



People with Learning Disabilities and their access to mainstream cultural activity

asist



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Introduction

The [Learning Disability Mortality Review \(2018\)](#) provides the most recent evidence of the vast inequalities between people with learning disabilities and the general UK population. Regular engagement with the arts and cultural activity has been proven to enhance social cohesion, educational attainment and health and wellbeing. However, people with learning disabilities are less likely to engage with mainstream arts and cultural activities than the general UK population.

Reach is an Advocacy Service for people with learning disabilities in Stoke-on-Trent. In 2017 members of Reach joined the SoTogether CAN (Community Advisory Network) to help influence and inform Stoke-on-Trent's bid to be City of Culture in 2021. As part of this they worked with Staffordshire University to consult with communities about the bid. The group felt that although they had opportunities to participate in art activities themselves, often in a therapeutic capacity, it was more difficult for them to attend mainstream arts and cultural activities, and be part of the community attending them.

To help understand the issue, a team of Reach members were trained to be Peer Researchers and carried out research into culture and the barriers to accessing mainstream arts and culture for people with learning disabilities. The research was conducted with people in Stoke-on-Trent although the findings are relevant to the cultural sector and other service providers across the UK.

The people involved

Ten Reach members were trained as Peer Researchers and in total spoke to eighty two people in November 2017. The Peer Researcher teams carried out focus groups and interviews. They were supported by three Advocates from Asist. Once the findings had been compiled the Peer Research group met again to discuss the findings, the impact of the peer researcher process and to identify how to disseminate their findings.

The questions

The questions the peer researchers asked were:

1. What does culture mean to you?
2. What stops people from being able to take part in culture?
3. What needs to happen to make sure everyone can take part (in mainstream cultural activity)?

The needs of the research participants were varied and therefore additional supporting questions were asked, such as, what activities do you like to do? and what stops you from going to places?

The research findings

Our findings about culture, and what it means to people with learning disabilities

Culture means different things to different people with learning disabilities. The arts were mentioned fewer times than other activities such as sports, shopping or going on daytrips. 'Daytrips' include local trips on the bus to one of the six towns as well as organised visits to other parts of the country. Where the arts were mentioned the most common were the theatre, drama and heritage. Crafts such as knitting and card making were also popular activities, many of which took place in day centre settings. Food, especially being able to go to a café or restaurant, and a person's faith were also important to the group's understanding of culture. Figure 1 illustrates the activities identified by the participants in the research.

Being part of a community or group was essential to people's cultural experience. Most of the activities they mentioned were social activities, in which other people were either involved or went to places with them. The role of support staff was important, and in some cases were the only means of finding out about mainstream arts and culture experiences, or being able to access them.

