

**Title** Getting involved in the community - what stops us? Findings from an inclusive research project

## **Title Page**

**Title** Getting involved in the community - what stops us? Findings from an inclusive research project

## **Running Title**

Getting involved in the community - what stops us?

## **Author 1**

Miss Fran Mooney  
Building Bridges Research Group  
c/o Building Bridges Training  
mail@building-bridges-training.org

## **Author 1**

Mrs Nazia Rafique  
Building Bridges Research Group  
c/o Building Bridges Training  
liz@building-bridges-training.org

**Author 3** – send correspondence and proofs to this address

Dr. Liz Tilly  
Senior Lecturer in Social Care  
University of Wolverhampton  
Room MC 325  
Faculty of Education, Health and Wellbeing  
City Campus (Wulfruna)  
Wulfruna Street  
Wolverhampton  
WV1 1LY  
Liz.Tilly@wlv.ac.uk

Tel 01902 518674

## **Acknowledgements**

We would also like to thank Samantha, Satnam, Vanessa and the other members of Building Bridges Research Group for getting involved in this research project.

## **Data availability Statement**

The data that support the findings of this study are available from the corresponding author Dr Liz Tilly [liz.tilly@wlv.ac.uk](mailto:liz.tilly@wlv.ac.uk) upon reasonable request.

## **Easy read abstract**

- Feeling alone and not connected to other people where you live affects many people and especially people with a learning disability. The government and the newspapers are talking a lot about this, they want to understand who is affected and what can be done.
- Our group did a research project to find out some of the things that stop us getting involved in local places with local people where we can make and keep friends. The people in the research project mainly lived independently and did not use learning disability services, so needed to use local community organisations.
- Pictorial cards, made by one of the group members, using photos were used to sort out all the things we talked about into groups. These included transport, fear and anxiety, limits on our choice and control, risks and personal safety.
- We then talked about what could be done, this included more easy read information, so people know what is available locally, more support to go to places and advocacy to get involved. There also needs to be better community safety including more Safe Places in the community.

## **Key words (from drop down list)**

Learning (intellectual) disabilities

Independent living

Empowerment issues

Leisure and Recreation

Community care

## **Author key words**

Social exclusion

Loneliness

Community safety

Safe places scheme

Community connections

## Inclusive research

### **Abstract**

Social isolation is an issue that affects many people and especially people with a learning disability. There is an association between social exclusion and feeling lonely; an issue currently highlighted as a growing concern which needs to be addressed both in the media and by the government. The Building Bridges Research Group do inclusive research projects about the issues that are important to them. Over the summer of 2018 the research group undertook an inclusive research project to identify some of the specific barriers that prevent community inclusion and the opportunity to develop friends. The people involved mainly lived independently and did not use learning disability services, with the exception of evening clubs, so needed to use universal services. Pictorial cards, made by one of the group, using photos were used to organise the data into themes. These included transport, fear and anxiety, limits on choice and control, risks and personal safety. The inclusive research design enabled people with a learning disability to contribute to all stages of the research project, from identifying the issue, gathering data, the analysis and writing up. They also made suggestions of ways to increase social networks, friendships and wellbeing and so decrease loneliness. These include more access to easy read information, more support and advocacy and measures to address community safety including a wider roll out of the Safe Places scheme. There also needs to be further research undertaken with other people with a learning disability in different areas to widen the understanding of the impact of these barriers on people's lives.

### **Background**

Addressing issues of social isolation and loneliness in our society is a current policy priority, with people with a learning disability, along with all disabled people, identified at high risk of being socially isolated (Gilmore and Cuskelly 2014). People with a learning disability face particular challenges and barriers to a full life in the community and the opportunity to develop meaningful relationships (Williams 2013). These include unemployment, transport issues, poverty, lack of opportunity for self-determination, poor accessibility in public spaces, and lack of acceptance and even harassment from others (Flynn, McKinstrie et al. 2010). Many rely on structured opportunities to meet with others such as social clubs for people with a learning disability. However such provision is not statutory and therefore is a 'postcode lottery' depending on local funding availability and initiatives. The importance of community connections has been high on the agenda for people with a learning disability since the 1980s (King's Fund Centre 1988, Towell 1988). The aim is that better connections within their community will help to increase the number of good networks of support which are vital to health and wellbeing. However, most people with learning disabilities have very limited opportunities to meet and make friends (McConkey, Dunne et al. 2009). The people in their social

networks are typically family members, or people who are paid to support them. Therefore living an 'ordinary life' in the community in its true sense is still an aspiration for many.

This inclusive research project was therefore undertaken to enable people with a learning disability themselves to identify some of the specific barriers that prevent community inclusion which is vital for giving both a sense of belonging and wellbeing and is essential for creating opportunities to develop and keep friends. The researchers used their findings to generate suggestions of ways to increase social networks, friendships and wellbeing and so decrease loneliness.

