

Research report

Experiences of people with dementia

A visit to the Churchill Theatre in Bromley

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Acknowledgements

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The Research Institute for Disabled Consumers

The Research Institute for Disabled Consumers (RiDC) is the leading expert in inclusive research involving disabled and older consumers. We are an independent, national charity with over 50 years of experience in consumer research and insight in this specialist area. We are run by, and for, people with a personal experience of disability.

Innovations in Dementia

Innovations in Dementia (ID) is a social enterprise that works with people with dementia, as partners and volunteers, to develop and test ideas that will enhance the lives of people with dementia. ID facilitates DEEP (Dementia Engagement and Empowerment Project), which brings together over 80 local groups of people with dementia across the UK

Churchill Theatre

The Churchill Theatre in Bromley has been one of the South East's leading live entertainment venues, welcoming over 200,000 customers through its doors every year. The theatre has worked hard to improve the accessibility of its venue and its shows.

Bromley Mindcare Young Onset Dementia Activists - YODA

The Bromley MindCare Young Onset Dementia
Activists group (YODA) is a proactive group of
individuals from the London boroughs of Bromley,
Lewisham and Greenwich who have developed
dementia before the age of 65, and their carers. They
meet weekly to support each other and find ways to
improve their communities. The group is run by
Bromley Mindcare, part of Bromley Lewisham and
Greenwich Mind, a mental health and dementia
charity that offers information and advice to people
with mental health and dementia and lobbies
government and local authorities on their behalf.

Introduction

DEEP groups in London all share a desire to change their communities to make them better for people with dementia. In addition to offering support to people with dementia and their carers, many DEEP groups have experience with conducting audits of venues and services to raise awareness of access needs of people with dementia. However, during a meeting with DEEP group leads from across the UK, it became evident that individual groups can struggle to scale their insights.

This partnership project between RiDC, ID and local DEEP groups offers an opportunity to bring together and share insights from local groups in London and document best practices. In doing so, our aim is to contribute to the wide distribution of knowledge and awareness about the needs of people with dementia and the removal of barriers that prevent their meaningful participation in society.

The research question that guided this project was as follows:

How might local venues be made more accessible for people with dementia?

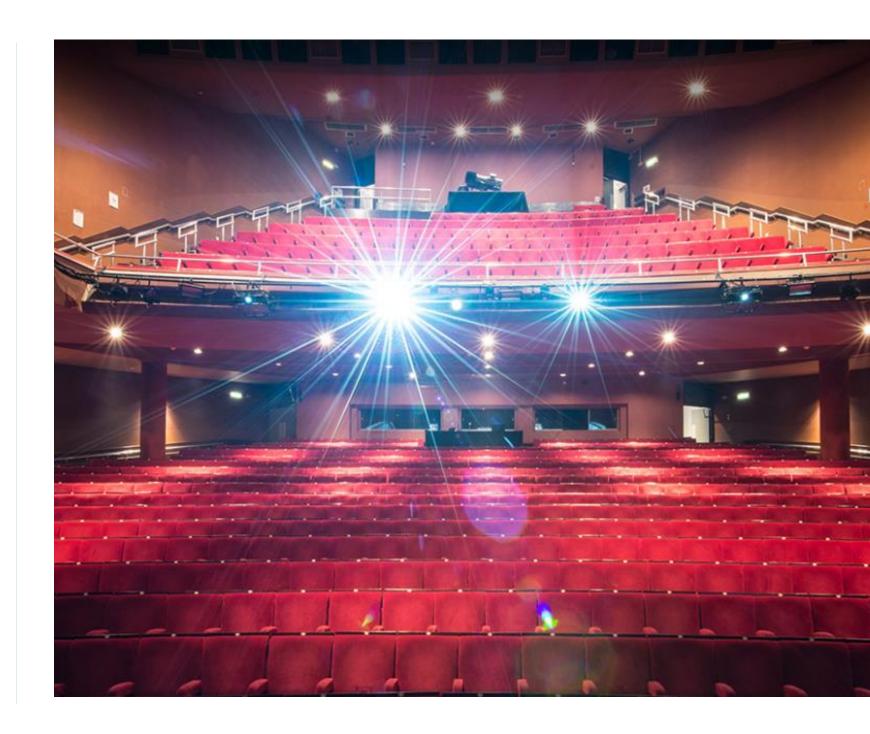
Background

RiDC visited the Bromley Mindcare YODA group on two occasions. First, to introduce the project and explore the willingness among the group to take part in an audit of a venue of their choice. Second, to discuss the research process and research deliverables.

