



Active, Connected, Included

How people with learning disabilities can be included in community life

The thinking behind the 'Active, Connected, Included' approach



Introduction

People with learning disabilities can be socially limited by expectations society places on them, and by the structures put in place around them. To change this, first we must understand what is happening.

The reasons why people with learning disabilities are socially excluded are numerous. This guide is aimed at helping people to think through these reasons, and what can be done about it.

This guide is in **four** parts:

- This part explains the thinking and ideas behind what we have done.
- One part tells people with learning disabilities about their rights to take part in community life, and is written in an Easy Read format.
- One part is for anyone who supports a person with a learning disability in either a paid or unpaid capacity. This could be family members or paid support workers for example.
- The other part is for people who organise activities and groups in the community.

Background

SCLD's work on asset-based (or strengths-based) approaches has highlighted the contribution that people with learning disabilities can make to communities as social citizens. The concept of asset-based work builds on place-based community development. This strengths-based approach sees geographical communities as places that offer something positive, and aims to develop 'community members' instead of 'residents'. It chooses to focus on what the community can offer rather than on social problems in that area.

In this way, people with learning disabilities can be seen as community members with strengths and assets to bring to their geographical communities.

In 2016, The Scottish Commission for Learning Disability (SCLD) commissioned a report on asset-based approaches for people with learning disabilities: 'Building Bridges to a Good Life.'¹

It found that there is still a way to go before people with learning disabilities are routinely viewed as having positive things to contribute to their local communities. There can be a number of physical, institutional, financial, and psychological barriers preventing a person with a learning disability from contributing their positive assets to the life of their community.

The title of the Building Bridges report refers to a commonly-cited experience: that there are people with learning disabilities who would like to be more involved in their communities, and there are activities provided by organisations, business and communities that they can - in theory - take part in, but a gap remains to be bridged between people's aspirations to be fully included and their current reality.

A number of factors appear to be at work: lack of an adequate income, lack of access to the support they need, or lack of confidence and skills required to attend the activity. On a psychological level, if people do not feel that they are truly part of the community, they are likely to feel that mainstream, generic groups are not for them, even if those groups are badged as 'open to all'. In addition, communities themselves may also feel they lack the skills required to engage appropriately with people who have learning disabilities. Bridges have been built, but people with learning disabilities are still not getting across.

The Candidacy Framework was originally developed to explain why people from different populations do not make use of services that are available to them, particularly health services². Essentially, they are not seen as 'candidates' for the service, by themselves or by others. The Framework provides a flexible model that can be used in relation to different areas of service provision. Most research on the subject links it to health and social care service provision, particularly health services, but it also has validity when considered in relation to social, leisure and community based activities³.

¹ *Building Bridges to a Good Life*, McNeish, Scott, Williams (2016).

² *Vulnerable Groups and access to health care: a critical interpretive review*, Dixon-woods et al, 2005.

³ *Is "Candidacy" a Useful Concept for Understanding Journeys through Public Services?*, M Mackenzie et al, 2012.

Background

This document applies the Candidacy Framework to the way people with learning disabilities do, or do not, join, use and enjoy resources and opportunities in their local communities that are open to them.

It considers barriers that people with learning disabilities face when it comes to accessing community based activities and services.

These barriers may be unintentional or previously unidentified. Therefore, we hope this will be a highly practical guide both for community organisations and for support workers to increase the participation of people with learning disabilities in community life. We hope it is useful to people with learning disabilities and their families as well.

In the Framework, there are seven 'dimensions', or themes, to candidacy.

This document considers each in turn, through a developing case study:

- 1. Identification**
- 2. Navigation**
- 3. Permeability**
- 4. Presentation/Appearance**
- 5. Professional Adjudication**
- 6. Offers and Resistance**
- 7. Operating Conditions**

1. Identification

Example

Paul has a learning disability. He has reached 65 years of age and is no longer able to attend the day centre he has been going to for most of his adult life. He is feeling isolated and bored. He has told his support staff that he wants to feel more connected to other people.

