



# BEE TOGETHER

#bringingpeopletogether  
#ChangeIdeas



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**FINDINGS FROM THE  
BEE TOGETHER PROJECT  
COMBATING LONELINESS  
AND SOCIAL ISOLATION IN  
OLDER PEOPLE WITH  
LEARNING DISABILITIES**

# BEE TOGETHER

## TIME TO SHINE PROJECT SUMMARY

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Bee Together was a Time to Shine project funded by The National Lottery Community Fund as part of their Ageing Better- Fulfilling Lives Campaign between November 2017 and September 2020. It was based in Leeds.

Bee Together was directed at Older People with a Learning Disability: investigating their feelings of loneliness and social isolation. The project aimed to find creative ways of combating their feelings and overcoming the barriers they have, or perceive to have, to inclusion. It became clear, soon after the beginning of the project, that the overriding cause of loneliness and social isolation for older people with a learning disability is other people's perceptions of the learning-disabled community. This situation is exacerbated by the mistrust of the system itself by these older people and their carers who can become over-protective, in their desire to keep people safe. Today, people with learning disabilities are living longer and many, who have mild learning disabilities, live in the community. They do not fit current learning-disabled services and society is not yet able to meet their needs. Therefore, they are at an increased risk of loneliness and social isolation. They need to be able to access services originally designed for older people. These services now need to adapt to be for older people with and without learning disabilities. New projects along these lines need to be developed.

Some people are accessing "mainstream" services, but many are not reached by these services or even projects that are ostensibly aimed at their needs. Bee Together identified that connections within a community are the best way of combating loneliness and social isolation. Being in the local community would mitigate transport issues and friendships would be easier to maintain when people are close by.



In getting to know the person you can see that they have the same needs, concerns and wish to be accepted we all have. They have different ways of interpreting the world and that can be refreshing and informative. They should not be defined by their disability. Interaction challenges any preconceptions people may hold and is one way of breaking down the barriers to older people with learning disabilities being included in society. \*

Many people have never encountered a person with learning disabilities and with the unknown can come anxiety and perhaps fear. \* \*

Within society, there need to be regular encounters between people of different abilities. In order to achieve this, people need to be educated about learning disabilities and how they can affect people and then regular contact with people of differing abilities needs to be established so that positive, meaningful relationships are developed. Some campaigns by charities such as Mencap are trying to do this.

<https://www.mencap.org.uk/get-involved/campaign-mencap/here-i-am>

These positive interactions will start to bring about a more inclusive society and are to be found at the heart of the Bee Together Project. As part of working towards this, throughout the project, I spoke to many different organisations discussing learning disabilities and providing information to aid further understanding. I supported them in developing the provision of safe places for older people with and without learning disabilities to come together to have meaningful positive interactions.

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Anna-Marie Garbutt Project Coordinator



*"Research fairly consistently points to the role of contact with members of an out-group as one of the most promising routes to improving attitudes, with the proviso that contact should be positive and challenge negative stereotypes rather than reinforce them."*

Mencap 2016 report into Changing Attitudes.

[https://www.mencap.org.uk/sites/default/files/2016-08/Attitudes\\_Changing\\_Report.pdf](https://www.mencap.org.uk/sites/default/files/2016-08/Attitudes_Changing_Report.pdf)



*"Nearly half of the British (43%) do not personally know anyone who is disabled Two-thirds (66%) of those surveyed said that they would worry about speaking about disability in front of a disabled person, with many worrying they would say something inappropriate or use an offensive term by mistake Many people said that getting to know someone disabled (33%), or getting advice from disabled people (28%), would make them feel more confident when meeting a disabled person."*

Brits feel uncomfortable with disabled people

<https://www.scope.org.uk/media/press-releases/brits-feel-uncomfortable-with-disabled-people/text>



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# BACKGROUND

## WHAT IS A LEARNING DISABILITY?

Mencap ([www.mencap.org.uk](http://www.mencap.org.uk)) defines learning disability as a reduced intellectual ability and difficulty with everyday activities (such as household tasks, socialising or managing money) which affects someone for their whole life. People with a learning disability tend to take longer to learn and may need support to develop new skills, understand complicated information and interact with other people.

Historically, people with learning disabilities have been hidden away from the public. Stigma, shame and intolerance led to children being taken off the streets and placed in homes or hospitals for their whole lives: hospitals such as Meanwood Park Hospital ([www.meanwoodpark.co.uk](http://www.meanwoodpark.co.uk)), in Leeds, which was set up as “a mentally deficient colony”: out of sight, out of mind. This is the system that older people, with and without learning disabilities, have grown up with, consolidating the perceived stigma of having a learning disability. For many, they were never given a diagnosis. They were “a bit slow, retarded or sub-normal”. Horrific to think of these days. Thankfully, things have changed but there is still stigma and people with a learning disability often have little or no voice.

Today, there is a growing realisation that every one of us is unique and in order to understand a person you need to get to know them. This is a change that needs nurturing and Bee Together was able to support this. Older people with a learning disability are wary of “the system” especially those living with elderly parents and carers. Bee Together began to break down some of these barriers to see their social inclusion.



# BEE TOGETHER PROJECT

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There were two main tasks to undertake that would enable the project to be effective:

1. The first task of the project was to locate older people with learning disabilities who felt or were lonely and socially isolated.
2. The second task was to use the questionnaire provided by the Ageing Better Programme to establish a baseline from which to assess the results of all the projects they run as part of this campaign.

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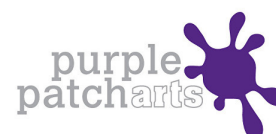
## 1. LOCATING OLDER PEOPLE WITH LEARNING DISABILITIES

Before the project could begin, it was necessary to identify those Older People with a Learning Disability who the project was aimed at. In Leeds, there is a good support network for people with learning disabilities. To maximise the effectiveness of this network, Bee Together ran in collaboration with Aspire CBS\* and Purple Patch Arts\*\*. Working with these partners, allowed me, as project coordinator, to contact older people with learning disabilities identified and supported by them.

\*Aspire CBS is the major provider of services for people with learning disabilities in Leeds. Formerly part of Adult Social Care.