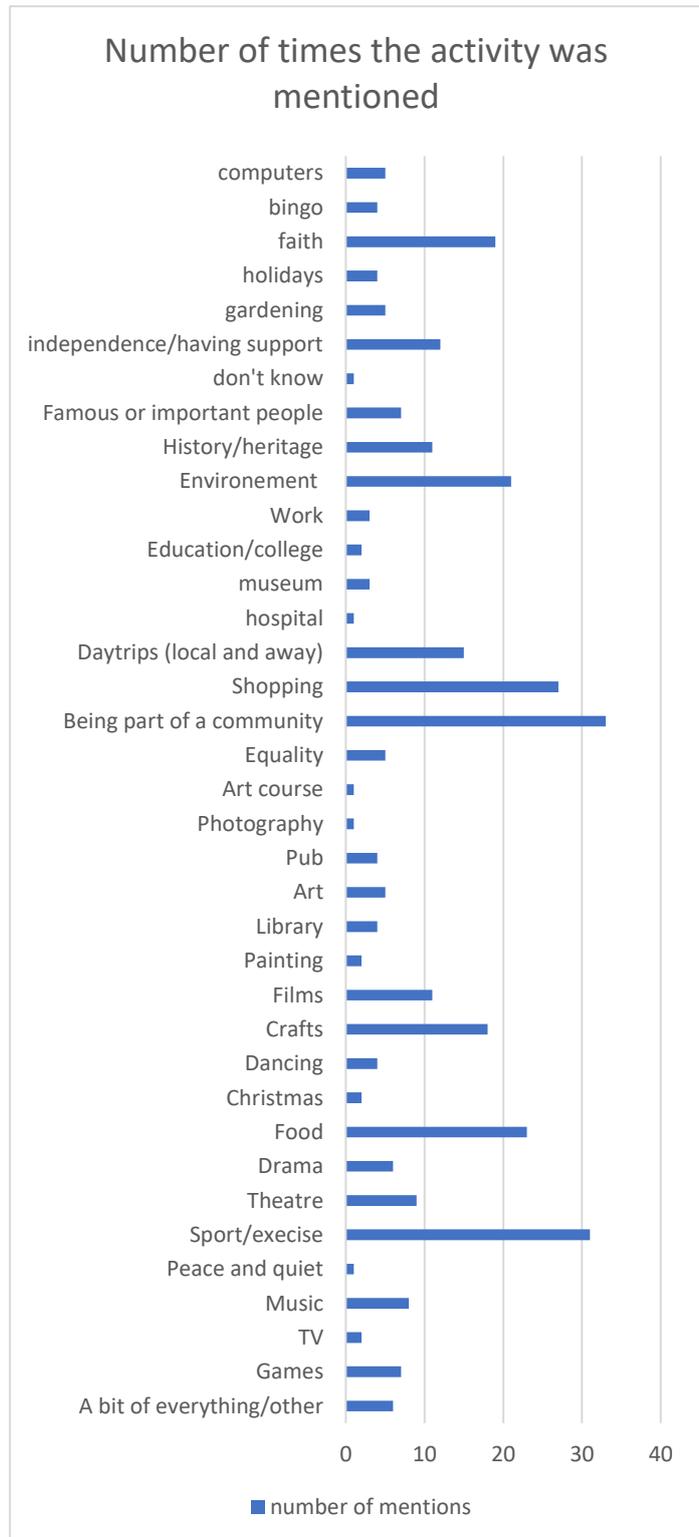


Figure 1. The range of activities identified by participants and the number of times each was mentioned.

Our findings about the barriers to accessing cultural activity for people with learning disabilities

Transport

Transport was one of the main barriers to accessing cultural experiences for people with learning disabilities. The majority of participants did not have access to their own transport, such as cars, and were therefore reliant either on other people or on public transport. In some cases, specialist transport was required which resulted in an extra cost. Where public transport was used, some participants said that the bus services did not run frequently enough or late enough in the evening for them to be able to rely on it to attend a cultural event. In some cases, participants who used wheelchairs said that they had been unable to fit on a bus when it is busy and so could not rely on public transport, especially in the evenings. The cost of transport, in addition to ticket prices and

refreshments whilst at a venue, also contributed to people feeling unable to prioritise arts and cultural activities.

Support

A number of participants were reliant on other people, either family members or carers, to attend cultural events with them. Some relied on others to offer support in organising events and transport. For some people, it was a perceived lack of safety, either at the event itself or between their home and venue, that increased their need for a carer to attend events. In some cases, the support was not available at the times required. Where support was available, taking a carer to a cultural event can add to the costs. People with learning disabilities told our researchers that they sometimes had to pay for two people's entry fees, because they have to pay for a ticket for their carers in order to attend, effectively doubling their cost of attending an arts or cultural activity. For people who rely on their carers to manage their finances, it can be difficult to argue the case to prioritise a visit to an art or cultural event over other activities.



Cost

In addition to the above, recent changes to disability welfare have resulted in a significant number of people with learning disabilities in Stoke-on-Trent either having a reduced income or losing Personal Independence Payments all together. Even for people who do not require a carer to attend events or venues with them, the cost of ticket prices, transport and refreshments can make attendance at mainstream cultural activities difficult.