Paul enjoys art and craft activities like he used to do at the day centre. His support staff have tried to identify learning disability services and activities that he can go to but have been unable to find any.

Paul has identified his need and that a social club would be a great way to meet this need. However, he and his support workers have only identified him as a candidate for learning disability specific activities, and have not considered that in the local area there are many opportunities for older people that are open to anyone as long as they are old enough.

Therefore, when someone suggests that Paul might want to start going to a resource centre for older people, Paul dismisses the idea.

⁴ A Report On Barriers to Accessing Health and Social Care Services for Older People from Black and Minority Ethnic Backgrounds in South Glasgow, Simon Malzer for The Advocacy Project (2013).

The first dimension in the Candidacy Framework relates to a person perceiving themselves as a 'candidate' for a service, group or organisation. They are aware of what is available, what the entry requirements are, and are able to see that this is something for them. In order to identify as a candidate for a community group/activity, people with learning disabilities and their supporters need to identify what they want to do.

They identify that they themselves would have some needs met by a particular group or service. They come to a conclusion about their eligibility for that service based on how they see themselves and how the service is perceived.

It has been suggested that some minority populations do not identify as candidates for generic groups or services because of a fear that they will be seen or treated as 'other'. In one study that looked at people from minority ethnic backgrounds, people rarely accessed mainstream health and social care services because they thought that these services had: *"very little cultural congruence with their own lives. Not only do people think they will not be understood through basic communication difficulties, they also feel there is very little sensitivity within services to other cultural norms"*⁴

An additional factor for people with learning disabilities is that they may require supporters to help them to identify what would help them to meet an identified goal and then where that can be found. There may be a number of conversations and processes required to ensure that a person with a learning disability has been fully supported to identify what they desire. A number of different professional and non-professional supporters may be involved in these conversations, together or separately.

Person centred planning techniques and outcomes plans developed as part of an assessment for self-directed support provide an opportunity to help a person with a learning disability to identify the outcomes they want to meet and to explore how these can be met.

2. Navigation

In order to identify as a candidate for a community group/activity people with learning disabilities and their supporters need to identify what is available to them, when and where it is and what they need to do to access it.

There is a challenge for supporters who have been working in the social care sector for some time. There have been changes in the ways in which people with learning disabilities are supported with a recent focus on making use of more informal support and participating in community based activities. This requires a level of knowledge about the local area. Paid supporters may not be local to the supported person and may not have local knowledge. There are also considerations such as transport, cost and timings to be considered in particular if a person needs support to plan or do any of these things.

For organisations they need to think about things like the suitability of premises including access to the building for people with mobility or sensory impairments. Remember that some buildings may not be welcoming for everyone, people who had bad experiences at school for example may not be happy to go to an event in that school hall, church halls may not seem welcoming to people who follow a different faith. Other things to think about include that saying an activity is open to everyone may mean that everyone would be welcomed but some people from a marginalised group might not see themselves as 'everyone'. Organisations need to be explicit about who they welcome.

Example

In our example, Paul has just become aware that he is allowed to attend groups for older people rather than specific groups for people with learning disabilities. His supporters have always worked within learning disability support services and have not had experience in helping someone to identify community based activities before. Searching on the internet for 'groups for older people' shows lists on the council's website as well as other tools such as ALISS.

Not all of the groups appeal to Paul but there are two that he is interested in. One is a weekly arts and crafts group in another village and the other is an activity afternoon once a week in an older people's care home local to him that is not only open to residents. The activity afternoon is funded by the local authority and is free to attend, and his supporters can walk round with him and they will be able to do a shift changeover at the care home during the afternoon with the new staff member taking him home again.

The arts and crafts group has a small fee attached and would require Paul to be driven to it. The timing does not suit the shift changeover times and although he has a car, not all of his support staff can drive. The service managers agree to look at making sure that a driver is on shift on that day each week and to consider flexibility around shift times so that he can be supported to attend. Should only one driver be available they can stay with Paul and drive him home again. Paul is able to afford it as he would normally go for a coffee with his staff on that day and the money could transfer to the fee for the group instead.