\*\* Purple Patch Arts provide weekly creative workshops for people with learning disabilities around Yorkshire.

Obviously, this only allowed identification of those people already in contact with these support services. Therefore, I also approached care services around Leeds that were not specifically aimed at older people with learning disabilities.



I did this because I wanted to connect with people with milder disabilities who did not already access regular learning-disabled services: those who did not associate as learning disabled but who had a need. This is a group of people I had encountered through my previous work in the sector and I was aware of their as yet unidentified needs.

In addition, I attended team meetings for social prescribing services around Leeds. Social prescribers work alongside GP services to connect patients with third sector organisations to give a more holistic approach to their health and well-being. These are the people I thought would encounter the older people with milder learning disabilities that I was so keen to find. I thought a face to face explanation of the aims of the project would provide more targeted referrals. However, referrals from social prescribers had mixed results. Initially I had people with physical, and not learning, disabilities referred to me, which soon caused offence to those contacted. This highlighted the need for training of social prescribers about different abilities when assessing people. Later in the project this issue was discussed, and plans were put in place to offer training via the community hubs around the city.

I approached housing services, attending team meetings and information events promoting the project and soliciting referrals. Mixed results came from the referrals from the housing officers. There were difficulties in identifying the differing needs of people with a learning disability, mental health difficulties and physical disabilities. A similar problem to that with the referrals from social prescribers.

I also approached private care companies, who often work 1:1 with a person so gaining a clearer understanding of their needs. These care providers were often able to support participation in new opportunities.

For similar reasons I connected with local Police Community Support Officers and the police. These people are in daily contact with the public and know their community. I believed they may be a good source of referrals.

The above contacts met with varying results. By far the best referrals came from the connections I had built up with carers and support staff from previous working relationships. The trust they had in me brought understanding of the vision of the project and a recognition of what the project could achieve. An accurate identification of the client group.

Meeting these groups, although time consuming, allowed me to identify a more complete target group. It also made it clear that having 1:1 support does not mean that you are not lonely: if someone is paid to spend time with you it is a different relationship to that of a friend.



It was not possible to support everyone who was referred. Some of the referrals did not fit the project criteria, they were already engaged in activities, were not lonely and wanted information on any other activities available. This, although not within the remit of my project, I provided on a regular basis.

Some of the people referred had significant mental health difficulties which needed further support before they would be able to access the project. These I referred to appropriate services if they were not already in contact.

This left an identified group of lonely older people with learning disabilities: my target group.

## 2. THE BASELINE QUESTIONNAIRE

The baseline questionnaire provided by the Ageing Better Programme, proved to be difficult for older people with learning disabilities to access: highlighting a recurring difficulty for this group. Overcoming this, then became my first task as the coordinator of the Bee Together Project: to create an EASY READ version of the questionnaire to improve access. Once I had completed this adaptation it was accepted by Ecorys\* as a valid form of data collection and will be included in the findings from the whole Ageing Better Campaign and will be used in future where appropriate. The data I collated will be used to inform future planning of services for older people by The National Lottery Community Fund and Councils around England.

\*Ecorys are an international provider of research, consulting, programme management and communications services they are the evaluators of the Ageing Better Campaign.

EASY READ simplifies text to increase accessibility.



**Bee Together**

**Time to Shine: Photo Permission Form**  
Thank you for being a part of Time to Shine.

We are very proud of what we do and we like to tell everyone. We take pictures and films of the **Bee Together** project so that we can spread the word about everything we do and how we help people.

		YES <input checked="" type="checkbox"/>	NO <input type="checkbox"/>
Would you be happy to give your consent for us to use your picture?		<input type="checkbox"/>	<input type="checkbox"/>
		YES <input checked="" type="checkbox"/>	NO <input type="checkbox"/>
Would you be happy for us to use your story?		<input type="checkbox"/>	<input type="checkbox"/>
		YES <input checked="" type="checkbox"/>	NO <input type="checkbox"/>
Would you be happy for us to use your first name?		<input type="checkbox"/>	<input type="checkbox"/>



**Time to Shine: Easy Read Photo Permission Form**  
Thank you for being a part of Time to Shine.

I also give consent for images, quotes and sounds to be shared with our partners including but not limited to The Big Lottery, Camelot, or other National Lottery funders and our supporters.

YES <input checked="" type="checkbox"/>	NO <input type="checkbox"/>
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NAME: \_\_\_\_\_

PROJECT: Bee Together

SIGNATURE:

DATE: \_\_\_\_\_

TTSLD ☐

[www.timetoshineleeds.org](http://www.timetoshineleeds.org) 0113 244 1697

Thanks to for the use of their image bank. © LYFT [www.ecorys.co.uk](http://www.ecorys.co.uk)

# BEE TOGETHER : THE PROCESS

## CONVERSATIONS

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It was clear that the questionnaire, even with the EASY READ version was not, in most part, going to be completed independently. The EASY READ made the document accessible but answering the questions would still need to be supported: older people with learning disabilities find the mechanics not just the content of filling in forms difficult.

After the initial referral, I arranged to meet with each person accompanied by someone they knew. The aim being to put them at ease. During the informal meeting, usually in a cafe or in a place where they felt comfortable, we would chat and get to know each other. This technique is known as the warm handover and is an essential part of building trusting relationships.

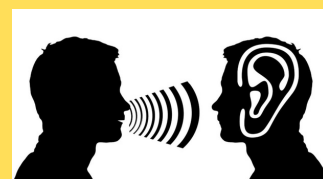
I would explain how I wanted to help them and talk through the questionnaire with them. I would show them the questions and answers. Then I encouraged them to select their answer. In many cases, I scribed for them and always made notes to ensure their point of view was recognised.

Throughout the process, conversations were had, and examples were given to aid understanding. For instance, the question about sexual orientation was supported by discussions such as, "If you were to send a Valentines card would you send it to a man or a woman?" The questions were aimed according to ability and sometimes using EASY READ symbol cards.

From these conversations and the completion of the questionnaire, I identified availability of time throughout the week, their interests and any new things they might like to experience.

After this, I explained that I would attempt to find new opportunities for them and come back to them to discuss the next steps.