Accessibility

Accessibility at venues was also a barrier to access for some people with learning disabilities. Physical access, or concerns about physical access, prevented some people from attending. This was supported by the wider community consultation for the City of Culture where participants who use wheelchairs told us that attending arts and cultural events took a significant level of planning and sometimes resulted in people who use wheelchairs being separated from their

families or friends to watch or participate in the activity. Importantly, participants also referenced the need to feel welcomed and safe at venues, and the need for staff working at cultural venues to understand learning disabilities. This friendly welcome, and the resulting feeling of personal safety this can bring, is as important to improving access to arts and cultural activities for people with learning disabilities as the need for ramps or lifts, adequate toilet and changing facilities and hearing loops.

Other barriers

Research participants also mentioned other barriers such as venues or activities feeling unfamiliar, raising anxiety for some people who are reluctant to try new activities. They also mentioned that they are often reliant on other people to tell them about events, as advertising materials are not always made accessible for people with learning disabilities. This adds to the perception for some people that the activities on offer are not for them.



Recommendations for the cultural sector to support people with learning disabilities to access mainstream arts and cultural opportunities

The Peer Researchers, based on their interviews and focus groups, and in discussion with Staffordshire University, make a number of recommendations to help more people with learning disabilities access mainstream arts and cultural experiences.

1. Making mainstream arts and culture relevant

Our learning

People with learning disabilities want to be able to access mainstream arts and culture, and not be treated as a separate group. People with learning disabilities feel that through access to mainstream cultural activities they can be part of a community that enjoys art for art's sake. They recognise the importance of, and enjoy, arts and crafts opportunities made available specifically for them through specialist day or residential settings. However, it is also their right to be able to enjoy mainstream experiences in addition to these. People with learning disabilities are rarely the cocreators or commissioners of mainstream arts activities, which perpetuates the problem of arts and cultural experiences not always being relevant or attractive to people with learning disabilities.

Recommendations

- Involve people with learning disabilities on governing boards, in planning groups and in consultations about arts and culture.
- Encourage more people with learning disabilities to attend mainstream cultural activities through targeted advertising and awareness raising. Challenge the perception that mainstream arts and culture is not for them.
- Challenge the perceptions of the wider public and cultural sector that people with learning disabilities do not usually attend arts and cultural events.

2. Advertising

Our learning

Advertising does not always reach people with learning disabilities. This may be because the print or text used are not accessible or clear, or it may be that people are reliant on carers or families to convey the information.

Recommendations

- Understand that people with learning disabilities are not a homogenous group and therefore a broad cultural offer and targeted advertising is required.
- Use clear words and pictures in any posters, websites or flyers.
- Tell carers directly about events and opportunities.
- Talk to people with learning disabilities about the event so they know what to expect.
- Offer free taster activities to increase familiarity of settings and activities.

3. Accessibility

Our learning

Being unable to easily get to and into a venue is a barrier for people with learning disabilities to access mainstream arts and cultural activity. However, access does not only refer to wheelchair ramps. These are important, but so are other facilities such as accessible toilets and changing facilities, disproportionate costs and, importantly, feeling safe at a venue or event.

Recommendations

- Consider making a small number of free tickets available for carers or support workers for shows, performances or opportunities.
- Ensure buildings are physically accessible wherever possible.
- Ensure there are adequate toilet and changing facilities at events, especially outdoor performances.
- Work with people with learning disabilities to train staff to help them understand needs of people with learning disabilities and specific barriers to access.
- Provide quiet spaces for people to go to if they start to feel anxious about being in a busy venue.

Importantly, the Reach members are keen to work with the cultural sector to help them understand how to implement these recommendations. For example, the team can work with organisations to help them understanding what a safe environment feels like for people with learning disabilities, how to include people with learning disabilities in planning, or to train staff to better understand the needs of people with learning disabilities.

Conclusions

Through consultation with people with learning disabilities across Stoke-on-Trent, our Peer Researchers concluded that people with learning disabilities need more opportunities and support to access mainstream arts and cultural activities.