The Bromley Mindcare YODA group wanted to investigate ways in which they could assess the suitability of attending a local theatre for people with dementia. In particular, they wanted to find out:

- What are the challenges for people with dementia in visiting or attending theatres?
- How might any barriers be overcome to make the building and/or its performances more suitable to the needs of people with dementia?

RiDC also visited the Churchill Theatre to plan the visit, who were enthusiastic and keen to receive the group. Prior to the start of the Covid19 pandemic, the theatre was in the process of organising staff training to cater to the needs of people with dementia which it had to postpone. During the visit the group was accompanied by a member of staff from BLG Mind's specialist dementia training team involved in organising the staff training and insights gathered during this project will be used to inform the training session.



Background (cont.)

The Bromley Mindcare YODA group is there to support both members with early onset dementia as well as their carers. Every single person in the group has a powerful story to share about why they joined the group and what it's like living with early onset dementia.

Several people shared how raising awareness about it and taking away the stigma was an important motivation for them to join the research. At the time of the research, the group counted approximately 15 members who attended the group on a regular basis.



Here for her

When RIDC researchers first walked into the room to meet the group, music was coming from the building and Ann and her husband Alan were dancing to their wedding song, 'Without you' by Harry Nilsson.

"No, I cant forget this evening.

No, your face as you were leaving,



But I guess that's just the way the story goes.."

They married 42 years ago on Ann's birthday. 'I forgot it was her birthday until we were on our way to our honeymoon!' says Alan when they sit down again. Ann started showing symptoms of early dementia 6 years ago but they only received a diagnosis last year. They were sent home without any support in coping with the diagnosis. They were grateful Saira, the Service Manager for BLG MIND's dementia services who runs the Bromley Mind's Young Onset Dementia Activist group (YODA), kept calling them, encouraging them to join the group. At first, Ann was and reluctant to join the group, but over time, Alan saw her confidence grow. 'She smiles again' he said.



Accessibility at the Churchill theatre

The Churchill Theatre is passionate about
Theatre for All, so much so that they
regularly consult directly with their
audiences through open access days and by
working with local support organisations so
they can better cater what they offer to their
community.

The Churchill Theatre is furthermore committed to providing a programme of accessible performances throughout the year.

Relaxed performances

These involve an adapted performance of the show for neuro diverse audiences, patrons with dementia and any other patrons who may find a theatre 'experience' overwhelming. The lights are turned up in the auditorium, noise and sound effects from the stage are reduced, and patrons are able to move around the auditorium if they wish as the theatre doors are opened throughout the show. A 'chill out' space is also provided and there is a TV monitor where patrons can watch the show outside the auditorium.

Physical access

The venue has wheelchair accessible spaces in both the Circle and the Stalls. They welcome working dogs, and the venue is used as a training venue for Guide Dogs for the Blind. The venue has an accessible toilet in the main foyer.

Audio Described performances

With a free bookable touch tour before the performance; the touch tour offers patrons with sight issues, a unique on-stage experience prior to the show to enhance their enjoyment of the production.

Sign Language Interpreted performances

These include a dedicated signer who is on stage and in clear sight of deaf patrons

Captioned performances

Using specialist caption boxes positioned to one side of the stage, for our deaf patrons and those with hearing issues.

Method

The group decided collectively to visit the 'Stevie Wonder Show' on the 18th of March 2022 to understand the accessibility of their local theatre (however the show itself and any dancing resulting from it would not be the subject of research!).