After matching the adult to the activity, the next steps meeting was held (sometimes 1:1, sometimes with another known person).





The options were discussed, I could attend with them if they wanted and visits were set up to any groups or events they wished to try. Pressure was never put on anyone to go out. Often people wanted time to think about it, some wanted to try things straight away.

It was clear that mental health played a large part in people's loneliness and disengagement.

Some were happy to attend new groups knowing I would be with them. Others made last minute excuses as to why they could not attend that day, "maybe next week". Patience was key.

A first visit was arranged accompanied by me, as project coordinator. Sometimes the sessions went well and after a couple of visits the person was happy to continue alone. On other occasions the visit seemed to go well but then a message was received to say they did not like it. In these cases, we would review why and see if they would like to try it again to make sure. Otherwise I would find alternative groups to try using the same warm handover method.

Some people needed more time to feel comfortable attending alone. The project had to be flexible to meet the needs of each person in each situation.

Once settled into a group I would reconnect every few months to assess how things were going for the participant and the session provider mitigating any perceived difficulties when required.

## CHALLENGES IDENTIFIED FROM THE EASY READ QUESTIONNAIRE

Initial findings from the accessible questionnaire and the individual meetings were that most people within the care system had good social lives but very structured. They would go to day services on certain days, work in a cafe on others and sometimes access one of the many social groups run around Leeds.

People who were not within the care system had a range of access to a social life. Some went out into society but there was little interaction with others. But others spent their lives within the four walls of their home isolated.

From all of this, several main issues became clear:



*"I used to think the worst thing in life was to be alone, it's not. The worst thing in life is to end up with people who make you feel all alone"*

*Robin Williams*

## Socialising within established learning disability groups.

These activities were often dependent on the availability of transport and support to take them there. In addition, people did not necessarily choose with whom or when they attended groups. This meant that they could be socialising with people they did not like or feel comfortable with. Their only choice, when attending a day service, was between the activities offered. There was no open question such as what would you like to do? But rather these are your choices, which would you like to do? A subtle but profound difference meaning that independence of choice was limited.

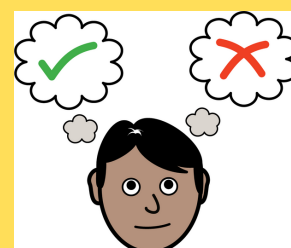
Changing groups could take months to organise and be frustrating for all involved. Due to austerity measures in some homes, one carer could be supporting 3-4 people so that any changes had to be a group decision, influenced always by the need for transport and staffing. These choices of how to spend our free time we, as non-learning-disabled adults, take for granted for people with a learning disability it was a rare occurrence.

## Attitudes of Carers and Support workers.

Most carers and support workers have people's best interests at heart. However, this sometimes resulted in people being over-protective. This could then lead to a reluctance of the carer and participant to try new activities and change routines. Carers attitudes could impact on the participants' confidence to try new things. In some cases, difficulties were exacerbated by money and time. Some care managers were incredibly supportive, but others were dismissive of the service.

Carers sometimes did not allow the voice of the older person to be heard. In one case, an elderly parent who had struggled to access services stated that they did not want to "rock the boat, she's fine". After communicating with the participant, myself I established that she was not entirely happy with her current situation. She wanted to go out more and make friends. In this I was able to make some changes.

Small changes can make a big difference. Having a choice, as I have stated before, is something new to many older people with learning disabilities.



## Loneliness and friendship

Some people I spoke to still had great reservations about trying new things despite feeling very lonely. Often, they were lonely in the evening, but some said they were lonely all the time, even though they were in shared, supported living and participating in some activities. These activities were mainly during the day and evenings were spent at home.

Increasingly through conversations, the word “friend” was being used more and more. People wanted to be able to make a mutual friendship with someone with whom they could socialise. “A mate to watch telly with”, “Someone I would like to talk to”. To have again the choice we all, as non-learning-disabled adults, take for granted. \*

Older people with learning disabilities do not choose with whom they spend their day. They live in houses with people that they may not get on with. Choices are limited. They still felt lonely and socially isolated.

When we, as non-learning disabled people, make friends, it happens organically. Friends from school or college and people we meet through work. Life events such as having children, joining mutual interest groups and going out for a drink spark friendship. We have the ability and autonomy to cultivate friendships freely. I found this was not the case for older people with learning disabilities. Older people with learning disabilities have not usually been employed, had children or been able to join groups outside of learning disabled services.

Some older people with learning disabilities struggle with social interaction and need support to maintain friendships. They all said they wanted more opportunities to make friends in a relaxed and informal way.

## Falling through the gaps.

In addition to the difficulties caused by loneliness, the people I spoke to with mild learning disabilities, who were living independently, often did not consider themselves as learning disabled. They do not access resources for the learning disabled but they understand that they do not “fit” into society (or society did not yet meet their needs). This can lead to difficulties when interacting with people. People need to feel safe before they have the courage to try something new. Older people with learning disabilities have had to deal with being rebuffed, ignored, demeaned and, in some cases, abused for much of their lives.

\* *Friendship and interpersonal relationships are a normal and expected necessity of life; friendship provides companionship, assistance, emotional support and fosters self-esteem and well-being (Hartup & Stevens 1999). Unfortunately, adults with intellectual disability have fewer social networks and less genuine friendships than those without intellectual disability, and often the networks and friendships that do exist are closely linked to family relationships, peers with similar disabilities and service providers (Gilmore & Cuskelly 2014).*

