

## Afraid to leave the house: issues leading to social exclusion and loneliness for people with a learning disability

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## Article on “**Afraid to leave the house; issues leading to social exclusion and loneliness for people with a learning disability**”

### Purpose

Tackling social exclusion, which can lead to social isolation and loneliness, is an important current issue. People with a learning disability have a right to be full members of their communities, yet often experience social exclusion. Community connections play a key role in people developing reciprocal relationships. It is therefore important to know the barriers to full inclusion.

### Approach

This article builds on an inclusive research project exploring these issues (Mooney, Rafique and Tilly, 2019) and aims to place that study’s main findings in a broader academic, policy and practice context

### Findings

Whilst there is a wide range of literature about social exclusion, lack of friendships and loneliness experienced by people with a learning disability, there is a gap in knowledge regarding some of the specific social barriers that prevent wider social inclusion, and therefore opportunities to make and keep friends. The inclusive research study highlighted that whilst the group had positive experiences of participating in local activities and events, other issues prevented wider community engagement. These included fear of harm, anxiety, challenges of travelling independently, family barriers, and lack of accessible information about what is available locally. Lack of money was also an issue for some.

### Originality/ value

This paper relates the findings of an inclusive research project to the current literature. It identifies the social barriers that limit community involvement and draws on the experience of people with a learning disability to find possible ways forward.

### Key words

Community inclusion  
Social inclusion  
Friendships  
Community safety  
Independent travel  
Safe places  
Loneliness

### Introduction

Social inclusion, an essential element in the process of making friends, is recognised as a basic human right in the United Nations Convention on the Rights of Persons with Disabilities (UNCRDP) (United Nations General Assembly, 2006) in Article 19 on ‘Living independently and being included in the community’ and Article 30 on

'Participation in cultural life, recreation, leisure and sport'. A community life is one that adds richness through the opportunity to develop relationships, and is described as one of the six keys to citizenship, along with self-determination, direction, home, support and money (Duffy, 2006).

Friendships and relationships are identified by most people as key to quality of life, and this is no different for people with a learning disability. They are a basic human need and our primary means of fulfilment and affirmation (Williams, 2013). They help develop our sense of identity and give us status and positive self-esteem. As such, they often feature in quality-of-life measurement scales (Schalock, 2004).

People with a learning disability make up about 2% of the population. Only one in ten receiving specialist learning disability services and many have unmet health and social care needs (Public Health England, 2015). With the ongoing drive to use universal services, increasingly people with a learning disability are becoming a 'hidden population', unknown to services, and particularly vulnerable to social isolation and loneliness (Gilmore and Cuskelly, 2014). This can escalate to further physical and mental health issues (Stacey and Edwards, 2013).

Key strategies over recent decades have included O'Brien's Five Accomplishments (O'Brien, 1987), Wolfensberger's social theories of Normalisation and Social Role Valorisation (Wolfensberger, 1989, Wolfensberger, 1972), An Ordinary Life (King's Fund Centre, 1980) and the current government strategy in Valuing People (Department of Health, 2009, Department of Health, 2001). These all recognise that people with learning disabilities should be full community members and therefore have the opportunity to grow social networks with people other than paid staff, and to build social capital.

Despite well-intentioned policies, people with learning disabilities still typically have a poor quality of life, being excluded from mainstream life, communities, work, social and political participation, and with inadequate income for their basic and disability-related needs (Bach, 1994, Department of Health, 2001, Hall, 2010, Williams et al., 2008, Felce, 1996, Ward, 2004). Those with a mild learning disability and in receipt of less disability welfare benefit income found poverty to be a barrier to wider social inclusion (Money Friends and Making Ends Meet Research Group, 2011). However, this group have demonstrated self-determination in affirming themselves as equal citizens and taking part in community activities (Björnsdóttir and Traustadóttir, 2010, Poll et al., 2009).

People with a learning disability, however, frequently experience a range of social barriers to meeting people in social settings and developing friendships, resulting in a paucity of meaningful relationships, including intimate relationships (Bates et al., 2017). Loneliness is understood as being a deficit in the number and depth of one's

social relationships, a complex issue with philosophical, medical and social aspects (Waldron, 2010).

Addressing this issue is a current policy priority (UK Government, 2018), as people with a learning disability are often socially isolated and even chronically lonely (Gilmore and Cuskelly, 2014, Department of Health, 2009).

### What do people with learning disabilities consider to be the barriers to getting involved in the community?

This article discusses some of the specific social barriers as identified by a group of people with a learning disability who undertook an inclusive research project (Mooney et al., 2019), and discusses their findings in context of the wider literature. The group used three focus groups to identify some of the specific barriers that prevented them from having community inclusion and the opportunity to develop friends. A basic topic guide was used to keep the conversation on track, developed from the previous group discussions identifying this topic as important for a formal research project. The research design enabled the group of eight people with a learning disability to contribute to the analysis, writing up and dissemination. All the issues raised from the transcripts of the first two focus groups were made into pictorial cards by one of the group members.