Preparations

Prior to the visit, a meeting was held between RiDC, the Event manager, group coordinator and chef of the theatre to plan the visit. This meeting addressed the scope of the research, and a walkthrough of possible scenarios and practical issues (travel to the theatre, access to seating, toilets, restaurant etc).

Seats and a pre-theatre dinner were arranged for the group and the RIDC researchers. After looking on a seating plan together with the group, seats were chosen on the circle level.

Getting the paper work in order

Consent forms were sent out to the group and returned signed prior to the visit. Tickets were booked as follows: staff members and people with dementia received a standard ticket and carers received an 'assistance' ticket which enabled them to join free of charge.

A statement was provided by Bromley Mindcare to confirm some in the group had a disability and were required to bring a carer, and this statement was shared with the theatre in advance along with special dietary requirements of members in the group.

This way, participants or their carers did not need to show their blue badge or provide any proof they had additional needs on the day.

On the day

Eight members of the group were able to participate in auditing the theatre, of which four people with dementia and 4 carers. There were three facilitators from Bromley Mindcare and two researchers from RICD.

As much as possible the visit by the panel to the theatre was viewed as a normal visit with no special consideration given except for a heightened critical eye. The group congregated at the restaurant and was met by two researchers from RiDC and two staff members from Bromley Mindcare.

The researchers explained the need to document people's thoughts and opinions throughout the visit. They also made participants aware that staff from Bromley Mindcare would take pictures and short video clips and that permission would be asked in case of use in any publication.

Research approach

The following approach was agreed upon in consultation with MIND staff to ensure the whole experience would not be too taxing on members of the group in addition to attending the dinner and attending an evening show.

The scope of the visit focused on the building and its facilities as well as staff interactions.



Checklist

RiDC researchers and MIND staff arrived early at the theatre and completed a brief evaluation of the accessibility of inside and outside spaces, guided by checklists developed by another local DEEP group that was made available online. The checklist was filled in pairs whilst navigating through the building and to highlight features that were of concern (facilities of the theatre such as toilets, box office and stairs). Results provided topics of discussion when people arrived and during the dinner.



Group discussion

During the dinner, members of the group were encouraged to share their experiences in relation to accessing the theatre and venues in general, while also exploring the meaning of being able to attend a performance and the role of peer-support. Similar conversations took place during the interval break. Short video clips were recorded of members of the group sharing their thoughts.

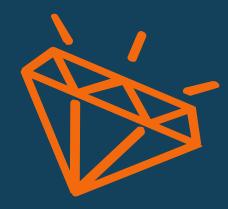


Observation

Throughout the experience the two RiDC researchers were sensitive to participants responses and documented these through observation and note taking. The researchers also listened to carers and facilitators, which often added different perspective and context.

Her night

When Carol arrives at the theatre, she is shining. She out with a fabulous dress, red lipstick and her face is glowing. Her daughter, who is also her carer, explains how important the group is to her. "When the group meets on Fridays, she gets up in the morning excited. She knows: this is her time." Carol is no longer able to communicate in words, but during the show she get's up out of her chair and sings along with all the songs. When she is playing air guitar, she glances over to another participant who is playing invisible drums. Words are not needed as music has become the medium through which Carol is able to feel part of the group, and the band too!





Planning a visit to the theatre

People with dementia want to have a nice day out in London just like anyone else. However, there are some conditions that can make planning a trip or making one more challenging. What did we learn from this trip about what is involved when planning a trip to the theatre for people with dementia and others may not be aware of?

Choosing an activity

Distance to and from the activity was an important factor not just for general comfort, but because it can take more energy. Temperature was also considered important for health reasons.

Some activities seemed fun initially, but due to their nature would not enable all members to participate. For example, a karaoke session would require processing song texts quite quickly.

Eventually the group decided they would like to attend a West End show.

Tip 1: When selecting an activity for people with dementia, always ask them first what they would like to do and only help them decide if they find it difficult to chose.

Tip 2: Consider things like weather, noise levels and travel distance and time to ensure comfort and safety, as well as capabilities that may be required to take part in the activity. Avoid anything that requires complex interactions so people can relax.

