (*anywhere in the article, not restricted to the title*)

The search was confined to literature published in the UK from 2000-2020. The following databases were searched: MEDLINE, ProQuest Central, Social Care Online, PsychINFO.

In addition to database searching, reference lists were hand-searched to identify further literature. Searching of relevant websites, policy and practice guidelines together with consultation with relevant experts in the field were also used to identify relevant sources.

Stage 2 – developing a matrix of key design features

Based on the scoping review findings, a matrix was developed to capture the key design elements relevant to areas accessed by patients in health centres. This made it possible to test if there was sufficient commonality in design elements to seek to develop a cognitively inclusive assessment tool. For the purpose of the matrix, people with dementia were deemed to be older people with associated disabilities of ageing and co-morbidities. Elements and recommendations from the two reports from patient organisations that related to the built environment were also included where relevant (Dimensions, 2020; Patient's Association, 2019).

Stage 3 - developing the assessment tools and guide

Using the commonalities in design features identified in Stage 2 it was possible to identify aspects of good environmental design for people living with dementia, autism and neurodiversity that would also enhance the experience of the increasingly elderly population who access health centres. These aspects formed the basis of draft versions of the assessment tools and guides, which were tested by relevant stakeholders and refined based on their feedback.

The project took place during the Covid-19 pandemic when access to health centres was severely restricted and it was therefore not possible to undertake any on-site testing. A Reference Group of staff drawn from across Assura plc provided a consultation and testing forum which was critical to ensuring that the tool was both user friendly and informed by practical experience. Dimensions also provided specialist advice on autism and patient experience by hosting an online seminar and

by commenting on various drafts. As Covid-19 restrictions eased, the company's first dementia friendly health centre was assessed using a draft of the tool. It is testament to the many perspectives that informed the development of the tool that following on-site testing only very minor wording changes to the tool were required.

Findings

The literature review identified considerable agreement that appropriate design of the environment can promote inclusion, independence and quality of life for people living with dementia. However, it highlighted the paucity of recent peer-reviewed literature on environmental design, indicating a need for further rigorous, large-scale studies with the potential to provide evidence on the impact of multiple design elements across all settings where people living with dementia live or are cared for (Bowes and Dawson, 2019; Evans *et al.,* 2022). The review also identified the lack of evidence for some more recent approaches such as the use of floor-to-ceiling murals, assistive technology and immersive reality, along with a critical need for the perspectives of people affected by dementia to be integral to all research.

To date, the majority of research on autism friendly design has focused on younger people. The 'ASPECTSS'™ design framework for schools developed by Mostafa (2014) and the work of Humphreys (2008) and Beaver (2006; 2011) in schools and special residential facilities have been highly influential.

A total of 22 policy and practice sources were identified with a significant overlap in material, scope and authorship with the findings of the autism specific literature cited above. Only one NHS source was identified (Simpson, 2015). It was however possible to identify an emerging commonality of features that represented good design for young people as exemplified by a list from the Department of Education (2009). This included:

- buildings with simple layouts;
- calm, ordered, low stimulus spaces;
- indirect lighting, and subdued colours;
- good acoustics, avoiding sudden / background noise; and

- safe indoor and outdoor areas.

The term ‘neurodiversity’ was most commonly encountered in relation to people with autism and there appears to be little indication that there is any recognised difference between design for autism or those that are neurodiverse (Helen Hamlyn Centre for Design, 2016). Specific information found on design for neurodiversity related to the workplace and overlaps with the design features previously identified as good design for young people with autism (BBC, 2022; BSI, 2021; HOK Group, 2019).

The matrix of key design features developed from the literature review had six main domains: ambience; sensory environment; safety; building design; interiors; and outdoor spaces. Each domain comprised a number of sub-sections and specific elements. In total, 23 different elements were considered along with the design considerations for each of the three conditions: dementia; autism; and neurodiversity. An extract from the matrix is given in Table 1 as an example, showing the issues for each condition mapped against an element, together with the appropriate response or advice.

…[Insert Table 1 here]…

Analysis of the matrix confirmed that it was possible to identify a range of design features that are important to those with neurodegenerative and neurodivergent conditions, particularly, but not exclusively, around the sensory elements of design. It is however essential to acknowledge that each individual person may respond to these design elements differently. For example, someone may be highly sensitive to physical or emotional stimuli (hypersensitive) or conversely under-responsive (hyposensitive) to noise, smell, touch or light. Critically, these responses are individual and do not appear to be determined by a person’s diagnosis.