<https://onlinelibrary.wiley.com/doi/epdf/10.1111/jar.12275>

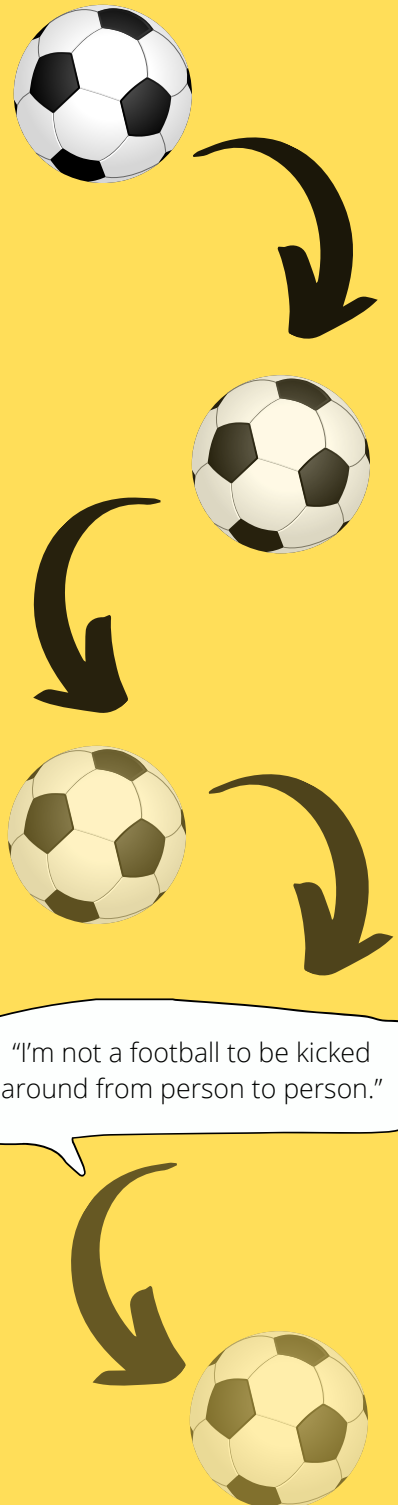


Understanding that you are not welcome when you go to the pub and being ignored when you want to order a drink all create further anxiety when you venture outside. They act as a deterrent to social interaction whilst in some cases leading to mental health difficulties and further isolation from society. Many sought support from housing services or social prescribing, for everyday tasks. These services were not provided for such support, but having no other options people were accessing them. This support was usually for a limited time, three months. After that it meant approaching another organisation, going over all their information again and building trust. People are being pushed from pillar to post. They can survive but want emotional support with decision making, where to get a plumber, how to get their cat to the vet. One gentleman found topping up his phone difficult. He had a very understanding postmaster but not everyone is helpful. He was vulnerable to abuse because of his need for support. Social services under current funding regimes are unable to support these people. One gentleman was told, "If you are able to get yourself here to ask for help you can cope on your own". A demoralising way to live. Another participant said,

*"I'm not a football to be kicked  
Around from person to person.  
Everyone I meet disappears,  
I like you; I get on with you, but I don't with everyone.  
Now you are going to disappear."*

75% of those I spoke to in this group suffered from mental health difficulties because of their situation, an added barrier to inclusion. If you were aware that people had taken advantage of you before anyone of us would be wary about going out and feel low.

People's lives are complex and there is no one cure for loneliness. A support system of some kind is needed for this group. No person should be left behind. The Bee Together project shows that with appropriate support change can be made. With further funding this would continue, improving the lives of this vulnerable group of people.





As a result of the project several main areas for development became clear. Some of which the project was able to begin to redress.

It became clear that there was a need to educate people to enable the accurate identification of individual needs. Although it was made clear what the client group was for this project, some referrals obviously did not fulfil these criteria. People with physical disabilities and people with severe mental health concerns were amongst those referred. Some of this was because these people needed help and carers were unable to provide this themselves. This led to them grabbing at anything available.

Some of these referrals resulted from a lack of understanding of learning disabilities and their impact on people's lives. Combating this is an issue for society but I was able to make some progress, working alongside people as a positive role model, educating and informing but this is progress with one person or a small group only.

To have a greater impact I worked across departments and organisations to begin to build a network of support for people with learning disabilities. Liaising and supporting to develop a system where people do not fall through the gaps. This will need continued commitment from all stakeholders to ensure that those with a learning disability receive all the care and support they need.

A sense of community is a way of feeling valued. As project coordinator I do not believe that people with learning disabilities of any age should be segregated unless they would cause harm to themselves or the public. The project worked towards connecting older people with learning disabilities to groups within their communities to foster new relationships. Connecting someone to a group in a different area from where they lived when it created further barriers to engagement such as transport issues, seemed counterproductive.

In order for people to feel safe and ready to engage, I visited the community groups alone and connected with the members and organisers prior to accompanying the participant. Using the warm handover method to placate any initial issues.

Inclusion in any group of a new member is down to good facilitation. Several of the Neighbourhood Networks in Leeds involve people with learning disabilities. Those who have staff or volunteers with previous experience of the learning-disabled community had more of an insight into this, but the majority of groups welcomed people.





This model works well but is limited. More groups need to offer this access. In order to do this there is a need for more training for community groups and volunteers working with older people to identify opportunities for the involvement of older people with learning disabilities. Leeds Libraries Community Hubs were identified as a location for this to take place. This was well received, and discussions are ongoing.

To support this and aid understanding, within community groups, I have created and distributed, with the help of the Time to Shine Team and Leeds Older People's Forum, two booklets:

*"Ideas on how to include accessible information"* and

*"Ideas on how to include people with learning disabilities"*

The booklets contain simple ideas and information with details of organisations providing further support. They have been well received and have been sent to all Ageing Better areas via The National Lottery Community Fund. I am hopeful they will start to make a difference.

The booklets are available to download via the Time to Shine website.

[www.timetoshineleeds.org.uk](http://www.timetoshineleeds.org.uk)

Along with educating the public, I strongly believe that the learning disability community needs to become more of what it wants to see in society.

If we want people to be accepted in general society, we need to be open to including them within the learning disabled community. For example, supported living services sometimes sit alongside sheltered housing for the elderly, yet there is no interaction between the two. My suggestions to trial some such interaction were met with scepticism. Facilitation is key and an open-mindedness to change.

## Easy read information

Part of the Bee Together Project was to map suitable activities around the city to increase participation. I became aware of the same difficulty with information, accessibility as with the original questionnaire, immediately.

Leeds has a vast number of third sector organisations, but none had EASY READ versions of their events. Leeds is fortunate to have an online directory aimed at people with learning disabilities. You can find information about activities mainly within the learning disabled community. But not everyone is able to access the internet and I saw a need.

To rectify this, I compiled an EASY READ file, by area, of activities. This went with me and I had copies to give out of the individual organisations. This became known as the WOW file. What's on Where. Copies were also given to the organisations to highlight the needs of older people with learning disabilities in the way they communicate. It had a dual purpose to inform people of activities and educate organisations about accessible information.