Selecting a venue

Many theatres are old buildings that don't have elevators and accessing the auditorium or toilets is only possible by climbing lots of stairs. This is a challenge for some members of the group who can't climb stairs because their dementia symptoms include distorted depth perception causing them to be at risk of falling.

In selecting a suitable venue, researchers at RIDC consulted the Access London Theatre Venue information (2021) guidance which was helpful, tough also slightly difficult to navigate.

Tip 1: Usability of the map could be improved with a landscape version, an explanation of terminology used and a map of the city. Also, disabled parking could a helpful additional category.

Tip 2: We noticed the Churchill Theatre was not listed in this access guide. Joining similar future initiatives could be a great opportunity for the theatre to improve access further!

Selecting a show

Barriers to accessibility were encountered before even entering a venue. Most West End shows were performed in the evening, whilst people with (early onset) dementia felt at their best during the day which would be a preferable time to enjoy a performance. Most West End shows are performed in the evening, whilst people with (early onset) dementia may feel at their best during the day.

An inclusive night out

Christopher has had to overcome many health challenges in his life. He has found the experience of being able to visit the theatre very encouraging and was very pleased the group was able to have dinner in a quiet area outside of the restaurant. Next time, he would like to sit in the stalls to avoid the steep stairs in the auditorium. He would not want to sit on the access row which is at the very back of the auditorium, as he would struggle to see the performance from there.

For carers like Veronica, the night is equally fun. She reflects: "Everything has been so inclusive, you are not aware of who is a carer and who are the people cared for"





Planning a visit to the theatre (cont.)

Some shows have matinée or relaxed day time performances for audiences with additional needs. Unfortunately these didn't match the dates on which the group could meet, but they generally are a great option for people with dementia.

The fact the group wanted to visit a regular show is an important reminder that not all people with disabilities want to fit 'special' categories – whilst these can be helpful, they also want to be able to take part in events like everyone else.

Shows with music or dancing can be especially fun for people with dementia and were especially popular with the group, as these are activities we can all relate to and stimulate us to feel with our hearts and bodies and not just with the brain.

In addition, the reason why the Stevie Wonder Show was especially appealing to the group is that this music was popular at a time when most members of the group were young.

Tip 1: Select performances or events for people with additional needs can be great, but don't forget to about the accessibility of regular shows to be as inclusive as possible.

Tip 2: consider access for people with dementia especially for events or shows that because of their nature may stimulate memories of a certain time period.

Carer access

There is a discount in many theatres for carers who are often able to join people with a disability for free, and this is also the case in the Churchill Theatre. Carers are generally required to show proof of their carer status on the day.

This could be a potential deterring factor for people with dementia and their carers to visit the theatre independently. Many members of the group do not have paid carers. Instead, family members – often sons or daughters – have taken on the role as carers to ensure their loved ones are able to enjoy a quality of life. They may not always have a badge.

Tip: The group worked around this barrier with a group statement, but theatres may want to consider flexible arrangements for individual visitors who may require a more personalised approach.

Refreshments

To enjoy the experience, having dinner at or as close to the local venue was preferable. Theatres like the Churchill theatre offer pre-theatre dinners at their restaurant and will often be able to arrange a nice quit space when requested.

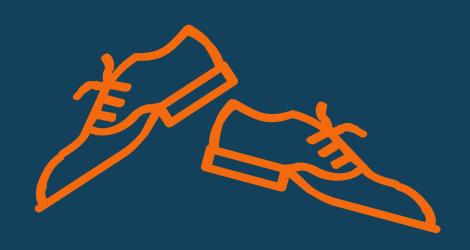
Tip: The Churchill theatre staff arranged to bring drinks and snacks to the group so they could stay in their seats!

Accessible toilets

Prior to the visit researchers made sure accessible toilet facilities were available at the venue.

Dancing Parkinsons away...!

Matthew has difficulties walking as a result of Parkinson Disease. His parents are joining him as his carers and help him descend the steep stairs of the auditorium. And yet, Matthew is an excellent dancer. During the show, as some members of the audience get up from their seats and start dancing, Matthew and Saira- the service manager of Bromley Mindcare YODA - find a little corner to move freely.. No ablebodied person in the audience came close to their dance moves that night!