These pictorial cards were then used to undertake a thematic analysis through a group sorting exercise. These themes then enabled the group to discuss suggestions for ways forward to overcome these barriers and so increase access to community activities and so expand their social networks. These overarching themes are discussed here in the context of the wider literature below.

### Travel, community safety and anxiety

The inclusive research project (Mooney et al., 2019) found that while people did not report personal experiences of harassment or abuse they feared going out alone, especially at night. These fears were magnified by hearing of increased reports of gun and knife crime. They also reported lack of confidence in using public transport, especially where more than one journey had to be made, and fear of getting lost in strange places, which was identified as a barrier to going to community places. A further restriction, particularly in the winter months, was an aversion to travelling when it was dark outside.

Those who had a smart phone and used map and travel apps found them helpful, as they could locate where they were and find out the nearest bus stops and when buses were due. The apps were also used on bus journeys to inform the passenger when to alight, however most people only had simple pay as you go phones, and were not able to use this technology .

With regard to perceived safety, the group stated that they would like there to be more 'Safe Places' in the community, identified by stickers on their doors and windows. This enables people to know they can find a source of help and support when out in the community, should they experience any problems. This is supported by a report published in 2012 (Gravell) found that 93% of 67 people interviewed had experienced a range of personal safety issues ranging from harassment through to disability hate crime, resulting in people not wanting to go into the community. Community safety fears were also identified in a study by Mason *et al.* (2013).

Without significant relationships people face isolation and loneliness which can lead to depression and self-neglect (McConkey *et al.*, 2009, Waldron, 2010). This in turn can add pressure to social care service delivery and budgets. There are also safeguarding implications; people who are isolated have no one to tell if they are undergoing any personal hardship or worse problems such as hate crime. Much has been written about people with a learning disability having a history of cumulative, and frequently overlooked, victimisation, including disability hate crime (Equality and Human Rights Commission, 2011, Mencap, 1999, Inclusion North and Coast 2 Coast, 2008, Richardson *et al.*, 2016). However, there is also a growing awareness of the more subtle exploitation of people with a learning disability by people who befriend them and abuse them, sometimes referred to as mate crime (ARC, 2012). This typically starts with a person initially making friends with a person, which then goes on to become an abusive relationship. Typical victims of 'mate crime' are people with a learning disability and other vulnerable people who live independently and outside of the support of services (ARC, 2012, Money Friends and Making Ends Meet Research Group, 2012, Flynn, 2007)

### Choice and control

In the inclusive research project some people reported restrictions to their choice and control happen in family relationships. These were due to both over-protectiveness and control over how much disability welfare benefit could be spent on social and leisure activities. For example one person's family used the person's limited mobility as a reason to limit opportunities. Another placed restrictions around evening activities due to cultural expectations. One person had no direct access to their PIP income, and had to ask for money from the family to take part in leisure and social activities, with mixed outcomes. This often lead to frustration and disappointment when this result in not being able to join in activities with friends such as a meal.

'Choice and control' for people with a learning disability has been recognised as an agenda needing support and been a priority for commissioners and providers alike since Valuing People (Department of Health, 2001). This is supported by the Mental Capacity Act 2005 which requires that people with a learning disability are assumed to have capacity to make decisions regarding their lives. However when it comes to forming friendships with people in the community there is evidence in the literature

for people who live with paid support, that staff undertaking their duty of care can be over-protective, for example with risk-averse policies and procedures and the need to undertake risk assessments, which can stifle the development of friendships (Abbott and McConkey, 2006).

### Access to information and digital exclusion

In the inclusive research project, the group said they wanted more 'easy read' information about what was available locally and suggested this could usefully be located in health settings, bus and train stations and places of worship. Typically an easy read document contains minimal text, using simple words and short sentences. Pictures and photographs enable the reader to understand the content. It is also presented in a simple format and uses larger font (Department of Health, 2010, Inclusion Europe, n/k). They also felt that this information should include travel advice and maps to aid navigation.

Their findings and suggestions of ways forward did not include references to technology and digital information, few had access to personal devices or broadband, so were unaware of how technology and the internet could be helpful in a range of ways to further community inclusion. This includes access to information and to use social media to increase their social networks.

However their lack of awareness also highlights that this group of people continue to also experience digital exclusion. Many people with learning disabilities have limited internet access and sometimes also limited skills to develop these connections, plus they frequently do not have smart devices and so experience digital exclusion (Department for Communities and Local Government, 2008, Chadwick et al., 2013). Research by (McClimens and Gordon, 2009) on people with learning disabilities and their use of blogging found that these people, who were socially isolated, enjoyed blogging. The study was not able to ascertain if use of the internet would help increase their social capital, 'yet it is the notion of "community" that intellectual disability and social capital coalesce. Both hold this concept as core to their values' (McClimens and Gordon, 2009:26).