## EASY READ accessible information

Easy Read is an accessible form of information using short and simple sentences.

Jargon and hard words are taken out and pictures or symbols are used along-side to illustrate the meaning further. The format usually sees illustrations, photos or symbols on the left and text on the right of a page. Information is separated out and should be about one thing only. Text layouts such as information boxes ease understanding. Short sentences allow greater access whilst the text is in a large font.

This format is useful for many people. People with dementia, sight impairment, hearing impairment, those with learning disabilities and even younger people who want to know the basics quickly. Bee Together had a request from one older person with learning disabilities who wanted to write his will, for easy read information. I researched and found there was some information but nothing that stated legally what was required. The majority of information was aimed at parents setting up trust funds for children. But as people with learning disabilities are now living longer, the emphasis needs to shift to their needs in deciding what will happen when they die.

With this in mind, I contacted groups such as the Dementia Action Alliance and Leeds Bereavement Forum, where I was able to connect with solicitors to assess their understanding of learning disabled clients. Again, the need for education around the needs of older people with learning disabilities was apparent. Contact with legal advice made it clear any EASY READ information would need to be legally correct and acceptable in design to both solicitors and the client group. I was fortunate to connect with Clarions Solicitors and Morrish Solicitors who offered funding for a graphic designer to produce booklets on "Thinking about writing your Will" and "Power of Attorney". Drafts have been produced by the graphic designer and are being critiqued by different learning disabled groups prior to production.

Along with these documents' I initiated discussions about creating a training course for solicitors in how to use the Easy Read information and how to work with older people with learning disabilities.

The COVID -19 pandemic has delayed this, but I am hopeful the work will continue now that the Bee Together Project is ended.

What is Easy Read information?



Easy Read is an accessible form of information using short and simple sentences.



Jargon and hard words are taken out and pictures or symbols are used along-side to illustrate the meaning further.



The information should be about one thing only. If possible with a box around it. Short sentences and in large text.



Use symbols or photos on the left hand side of the page with text on the right.

I want to write my own Will.

**Clarion**



## Working with individuals and groups:

### Bee Friends

In addition, many people I spoke to expressed a desire to have a friend: someone with mutual interests, someone they got along with and could socialise with.

To fill this need I initiated the Bee Friends Social group. The group was to be purely a place to chat so I thought a cafe setting would be best. It would be informal and having a drink would enable interactions. Fortunately, the learning disability arm of Health for All, The Bridge, ran a cafe staffed in part by people with learning disabilities. After discussion with the cafe staff, it was decided that this would be a good place to trial the idea.

### How to let people know about it.

Promoting the cafe was challenging for several reasons. Communication with support organisations is unreliable, especially those offering outreach work (supporting people in the community).

Getting the information through to the right people proved difficult, shift working, staff changes and other priorities were possibly the causes of this.

Some staff did not see the relevance of socialising for their clients.

People with learning difficulties do not for the most access social media, they have difficulty reading and understanding information. So normal use of social media would not be effective

Logistical reasons also had an effect. Activities for people are booked months in advance so changing them takes time. This includes changing transport rotas and staff rotas. Staff and participants can get used to routines and to persuade them to change a great task.

As a result, it took about six months before a regular group of people were attending. The most frequent participants came from my connections to support staff from my past employment.



*It is likely that contact needs to occur alongside education about learning disability, the range of abilities and needs of individuals with learning disabilities, and their capabilities to counter misconceptions and challenge negative stereotypes. CHANGING ATTITUDES TO LEARNING DISABILITY*



I did use social media and aimed it at support staff. Visiting different social activities for people with learning disabilities, using contacts from previous work and handing out EASY READ invites to promote the group eventually began to see a response.

Prior to lock down, due to COVID-19, 20 -25 people were attending the group plus staff.

Not all were over 50. Many younger people with learning disabilities struggle to make friends. There are few safe places for them to meet, as one person said,

*"I like it here, people get me."*

After many requests to set up "one near me" three further groups were started in cafes around Leeds. Venues were decided on by location, to offer a spread around the city, accessibility and offers of support from other Time to Shine providers.

Meeting places within the community would also give opportunities for positive social interactions with the public. This, as stated earlier, is one way of breaking down the barriers to inclusion.

Due to lock down these did not become established. I am working to make the initial cafe sustainable once restrictions are alleviated with workers from The Bridge and the Health for All Charity.

Feedback from one support worker, parent and client was positive:

*Stevie came to the group at Cross Flatts Park from the beginning. He and his support worker knew me from a previous project. Stevie has autism and does not speak but communicates in other ways. He loves to dress up and dance. Prior to coming to the group, he would sit alone and not interact with anyone. After several visits, he started to play games with other visitors to the group. He went and ordered his own coffee and when he left walked around the tables waving goodbye to everyone. His father remarked to his support the big difference he had seen in Stevie at home. He stressed he wanted him to attend the cafe every week. His support worker reported that he really looked forward to his visits.*

The group was also successful because it was open to non-learning disabled people in the community who may be lonely. Working with previous learning from Time to Shine Projects around Leeds, the café was not promoted as "do you feel lonely" but more "come along for a chat and to meet new people". It was advertised it in the local paper, I handed leaflets out to care homes and displayed posters in local businesses.





Local people did come along and join in with games and events. Lots of wonderful interactions took place between different age groups and differing abilities including school children and parents during school holidays. Dogs being walked in the park proved to be popular visitors to the group and a great tool to stimulate conversations.

In order to promote this simple idea I connected via social media with [www.thechattycafescheme.com](http://www.thechattycafescheme.com) The scheme was set up by Alex, when as a new mum she felt lonely sat in a café with her baby having no-one to talk to. She looked around and saw other people alone and thought of having a table where you could sit and be willing to chat to others. The idea has grown and is now worldwide. Alex is a social worker, working with children with learning disabilities.

The scheme is now run by Alex and her sister and they were happy to provide a platform for my idea. During Learning Disability Awareness Week 2020, they ran a blog I had written and displayed easy read versions of café menus. Bee Together has always been about raising awareness and pollination of ideas, I wrote blogs for many different learning disability groups. I am grateful to all for their support.