Arts and cultural activities are recognised by people with learning disabilities as both enjoyable, supporting their health and wellbeing and, importantly, helping them to be part of a wider mainstream community. Through minimising the barriers to the participation of people with learning disabilities in mainstream arts and culture, the cultural sector could play a lead role in supporting this often-excluded group to not only experience more mainstream arts and cultural activity, but to shape and co-create it. Arts and culture captured the imagination of the peer researchers for this project. However, it was the inclusive approach to research that helped the group to recognise that mainstream arts and cultural activity is within reach for people with learning disabilities. The group's challenge to the cultural sector is will you do the same?

Appendix 1. The impact of taking an inclusive approach to research.

This research was a partnership between Staffordshire University and Asist Advocacy Service, who support Reach. Developing a Participatory Action Research methodology was important to the whole team, to ensure the research process mirrored its main aims of creating a more inclusive and participatory cultural sector.

As a result, ten Peer Researchers, nine members of Reach and one radio presenter for Embrace Radio, a local radio programme on 6 Towns Radio, presented and produced by people with learning disabilities. The team of peer researchers were introduced to the wider community consultation for Stoke-on-Trent's bid to be City of Culture 2021 and supported to engage with the research questions by taking part as research participants. They were then trained in how to conduct semi-structured interviews and focus groups and supported to prepare questions and plan the research events. An Advocate was present at the focus groups and interviews to support as required.

The group conducted interviews and focus groups, reaching a total of eighty two people, all based in Stoke-on-Trent with a wide range of support needs. In addition to this, the radio presenter for Embrace Radio opened up the conversation through the radio station and collected responses on social media. These responses supported overall findings, although they were not included in the findings themselves because there was no way of identifying whether the respondents on social media had a learning disability.

As part of the process, following collection and discussion of the findings, the team of Peer Researchers reflected on the impact of using this approach on them and the other research participants.

Being a peer researcher for the project was a positive experience for all the peer researchers and helped to make members of the group feel 'happy', 'proud' and 'helpful'. The group recognised that they were able to take a lead in the sessions and that others, both participants and support staff, saw the group as having an in-depth knowledge of the research topic.

“People kept asking me questions afterwards.”

The Peer Researchers valued being representatives for Reach and being a part of a team of community champions.

“Being part of a team [and] being able to help out was good.”

However, the group also recognised that some aspects of the research delivery were more challenging. Taking on the new role of Peer Researcher was 'nerve-racking' for some members. The group also found the interviews with participants they already knew easier than those where the participant was someone they had not met previously. In some cases, the Peer Researchers struggled to get responses from the participants, and it was in these cases that they needed most support from the Advocates.

The group also recognised that adopting an inclusive approach to research had a positive impact on them as individuals and the wider group of research participants.

The greatest individual impact was on confidence levels and feelings of independence. The group feel that the process made them both more skilled and knowledgeable and gave them the confidence to take a lead.

“I spoke up to [a member of support] staff and said, ‘I don’t need help with this.’”

The group recognise that since getting involved as Peer Researchers they have more ideas on how to give others a voice and feel more able to socialise.

This increased confidence was evidenced in members of the group becoming more independent. For example two members of the peer researcher team travelled to Hull with the Community Advisory Network to support the Stoke-on-Trent bidding team without the support of a carer, which had not happened before their involvement in this project.

“It means a lot for me.”

The group also reflected on how the process impacted on others. There is strong sense from the group that using a participatory approach that was driven by a team of Peer Researchers was important to demonstrate that the whole team were committed to the values that underpin the research questions. It demonstrated to participants and support staff that the process of research can be inclusive as well as the theme of the research. There was a sense that through this approach the Peer Researchers shared their knowledge with participants and support staff, not only about the City of Culture and barriers to accessing culture for people with learning disabilities, but also about how a peer research process can be beneficial to individuals, groups and understanding of issues.

The Peer Researchers feel strongly that the peer research process produced better results from participants than if a more traditional or academic researcher had conducted all the interviews and focus groups. They feel that having a lived experience of learning disability is needed to understand people’s perspectives, build an equal relationship and get more honest answers.

“[It is] better for people with learning disabilities [to do it]... They would talk to us but... [they would find it harder to talk] to you.”



NOTES

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