A systematic review by Caton and Chapman (2016) found that some people with a learning disability did have positive experiences of using social media. It helped with maintaining friendships and the development of social identity and self-esteem, as well as enjoyment. The study found that the barriers preventing people with a learning disability from successfully accessing social media were safeguarding concerns, difficulties caused by literacy and communication skills, cyber-language, cyber-etiquette, and accessibility (Caton and Chapman, 2016).

Increasingly social media is the way people hear of local opportunities and maintain friendships. However, digital exclusion, lack of access to digital devices, the internet and IT skills, is another social barrier experienced by many people with a learning disability (Chadwick et al., 2013, Chadwick and Fullwood, 2018). For people with access to the internet and with online skills, this has enabled a wider group of social contacts beyond those typically limited by geographical boundaries. But digital exclusion limits this opportunity for many people with a learning disability as it can

limit forming friendships, hearing about what's on, and getting involved locally (Owuor et al., 2017).

## Discussion

Firth and Rapley (1990) identify the key features of friendships as choice, mutuality, commitment, persistence and intimacy. People named as friends in the social networks of many people with a learning disability may also be family members, or people who are paid to support them (Bane et al., 2012, Williams, 2013). Many identify with the experience of loneliness (Stacey and Edwards, 2013). Furthermore, Emerson and Hatton (2008) found that they were less likely than people without learning disabilities to have contact with friends and family members outside of the home.

People with a learning disability are typically friends with other people with a learning disability (Emerson and McVilly, 2004). Many rely on structured group opportunities such as social clubs and sports or activity groups for people with a learning disability (Wilson et al., 2017), using the support of paid staff to meet with others. However, such provision is not statutory and is therefore a 'postcode lottery', dependent on local funding availability and initiatives. For those who live independently, friendships with peers often provide a vital form of support to meet financial and other needs, such as help with reading, fixing things in their home and sharing local information such as about Food Banks (Tilly, 2012, Money Friends and Making Ends Meet Research Group, 2012).

Contact and friendships with people with a learning disability can also enrich the lives of non-disabled people (Perske, 1988, Wertheimer, 1995, Burke, 2006). The boundary between a friend and an acquaintance is very blurred and both types of relationship are important. Research by (Rath, 2006, Granovetter, 1973) has highlighted the value of having people with different roles and skills within our immediate circle. A research study involving people with a mild learning disability found they had very few reciprocal friendships with people outside their immediate circle, and their relationships with people who did not have a learning disability tended to be people who were informal supporters, such as people they knew from church (Tilly, 2012).

Gilmore and Cuskelly's model illustrates the pathways of influence that create and maintain loneliness for people with a learning disability; these are negative social attitudes and low expectations; reduced opportunities and limited experiences of social interaction, and skill deficits associated with learning disability (Gilmore and Cuskelly, 2014:195). Community spaces are restricted for people with a learning disability for a range of reasons and the friendships they have are therefore often

limited to segregated places such as leisure clubs. This reduces the opportunities to make and maintain friendships (McVilly et al., 2006).

People with a learning disability face particular social challenges and barriers such as unemployment, transport issues, poverty, lack of opportunity for self-determination, poor accessibility in public spaces, and lack of acceptance and even harassment from others (Abbott and McConkey, 2006). People who live in segregated learning disability provision have been found to be especially disadvantaged. It can be difficult for people with a learning disability to meet up with just one or two friends in a public setting such as a pub or a restaurant, or to go to sporting or music events due to a range of logistical challenges, mainly having support to make arrangements and use the facilities and transport to get there (Emerson and McVilly, 2004, Beart et al., 2001).

Social exclusion and loneliness remain serious issues for people with a learning disability and much more needs to be done to realise their right to a full life in the community. This article suggests that specific support should be targeted to overcome the barriers identified above that prevent people living full and safe lives in their communities.

The group themselves suggest the ways forward, in keeping with the principles of inclusive research. Some are easier to address than others. For example wider awareness and use of the Safe Places scheme, access to community safety training are achievable at the local level. Policy makers need to continue to recognise learning disability as being part of the group who experience digital exclusion, and need specific support to gain skills and safe access to the internet. But it will continue to be a challenge to address some of those family dynamics for adults with a learning disability still living at home, who do not enjoy full autonomy of their choices and decisions.

A further suggestion made by the group was for low levels of support to accompany people to activities for the first time, or enable them to attend big events such as pop concerts. Many of this type of low level support has been reduced or lost in the austerity measures in the past decade, but the funding of them can make considerable differences to the lives of people with a learning disability.

Finally the group suggested increased staff awareness of the needs of people with a learning disability and autism in community venues, which can easily be addressed by inclusive training and is important to address equality and inclusivity.

Only when these various barriers are addressed can people make and keep acquaintances, friends and become active citizens, and so enrich their lives, increase their well-being and indeed the lives of all community members.



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