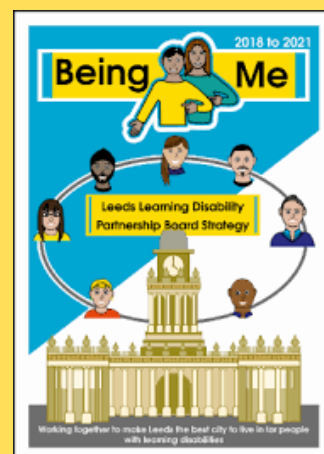
I have been working alongside an Assets Based Community Development (ABCD) worker to create a sustainable social group, pooling resources rather than relying on one person. Once the restrictions of the pandemic are eased, I am hopeful this group will become a valued part of peoples' lives in the future.

The Bee Friends Social group was successful and made a huge difference to people with and without learning disabilities.

## Pollination

The Bee Together project offered me an opportunity to look at how different groups around the city operated and how they could possibly work together differently. As a creative thinker, it gave me the chance to put forward new ideas, knowing that things would not change instantly but to sow the seeds: pollination.

Leeds City Council in partnership with third sector learning disability groups around Leeds have put together a strategy enabling the views of this group to influence council policies. The "Being Me" strategy combines the work from different Task groups: Being Safe, Being Connected and Being Well. It was collated by the Learning Disability Partnership Board.





<https://www.through-the-maze.org.uk/wp-content/uploads/2018/06/Leeds-Learning-Disability-Partnership-Board-Strategy-2018-2021.pdf>

I volunteered to join the Being Safe, Being Connected- Travel and Being Connected - Social Groups.

These were wonderful safe places for people to express opinions and form plans to put forward to the council. Members were from the learning disabled community, public sector and the third sector.

**Being Connected - Travel:** One of the pieces of work I instigated was a guide for taxi drivers about how to support learning disabled clients. The idea came from a Dementia Friendly Taxi Guide that had been produced by Leeds City Council. As with the Easy Read Will writing information education will be needed to back up the guide. The pandemic has put this on hold, but work is ongoing via social workers in the Travel Team. Learning disabled peoples' experiences of travelling by taxi were varied. This booklet hoped to promote their needs and help the drivers gain an understanding of how their actions impacted on their learning disabled clients.

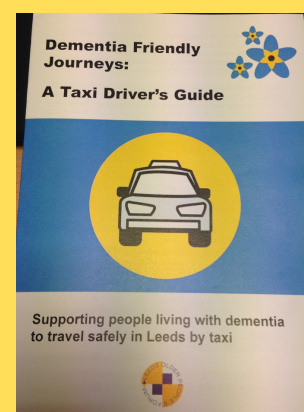
**Being Safe:** This group comprised of people from West Yorkshire Police, transport companies, third sector and the public sector. Here we discussed the idea of using data of disability hate crime around the city to pinpoint areas that could be targeted for education via promotional posters and interactive events. Due to staffing changes and changes in priorities within some of the bodies taking part these ideas did not come to fruition.

**Being Connected - Social.** Here we discussed amongst other things the availability of staff to take people out in the evenings. Some private care providers had trialed new ways of working which seemed to be having a positive impact. Other providers seemed sceptical of their ability to change the systems in place. I put forward the idea of utilising staff from different organisations creating friendship groups across organisations to enable greater participation. The discussions were on going and I am hopeful change will happen. As discussed, earlier independence of choice in what social activities you wish to attend, where and with whom would increase a person's feeling of connectedness and allay feelings of isolation and loneliness

When in conversation with some of the participants, I could see that their mental health was a barrier to overcoming loneliness. As stated in the Ageing Better Middlesbrough:

*"You can't always fix loneliness"* mental health report

*"we now no longer talk about loneliness as if it is a stand-alone issue. We know that loneliness is a piece of a much bigger picture".*



*"we now no longer talk about loneliness as if it is a stand-alone issue. We know that loneliness is a piece of a much bigger picture". You can't always fix loneliness. Ageing Better Middlesbrough*

When I was unable to help a person because their mental health issues were too great, I referred them to appropriate services. Finding appropriate services though proved difficult. In my previous work I had heard that services were sparse for people with learning disabilities. Very few practitioners work with this group so waiting lists are long. In order to find help I contacted many private counsellors in the Leeds area to ask if they had experience of the client group. My aim was to start a conversation between any willing parties to begin to think about ways to alleviate this. From contacting the many private counsellors, I found two ladies interested in discussing the issues, of which they were both aware. I asked if they would perhaps keep these in mind and promote looking into different ways of working together with other colleagues. Lack of time on my part meant I have been unable to actively pursue this, but I am hopeful that through planting the seeds of an idea things may change.

## On-line Knitting

In Leeds we have a great resource as part of the Library Services called 100% Digital. An award winning service promoting digital inclusion across the city. At the beginning of the Bee Together Project they started to promote a tablet lending scheme: third sector organisations could loan 4G enabled tablets to people they supported. The hope was to encourage people to get online. This was all pre-Covid. A situation that has reinforced the value of this project.

Being aware of this scheme and thinking about what people had been telling me, they wanted someone to have a chat with on night when they were lonely at home and finding out their interests, I trialled an on-line knitting group. With help from an Aspire CBS Community Coordinator, I found four older ladies with learning disabilities who enjoyed knitting. None knew each other and all lived in different parts of the city.

Over a few weeks I visited each lady, all of whom were in supported living accommodation. I produced an EASY READ "How to use your iPad and Zoom" booklet for both them and their staff to use. We found the best time and a three month trial went ahead. There were mixed results. The main sticking point came with the staff supporting at the time of the chat. Some had no digital skills themselves and could not support the session. One lady had been playing around with the tablet, which I had encouraged, and had switched off the Wi-Fi. I was pleased she had shown such interest. I downloaded game apps to help with engagement and it worked for some. More time was needed to embed the idea and get people onboard.

The pandemic has shown digital to be a useful tool in helping people be connected. I am hopeful steps will be taken to train staff more fully so they can support older people with learning disabilities to create friendship groups like this on-line. Groups would need to be facilitated and supported by management in order to develop.