Key elements of cognitively inclusive design

Five overarching domains in terms of cognitively inclusive design emerged in respect of health centres: safety; the sensory environment; building design; interiors; and outdoor spaces. In view of these commonalities in design features, the following aspects of good environmental design for people living with dementia, autism and neurodiversity were identified:

- the critical importance of the general ambience and cleanliness of health centre premises to the wellbeing of patients and for the delivery of person-centred, high quality primary care services;
- the key role that design should play in enhancing a person's privacy, dignity, independence, choice and control;
- the importance of recognising differences in the sensory experience of those living with cognitive challenges and neurodiversity;
- the adaptability of spaces to meet individual needs and circumstances; and
- the importance in relation to the built environment of:
    - approach and access to buildings
    - spatial sequencing and transition zones
    - design of reception areas and waiting spaces
    - provision of alternative spaces
    - toilet provision especially for people with impaired mobility
    - decoration, furnishings and signage
    - outdoor spaces.

With the implementation of these cognitively inclusive design principles, health centres would be expected to provide an environment, both internally and externally, that promotes accessibility and support, care and comfort, independence and privacy, safety and security.

The assessment tools and guides

During the development process and in consultation with Dimensions, it was decided to produce two versions of the assessment tool:

1. A full tool, including information on environmental changes that may be required during a pandemic, designed to be used to inform the design of new builds and major refurbishments;

2. A shorter summary tool for use by staff who undertake routine inspections of premises.

Both tools focus on the same aspects of the physical environment known to affect people living with dementia, cognitive impairment and neurodiversity.

The full assessment tool contains four sections:

- First impressions
- Core design features which apply across the health centre
- Specific design features which apply to particular areas
- Additional considerations during a pandemic

The summary tool contains two sections:

- Core design features which apply across the health centre
- Specific design features which apply to particular areas

The sections within the tools were developed to be as flexible as possible to take account of the varied nature of health centres, and it is acknowledged that not all questions within the sections will necessarily apply to every building. The rationale for each element is included in the tools and a short introductory guide was produced to support those using the tools.

To ensure inclusivity and maximise patient and public involvement and engagement in carrying out assessments, an easy read version of the summary tool and guide were also developed (Dimensions UK, University of Worcester and Assura, 2022).

Discussion

The scoping literature review indicated that the development of an assessment tool for cognitively inclusive design was innovative. Despite the higher incidence of dementia amongst people with learning disabilities and autism, their particular needs have not been addressed previously in relation to environmental design, and there is a paucity of research focused on autism friendly design for the adult population. It was also evident that peer reviewed research into dementia friendly design has stalled in the UK, and that there is a need for further large-scale, multi-service

evaluations involving the perspectives of those affected by dementia and particularly in areas involving new technology.

Despite the majority of patient contacts with the NHS taking place in health centres, little attention has been given to the design of premises from the perspective of those with neurodegenerative or neurodivergent conditions such as dementia, learning disabilities and autism. Although it is not possible to adapt the health centre environment for each individual patient, environmental design should offer as much flexibility as possible to be inclusive and to meet the needs of those with cognitive impairment, autism, neurodiversity and physical or other disabilities. The outcomes of the project indicate that there is convergence on many of the aspects of design that are known to be important to people living with dementia, the majority of whom are older people, and those with other neurodivergent and neurodegenerative conditions regardless of their age. It is also apparent that the responses of each individual to particular sensory design features are different and not necessarily determined by their diagnosis.

The cognitively supportive environmental assessment tool developed during this project focuses on the internal and external built environment rather than the interactions between staff and patients, which are an integral part of the patient experience. Although it is possible to deliver exceptional care in a less than ideal environment, attitudes and behaviours can negatively affect the patient experience. Staff can equally be affected by the environment in which they work, with experience from dementia friendly design projects indicating improvements in staff morale and reductions in sickness absence following dementia friendly refurbishments (Waller 2013).

Conclusion

This project has confirmed that the principles of good design for people living with dementia are applicable, with modifications, to a wider group of people including those with autism and other neurodegenerative and neurodivergent conditions.

A key finding is that each individual person may respond to these design elements differently as, for example, they may be highly sensitive to physical or emotional stimuli or conversely under-responsive to noise, smell, touch or light. Critically these

responses, often to sensory stimuli, are individual and not determined by the person's condition or cognitive ability.

Although this work focused on the health centre environment, the authors believe that the underlying principles, and indeed the tools themselves, have applicability across all health and care settings and more widely across the public realm.

The overarching concept of neurodiversity may therefore have the potential to bridge the gap between designing for separate conditions such as dementia, supporting the alternative and more inclusive approach of 'Designing for Everyone'.

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Figure 1 – Illustrative example from the building design section of the matrix of key design elements

Transition zones (including corridors)	Dementia	Autism (school/residential care setting)	Neurodiversity (offices/multi-setting)
Issues	Uncertainty about where to go or what is beyond a door.	Needed between low & high stimulus environments. Long corridors may make it easier for people to “elope”.	Anxiety & uncertainty about the next space.
Responses	Vision panels in doors so that people know what is beyond. Avoid dead ends & tight corners.	Help to recalibrate between sensory zones. Clear views. Wide corridors. Curved walls so people can see what is ahead. Avoid long corridors.	Preview what is going on in the next space. Allow people to sit with their back to a wall.