### **About Building Bridges Research Group**

We are a group of 8 people with a learning disability who don't go to day services or have learning disability support services. The research group is part of Building Bridges Training and started in 2008. We meet once a month to talk about things that are important to us and do research projects about some of these issues. We are supported by Liz Tilly. Please see our website page for more information [www.building-bridges-training.org](http://www.building-bridges-training.org)

### **Why we did our research**

We all describe ourselves as having a learning disability. We all have different home situations, two of us live with our parents, and five of us are married and one lives on their own. But we all share similar experiences. We don't use learning disability services and we are not as involved in local activities as much as we'd like to. We think that people like us are more likely to feel lonely and isolated because it is hard to be more involved in our communities.

This research project looked at the things that stop us from being more involved with local people in community venues and activities, and building up more friendships. Most of us have experienced many sad losses in our lives such as losing our parents and other close family members or having children removed. This still makes us feel very sad, and some people in the group are still struggling with the losses they have had in their lives. Because we see our friends mainly in organised group settings, if these groups finish, or if the person stops coming, then we can't see them anymore and we feel upset as we have lost a friend.

So we did this research project to find out more about the barriers that stop us being more involved in the community - those things that we think could be challenged and changed.

### **How we did the research**

We did this research project during the summer of 2018. Before we started ethical approval was gained from University of Wolverhampton FEHW ethics committee.

We had four discussion groups, one a month. We all signed an easy read consent form at the beginning of the research project and we agreed ground rules at the beginning of each meeting. For example 'what's said in the room stays in the room'. We also used traffic light cards to manage any situations where people broke the ground rules. These are red, yellow and green cards we can use to interrupt or pause the meeting if there is something we aren't happy about. We agreed not to talk about personal feelings about being lonely, and if anyone felt sad they didn't have to stay in the discussion and would get support. This didn't happen. The discussions were recorded on a digital recorder and someone typed up what we said. Liz read through these notes and made a long list of all the key thoughts and issues we had talked about. Fran, one of the group members then produced large picture cards for each of the issues. She found the images for the key thoughts and ideas on PhotoSymbols and other websites on the internet, so the people in the group who can't read would know what the words meant. The cards were then laminated.

At our third meeting we put all the picture cards on the table and worked together to put the cards into groups of similar issues. We then gave these group names such as 'family', 'money' and 'anxiety'. This meeting was also recorded.

Liz then wrote up the first version of the article and we all talked about it and suggested changes when she read it to us at our July meeting. Fran and Nazia then met on their own to add more and make further changes and Liz finished the paper.

### **What we found out**

This research project wasn't to talk about our experiences of loneliness but to look at what things stop us from being more involved locally, so that we feel more included, have more friends and connections and feelings of loneliness can be reduced. Everyone understood what loneliness meant and one person summed it up by saying 'lonely means feeling sad, depressed, having nobody to turn to, nowhere to go and nobody believes you feel lonely'.

### **Feeling welcome**

We all spoke about our positive experiences joining in and using community places and gave examples of how they have been made to feel welcome. These included churches and clubs specifically for people with a learning disability, as well as church coffee morning drop-ins, libraries and the sports centre. We liked it when people said hello, talked to us and treated us with kindness. One person talked about the importance for him when someone at church greeted him by shaking his hand. It made him feel welcome and involved.

Going to the gym in the sports centre was really important to many in the group. We talked of using a number of local sports facilities, and enjoyed the activities such as swimming and using the gym or going to keep fit classes. We also valued owning a gym membership card, issued to people who received disability benefits and allowed

people to use the gym for free at off peak times. This gave us status as belonging to a local community facility. We generally found the other gym users and staff to generally be very welcoming and friendly. And going to the gym has the added bonus of helping people to keep fit!

Only one person went regularly to a local pub, others did not go as for a variety of reasons including cost, not drinking alcohol and not feeling welcome there.

However we found out that there were a lot of issues and barriers that can stop us being more involved in our communities. These are the main issues we talked about, and agreed on by sorting the picture cards into groups.

### **Fear of harm and being a victim of crime**

This issue had three times the number of picture cards than the other issues – this means it was the biggest barrier the group experienced to getting involved in their local community. We said that needing to feel safe when they go out was really important. Many expressed their fears about being out in the dark, which was made worse by hearing about a lot of recent reports in the news of stabbings, acid attacks and shootings. A number of us were also afraid to use local alleyways in the dark. Travelling to new places made us feel very anxious and everyone had the experience of getting lost in unfamiliar places and being frightened of this happening again. Everyone was frightened of using public transport at night. We said we felt safer when we had a mobile phone on us, which was switched on and had some credit. Road safety was also an issue – we said we were frightened to cross busy roads. Many of us knew someone in our social network who had died in a hit and run accident a few years ago, and this added to their own fears.