*"A recent review concluded that people with mental health problems and/or learning disabilities are the most likely section of the population to be affected by targeted violence and hostility".*

CHANGING ATTITUDES TO  
LEARNING DISABILITY



100%  
Digital  
Leeds

*McMillan & Chavis (1986) define a sense of community as "a feeling that members have of belonging, a feeling that members matter to one another and to the group, and a shared faith that members' needs will be met through their commitment to be together."*

[https://www.researchgate.net/publication/235356904\\_Sense\\_of\\_Community\\_A\\_Definition\\_and\\_Theory](https://www.researchgate.net/publication/235356904_Sense_of_Community_A_Definition_and_Theory)



How does being lonely make you feel?

as if I don't belong – I have an imaginary friend  
and an imaginary dog

FRUSTRATED

*stressed*

ANXIOUS

*I lose my  
temper*

I HAVE TROUBLE  
SLEEPING

*bored*



*uncomfortable*

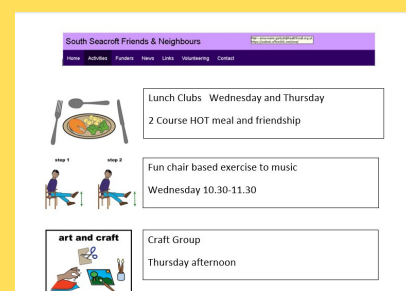
# CONCLUSION

There are many difficulties to overcome in combating loneliness and social isolation in older people with learning disabilities. Bee Together has made steps to overcome these and has established a legacy, which if supported will see continued progress in the future. Social groups such as Bee Friends and on-line knitting can and have made huge differences to peoples' lives.

People with learning disabilities are living longer. They need to be able to access all the services older people require for instance, mental health services, elderly care support services, end of life services such as writing your own Will, decision making i.e. power of attorney and social activities. Bee Together has connected with organisations outside the learning disability community to promote this idea. It has instigated communication and positive interactions to help develop a better understanding of differing needs. Further facilitation of these interactions would enable progression towards a more inclusive society.

The Bee Together project's development of EASY READ documentation to support both carers and participants has increased effective communication. These documents are now available and have been provided to all Neighbourhood Networks in Leeds and shared via The National Lottery Community Fund with all participating areas of the Ageing Better Programme. These booklets and the links to services included, will make accessible information available to many more people. Information needs to be more accessible and not just online. Some older people with learning disabilities will never be able to access online services. Education and support should be available for community groups to be able to include older people with learning disabilities. This could be based around the community hubs we have in Leeds. Far better would be people, from learning disabled and non-learning disabled organisations working together.

Attitudes towards the learning disabled community underline all the issues older people with learning disabilities have in being lonely and socially isolated. Challenging and beginning to change these attitudes will help to combat this. Positive social interactions along with education are ways of starting the process of changing ideas about learning disabilities. As project coordinator I have striven to highlight the needs of older people with learning disabilities by working with non-learning disabled groups. Bringing people together to get to know each other as people and not just a diagnosis. Relationships need to be nurtured, being out in society is not the same as being included. It will take time but talking and involving everyone can only make these changes, scary but so worth it.





Attitudes of carers and support staff also need to be challenged. Their understandable reluctance to getting out there, needs to be tempered with the knowledge that the supported pushing of boundaries will make such a difference. Profound changes to the way people with learning disabilities are treated have taken place and we need to keep the momentum going. The learning disabled community needs to reach out to other non-disabled organisations to promote inclusion. Integrating services could lead to much better outcomes for all.

#### Scenario:

An older person with learning disabilities has moved away from their home of many years to be near to their child, who also has learning disabilities and lives in supported accommodation. They were referred by housing officers. In the same area is a day service for people with learning disabilities a thriving neighbourhood network and a social prescribing service. Because they had moved away, they had lost all their contacts and their partner had died. They felt very lonely. They suffered from social anxiety and had mobility problems. Help given from housing was understandably limited. The neighbourhood network had tried to engage but the anxiety had proved too great. Perhaps if they could work together, share knowledge and skills something could be done to help this person. This I believe would be a good way forward, counteracting lack of resources, money and staff. Working with the ABCD method. Facilitation is the key.

## Covid-19

The pandemic has highlighted loneliness and social isolation and the effects it can have on people.

It has shown the need for support for the more vulnerable in society.

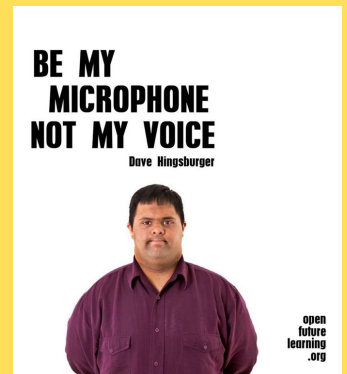
It has displayed the discrepancies in awareness of who those vulnerable people are. Not all councils included people with learning disabilities as a shielding group at the beginning of lockdown.

It highlighted again the lack of accessible information exacerbated by the digital divide.

It has changed priorities and people have realised how important social connection is for us all.

As project coordinator I had hoped to make the work I have started sustainable. The uncertainty of the lock down process and the ending for the Bee Together project has meant this task I now have to leave with others.

The good thing about lock down though, has been the chance for organisations to stop or slow down. To think about how they will build back their services. With the publication of the Bee Together Booklets I am hopeful that they will include accessible information and be more open to including older people with learning disabilities in future. Combating loneliness and social isolation, the premise of the Bee Together Project.



**MAKE THE  
DIFFERENCE**  
*creating the future together*





## Case Study

F lived in a flat in a shared house with support once a week. The referral came from care management (a social worker). They suffer from anxiety and have difficulty reading, writing, understanding body language and social etiquette. They are very vulnerable. F had a friend who visited when they needed money. F gave money to them leaving themselves without. F likes to talk to people, this has caused problems on public transport when they are out on their own.

F has a sister who is in control of their finances for their own safety.

F has a love of art and crafts and tells of how with their mother they attended pottery classes and talked through their creations around the flat.