3. Permeability

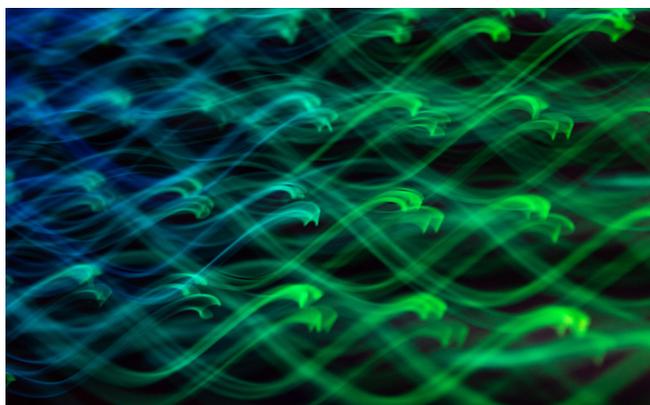
The analogy here is of a permeable membrane, which presents a barrier, but a barrier through which it is possible to find a way. A semi-permeable membrane permits some types of cell to pass through, but not others.

This raises the question: How permeable is the membrane around each organisation? Can some people pass through easily, and others not at all?

Health and social care services may require a referral from a professional, and some may have their own eligibility criteria.

A number of further barriers may exist for people with learning disabilities. Inaccessible language and communication, both written and spoken, may prevent them from getting the information they need to join a group. Application processes may be too complex for some people. And someone's participation may depend on a group's rules or culture being flexible. For example, it being acceptable for support workers to attend for free.

Example



The activity afternoon in the care home is funded by the local authority and requires a social work referral to be able to attend. There is a waiting list as this service is oversubscribed.

Paul does not currently have an allocated social worker as his support needs have been steady for a long time. He chose his support provider and is happy with them to continue with his support. His support workers are not sure how to get a social work referral for Paul; they think they will need to contact the duty social work team first and ask for a referral to be made.

The arts and crafts group is a drop-in and people do not need to do anything other than turn up at the specified time. Paul does not know if the group would make him pay for himself as well as the worker if he needed them to come with him.

4. Presentation/Appearance

This dimension refers to someone's ability to present themselves, communicate and articulate the 'need' or issue that they feel can be addressed by the service or group (this means need in the broad sense, including social needs).

This relates to the work that an individual has to do to assert their candidacy for a particular service or group. People may have to, or feel they have to, display a certain ability to articulate why they are a candidate for this service or group, and to appear like a credible group member. People's willingness to do this work depends on a complex interaction between their own confidence and self-esteem, the work done by the organisation or service to minimise any objective requirements, and the perceived outcome of joining or taking part.

As a secondary point, this dimension also relates to people's ability to make suggestions for change or to complain if required. In a broader political sphere it relates to the ability of people with learning disabilities as a group to increase their access to the community.

Example

Paul can understand others well but has some difficulty with speech and expressing himself clearly. It can take him a long time to respond to questions. When he went to the day centre staff learned over time how best to work with Paul to ensure that he could take part. For him to participate, others at the activity will need to be patient, clear, and give him time to respond.

Paul has a trial visit to the care home activity afternoon. He is offered a range of activities, but because he doesn't respond quickly enough, staff at the centre assume he can't express a preference or is uninterested in all the options. He is left in front of the TV instead.



5. Professional Adjudication

Example

When Paul's supporters call to check information, the organisers of the arts and craft group express some anxiety about a person with a learning disability attending.

They are concerned that he will not be able to keep up with others, they say they do not have the skills needed to support a person with a learning disability, no one has been trained.

The support workers think that Paul shouldn't go because of this.

Paul's team leader suggests that there could be an agreement that a support worker will attend with Paul the first few times until the group members are reassured that they have the skills they need to enable Paul to participate.

⁵ Convention on the rights of persons with disabilities, United Nations Committee on the rights of persons with disabilities, 2006.