One person gave an example of a neighbour showing kindness by going with them to the Chinese takeaway when it was dark, as they were scared to go alone. All the group recognised the importance of the 'Safe Places' scheme and wanted there to be more safe places in the community which are identified by having 'safe places' stickers on display. At these places people with a learning disability who have problems or are scared can go inside and they will be given a welcome and practical help and support.

### **Family members having control**

Only a few people in our group had issues relating to their family that prevented community inclusion. One person was restricted from going out by her husband who had health issues and he was frightened about being left at home on his own so he wouldn't let his wife go out much. As he had become more ill he had become more controlling and restrictive on what she could do. Another person lived with a family member who had to get up very early for work, so everyone in the household had to go to bed at 9pm, which meant she couldn't do any evening activities.

Other family control issues were related to not spending much money on leisure and social activities. This was frustrating when the person couldn't spend their PIP

benefit (*Personal Independence Payment; the UK disability welfare benefit received by all but one of the group who has not made a claim for it*) on the things they wanted to. One person's family had concerns regarding her mobility and stopped her from doing some activities where they felt it would be too difficult for her. Family control left those people feeling really frustrated, but it was very difficult as these were also their close relationships and loved ones, so it was difficult to challenge them.

### **Lack of local opportunities**

Everyone wanted more community activities to do, especially in the day time. None of the people in this research project had any paid work, voluntary work nor day services so they were frustrated at the lack of purposeful activities. This led to boredom and there was an interest in any activities that would enable us to get out and mix with other people more. Activities of particular interest included ten pin bowling, day trips by coach to the seaside and other places, and horse riding. We also wanted the opportunity to go on holiday as four of our group members had not had a holiday for many years, with the exception of day trips by coach to the seaside. Such activities enable us to make new friends and build up confidence by doing new activities and travelling to new places. We also mentioned a number of unmet dreams we had, to do things such as visiting London, travelling abroad, going to league football matches, pop concerts and even have meals out at a pub. We also spoke about the importance of celebrating birthdays with friends but that the barriers such as travel, knowing what's on and anxiety which are talked about later, also prevented them from making arrangements and meeting up. The timing of social activities was also important; we preferred daytime opportunities which started later in the day so people could travel after 9.30am and use their concessionary bus passes. Evening activities, although of interest were less popular due to the fear of travelling using public transport in the evening and particularly when it was dark. Most of us who did enjoy social activities in the community attended activities and opportunities provided by learning disability charities. Very few of us attended general social activities except for several people going to churches and the Gurdwara (a place of worship for the Sikh community), and one woman going weekly to the local bingo hall, where she met with her non-disabled friends.

### **Not knowing what is available locally**

We said we felt that we didn't always know what was available locally as there was not enough easy read information about local activities available. We said that we would like to have easy read leaflets as not everyone is active online and also it's hard to find things out from the internet, as you have to know how to spell things correctly.

It was suggested that it would be helpful to be able to get easy read leaflets and fliers from the GP surgery, dentists, places of worship, and the library and bus and

train stations. The information leaflets should also include travel information and maps that are clear, with local landmarks to help with finding your way around.

### **Anxiety of going to new places**

Several of us talked about anxiety as being a barrier to getting involved in community groups. Many people were afraid of going to places on their own, and especially for the first time, meeting new people, of large groups and of crowded places. Meeting new people, not knowing what to say and starting conversations were also identified as issues.

### **Travel difficulties**

Travelling to new places was identified as both very difficult and also a major cause of anxiety. We spoke about our fear of getting lost, and having to ask for directions, having no Wi-Fi or internet access and not being able to use map apps. Also, travelling in the rush hour when there were a large number of commuters was identified as being particularly stressful, as there was no personal space. Travelling in the evening was also disliked due to fear and anxiety mentioned before.

Most of us found it very difficult having to travel to a venue using more than one bus, as timetables are so hard to understand. It was felt that train travel was more difficult than using the buses, which was the preferred way of travelling. Many said it was very difficult using bus timetables; the font was too small and we think that they should be printed with larger letters and numbers. There were also complaints that the bus routes and numbers changed too frequently and that this was very confusing for independent travellers.

One person had opened an Uber taxi account, but the rest of the group found that using taxis was too expensive and using them also made them feel anxious.

### **Lack of money**

We talked about not having enough money and how this stopped us being more involved locally; but this wasn't the main barrier. Some people said that they couldn't do as many things locally as they wanted to do because they couldn't afford it out of their welfare benefits. Their spending priorities included paying for utility bills, phone credit and buying food before spending on social activities.