F had become socially isolated and lonely and needed a safe place to socialise and hopefully make friends

Inkwell Creative Arts is run by Leeds Mind and had various activities going on during the week. F and I decided we could attend the craft café on Thursday afternoons and the felting class on a Friday morning. We attended for 4 weeks. F was apprehensive but seemed to settle in nicely. When I asked if they wanted to join in the session they said,

*"I'm really enjoying myself watching."*

*"This is a nice place this."*

*"I'm happy like a bumble bee" no prompts given!!*

We went on a Thursday afternoon to the Craft Café where F can try different art-forms.

On Friday mornings we went to Felting Classes. F gets on well with the other people, they have been very welcoming and friendly.

F said they felt better already for going to the group. They did not want to access anything else at the time "until they get their head straight."

When I explained to F that I would not always be able to attend with them they were deflated and said:

*"It's okay this always happens, I want someone a buddy all the time."* F

*"Things, people, change and we never get told about it, it's annoying"* F

I discussed this with F's Housing Support Worker and Care manager, but we were unable to find support for them. Despite this I was pleased to see after a few months they were still attending alone.



"I'm happy as a bumble bee."



"It takes time for people to build relationships and trust and this has been a recurring theme that constant support is what people are looking for, stability and friendship. As well as being involved in the decision making or at least made aware of changes wherever possible before they happen.

*I'm going to have a dalliance with felt-making" F*

A year after first referring F to the group I was made aware they had relocated to a different area of the city. I reconnected and we discussed finding new activities in their locality. I found a craft group within one of the Neighbourhood Networks. Using the warm handover method, I introduced them to the group. This time it did not take as long for them to settle in.

## THE EFFECT OF LOCK DOWN DUE TO COVID-19

Moving had created a lot of anxiety for F. They had been at their previous address for nearly 20 years. The event of lock down has had a further detrimental effect on their mental health.

In the first instance they had no understanding of what was happening. They were still going out as normal and wondering where everyone was. F now lives in sheltered housing without any support.

I found some EASY READ guides explaining the virus, what they were and were not able to do and sent paper copies to them and to the manager of the home.

Boredom, being unsettled and not knowing when things are getting back to "normal" have been a challenge for them. During this period, I sent EASY READ letters with ideas of arts activities they could try. I also sent art materials. I could not talk to them on the phone as because of past experiences they would not give out their number. Keeping in contact with the home manager I knew that these were gratefully received. Since the easing of restrictions, I have visited F and explained the ending of the project. This was not well received as they feel left again, leading to the quote in the previous section.

"I feel like a football"

I reiterated the positives from our relationship and gave information about other organisations who would be able to support them further. This information was sent via the home manager to their family. Unfortunately, the response was not favourable. I am hopeful the Neighbourhood Network will reconnect with them when circumstances allow. They have many differing needs that cannot be supported in the current system.



"I'm not a football to be kicked around from person to person."



# Appendix

Many thanks to all the organisations and participants who have contributed to the Bee Together Project. Special thanks to Amanda Erskine for her help in compiling this report.

Quotes have been taken from the following publications:

## **Ageing Better Middlesbrough** **"You can't always fix loneliness"**

<https://www.ageingbettermiddlesbrough.org.uk/wp-content/uploads/2018/10/Ageing-Better-Middlesbrough-Learning-about-Loneliness-Report.pdf>

## **Changing attitudes to Learning Disabilities.**

Dr Katrina Scior

University College London

Dr Shirli Werner

Paul Baerwald School of Social Work and Social Welfare, Hebrew University of Jerusalem

[https://www.mencap.org.uk/sites/default/files/2016-08/Attitudes\\_Changing\\_Report.pdf](https://www.mencap.org.uk/sites/default/files/2016-08/Attitudes_Changing_Report.pdf)

## **From supported exclusion to supported inclusion: Adults with intellectual disability discuss their lived experiences of a structured social group.**

Nathan J. Wilson \*, Hayden Jaques\* , Amanda Johnson\*+ and Michael Brotherton \*\*

\*School of Nursing and Midwifery, Western Sydney University, Richmond, NSW Australia.

+School of Nursing, Midwifery and Paramedicine (NSW/ACT), Australian Catholic University and Policy, Sydney, NSW. Australia

\*\* Centre for Disability Research University of Sydney, Lidcombe, NSW. Australia

<https://onlinelibrary.wiley.com/doi/epdf/10.1111/jar.12275>

## **Sense of community: A definition and theory**

David W McMillan. David M Chavis

First published January 1986

[https://www.researchgate.net/publication/235356904\\_Sense\\_of\\_Community\\_A\\_Definition\\_and\\_Theory](https://www.researchgate.net/publication/235356904_Sense_of_Community_A_Definition_and_Theory)



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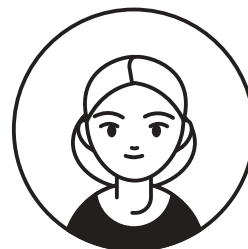


# Findings from questionnaire

Bee Together completed 32 questionnaires.

## Age ranges were:

28%	50-55
14%	56-60
34%	61-65
15%	66-70
9%	70+



## Gender

59%	Male
41%	Female

## Ethnicity

82%	White British
6%	BAME
3%	Irish
3%	Jewish
6%	Didn't say



## Sexual Orientation

78%	Heterosexual
3%	Bi sexual
18%	Didn't say



## Living Arrangements

13%	Live with family
25%	Live Alone
22%	Live Alone but have support daily/ weekly
6%	Live in sheltered housing
34%	Live in supported living



### When are people feeling lonely

53%	All the time
47%	Evenings
16%	Weekends

### How do they have access to accessible information about social or community activities?

13%	Independently
84%	via support
3%	Don't have any access



### Do they identify as having a learning disability?

37%	Yes
13%	No
50%	Didn't answer



### How often do they see family?

34%	1 - 2 times a week
3%	1 - 2 times a month
22%	Never
38%	Didn't answer



### Do they speak to people in your area?

9%	Everyday
16%	1 - 2 times a week
22%	Every few months / Never
47%	Didn't answer



### Do they have access to a computer?

9%	Yes
40%	No
51%	Didn't answer



### Do they have access to the internet?

50%	No
50%	Didn't answer