This refers to perceptions held by others on the ability of people with learning disabilities to take part. These perceptions may prevent someone from engaging with the organisation or service.

The United Nations Convention on the Rights of People with Disabilities states that disabled people should have equal access to community facilities and services⁵. The Equalities Act (2010) makes it illegal to discriminate against anyone on the grounds of their disability. It places a duty on public bodies to make reasonable adjustments to services to remove disadvantage faced by disabled people in accessing that service.

Nevertheless, people with learning disabilities may have a number of people in their lives who play the role of 'gatekeeper' to services and community activities. These are people who have enough influence in someone's life to effectively rule something in or out. It might be someone's social worker, doctor, support worker, or the person running a community organisation.

Although this dimension has the name 'professional adjudication', a person's relatives may play the same role in deciding that a service or activity is not appropriate. This adjudication may be justified in different ways. Statements like: 'I'm not sure how the other members would feel', 'I'm not sure they are quite ready', 'We haven't risk assessed this situation' can all be used to exclude someone from asserting their candidacy.

Even some support workers who should have an enabling role actively discourage the people they support from accessing a service because they assume the person doesn't have the capacity to take part. This may come across as protective e.g. 'I'd hate her to go along and feel excluded/not cope'. Making negative assumptions or simply not considering their needs may prevent a person with a learning disability from engaging.

6. Offers and Resistance

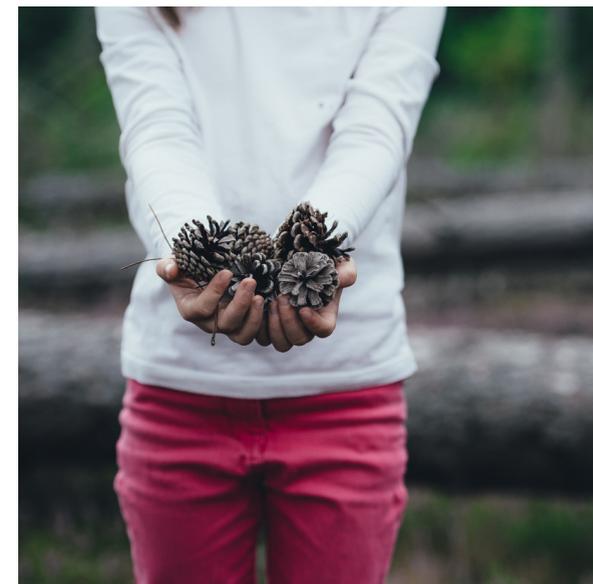
Reluctance from the person with a learning disability to take part even after an 'offer' has been made.

Despite being assured of their candidacy status, people with learning disabilities may still not join a group or take up a service. Alternatively, they may attend at first, and then withdraw.

There are a number of possible reasons for this: some people with learning disabilities have spent much of their life participating in activities separately from other people and may not feel that they are welcome or able to take part in community based activities with members of the wider (non-learning disabled) community. In addition many people with learning disabilities have experienced negative feedback from the wider community.

Example

When the idea of attending a social group in an older people's care home was suggested to Paul he did not want to go as he does not see himself as an older person. His identity has been formed, in part, by being a user of learning disability services and he sees himself as a candidate for these but not for activities that take place with a focus on another group that he is also a part of. He is worried that people will not be nice to him because of his learning disability.



7. Operating Conditions

This relates to other factors that have an effect on a person's ability to get involved in their community such as economic and political factors.

Until recently a common attitude towards people with learning disabilities was that they should live separately from the rest of the community without aspirations to be included in mainstream community life. Although thinking has changed, a number of people still have low expectations of what people with learning disabilities can and should achieve; this can include people with learning disabilities themselves. This has an effect on the confidence and skills of people with learning disabilities, those who support them and the community in general.

Example

Paul has not been active in his community since he reached the age when his day centre place expired. He has never taken part in a mainstream activity. He and his support staff assumed that there were no opportunities for a person with a learning disability once they reached this age as the 'service' had stopped.



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