What worked really well?

Here are some highlights of the visit that illustrate the fantastic efforts the Churchill Theatre made in catering for the needs of the visitors with dementia and their carers.



Personal advice from box office staff

The friendly staff member at the counter pointed the carer discount out to us which was very helpful as this was not obvious when booking tickets online.



Pre-theatre dinner

The group had a fantastic experience dining in a quiet area just outside the restaurant. The table that was arranged was perfect to enjoy a conversation and staff were incredible friendly in taking the groups orders.



Seat service!

On initiative of the theatre, interval snacks were brought to the group, who could stay in their seats. This helped to avoid having to navigate stairs and crowds and focus on enjoying the experience. It also made us all feel a little special!



Accessing the auditorium

Whilst the group had themselves chosen not to book tickets on the access row which required them to move down steep stairs to reach their seats, staff made sure the group was able to enter the venue prior to other visitors so they could take their time.

What could be improved further?

Here are some challenges the group identified during the visit that might benefit from improvement to increase access for visitors with dementia and their carers.

A more detailed set of recommendations was shared with the theatre in a separate document for internal use.



Parking

Some in the group who arrived with their own car struggled to park close by, which could be improved with disabled parking signage and information.

Potentially this could automatically be provided as part of access bookings.



Taxi

Taxis park at the stage door, which was difficult to reach for the group using the outside stairs which was dark and slippery. Potentially, information could be provided at booking stage to take the longer road through the park (providing it is well lit) or use the stage lift.



Signage

The layout of the theatre can be confusing to navigate due to the way the building is structured. Generally people felt signage in the theatre could be more visible, readable and include icons in addition to text.



Accessible toilet

Whilst staff were available to assist some members of the group make use of the accessible toilet, step-free access from the restaurant to the toilet could make visitors experience a higher level of independence and not having to ask for help.

Visual guide

The Churchill Theatre provided the group with a visual guide to further help in making their visit as accessible as possible, which was really helpful.

The group took the time to look at how this visual guide could be further improved to suit a diversity of needs and provided the following feedback:

Readability

- To increase the font size and font use so it is easier to read.
- Increase amount of photos and reduce text
- Information could be simplified in smaller bullets instead of long sentences to make it easier to process
- Some images were a bit 'blurry (low resolution) and could be improved
- Descriptions under imagery could be a bit more clearer and in bold
- The fire page could be more 'dramatic' and include a fire sign

Information provided

- Mention the presence of a lift
- A designated help point photo of where to go if you got confused or lost would be helpful.

Format

- Some suggested to use a cartoon style format with people and bubbles as they walked through the theatre, that read more like a story.
- Some felt a video highlighting what was in the guide could compliment the document

The group also looked at a 3D tool on the website of the Churchill Theatre called 'view from your seat'. The carers found it quite helpful but for people with dementia it was challenging to use.

Tip: Consider making the visual guide available on the website instead of upon request.



Further information

RiDC

- http://www.ridc.org.uk/news/improving-experiences-peopledementia-london
- http://www.ridc.org.uk/

Bromley Mindcare, part of BLG Mind Ltd

- https://blgmind.org.uk/bromley-dementia/yoda/
- https://blgmind.org.uk/

Churchill Theatre

- https://churchilltheatre.co.uk/Online/default.asp
- https://churchilltheatre.co.uk/Online/accessibility-churchill

DEEP Network

- DEEP guides to support the involvement of people with dementia http://dementiavoices.org.uk/resources/deep-guides/
- Inside checklist: https://www.dementiavoices.org.uk/wp-content/uploads/2017/04/Inside-checklist-VFINAL.pdf
- Outside checklist: https://www.dementiavoices.org.uk/wp-content/uploads/2019/01/Audit-Checklist-%E2%80%93-Is-this-outside-public-space-dementia-inclusive.pdf

Innovations in Dementia

http://www.innovationsindementia.org.uk/resources.htm

City Bridge Trust

https://www.citybridgetrust.org.uk/

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