PIP money, typically received on a four weekly basis was usually considered as the income for social activities. However, some people living with family carers didn't get control of all their PIP money, and some had to ask for some of this money to spend on social activities, whilst others found it hard to make this money last for the four weeks. This limited what social and leisure activities they could do. To get around this some in the group would borrowed from friends and family.

Also the cost of a taxi prevented some people from taking part in activities, especially those in the evening when people were afraid to use public transport and be out in the dark. One person's family controlled their PIP money and so controlled what they can and can't do which they found very frustrating, as she had to miss out on

things she wanted to do. Someone else said it was a problem if you lost your concessionary bus pass as you had to pay to renew it and wait for the new pass to come. Many in the group had either lost their pass in the past or even had it stolen by others in their network, as it enables free travel and is therefore very valuable to other people on benefits. This meant the person who temporarily had no bus pass could be housebound until the new pass came.

### **What we think this means**

We think that there are a lot of barriers to us, and other people with a learning disability like us from getting involved in the life of our local community. The main barriers are not because people are unwelcoming at community places, or lack of money (due to having PIP). The barriers are about more practical issues such as finding out what is available to do locally, having help and support to get involved at the beginning and travelling safety. This research project has shown how we all experience a lot of anxiety and fear, mainly to do with community safety. We have thought about what we think should change to enable more community inclusion and so help reduce feelings of isolation and loneliness.

### **What should happen now**

To enable people with a learning disability to have a full life in the community we think that these things need to change:

Changes in support for people with a learning disability

1. There needs to be more easy read information available of local social and leisure activities, which includes information on how to get there, eg what bus goes there, and how much it costs.
2. There needs to be more help and someone to speak up for you (*advocacy*) for those people with difficult family situations, and who are limited in what they can do and how much of their own PIP money they can spend on community activities.
3. It would be good to have more support to go to community places for the first few times, to help us know how to get there and start to make friends.
4. There also needs to be more opportunities to do things with support, where we don't have the skills to arrange it ourselves, such as going to big pop concerts or arrange other activities in the community such as pub meals.

Changes in community venues

1. Places in the community should all be more welcoming. Staff at local sports and leisure venues need to be more aware of the different people in their community who might need support to use the facilities. It is also important that they understand that not all people with a learning disability or autism look different and so they might not easily be recognised as people needing extra support. This could be done by the staff at these venues having training sessions delivered by people with a learning disability.

### Changes in community safety

1. There should be more Safe Places available that are easily identified by their stickers, so we have more places to go to if we need help and support when we are out.
2. There needs to be more done about community safety, so all people can feel safe when they are out, especially at night. We would like to see more police about.

### Further research

1. We think we need to do more research with other people with a learning disability to see if they agree with the barriers that we have identified. Then we need to find out what they think should change so that they and other people with a learning disability can be more included.

### Telling other people

We know that after doing research we want to see things change for people with a learning disability. So we will tell other people about this research project at conferences and we will also make a short film about the issues and some of the solutions on our YouTube channel. We will also try and get some grant funding to do more research with other people with a learning disability to find out about their experiences and solutions.

### A final note

We all love our pets, their importance in our lives came up in this and in our other research projects (Money Friends and Making Ends Meet Research Group 2012, Building Bridges Research Group 2014, Building Bridges Research Group 2016). Five of us have one or more cats, and one member also has a dog. We feel that having our pets stops us from feeling lonely and we wanted this to be included in this article too.

### References

Building Bridges Research Group (2014). Small Things That Make a Big Difference Sandwell, Building Bridges Training  
Building Bridges Research Group (2016). Living Our Lives.  
Flynn, M., K. McKinstrie and R. Parrot (2010). Work, supported employment and leisure. Learning Disability: A life cycle approach. G. Grant, P. Ramcharan, M. Flynn and M. Richardson. Maidenhead, McGraw Hill/Open University Press.  
Gilmore, L. and M. Cuskelly (2014). "Vulnerability to Loneliness in People with Intellectual Disability: An Explanatory Model." Journal of Policy and Practice in Intellectual Disabilities **11**(3): 192-199.

King's Fund Centre (1988). Ties and Connections : an ordinary community life for people with learning difficulties. London, King's Fund Centre.

McConkey, R., J. Dunne and N. Blitz (2009). Shared Lives; Building relationships and community with people with intellectual disabilities. Rotterdam, Sense Publishers.

Money Friends and Making Ends Meet Research Group (2012). "Having Friends - They help you when you're stuck." British Journal of Learning Disabilities Special Issue: The research and work of learning disabled people with their allies and supporters **40**(2): 83-164.

Towell, D. (1988). An ordinary life in practice: Developing comprehensive community-based services for people with learning disabilities. London, King Edward's Hospital Fund for London.

Williams, V. (2013). Learning Disability Policy and Practice. London, Palgrave-Macmillan.