



Changing the experience of older people with a learning disability in their communities

Link Me project report

Mencap Northern Ireland

November 2017





Introduction

Mencap is the leading voice of learning disability in the UK. Everything we do is about valuing and supporting people with a learning disability, their families and carers.

Our vision is a world where people with a learning disability are valued equally, listened to and included. Within the next five years, we want more people with a learning disability to have stronger friendships and relationships, and be better connected to their communities.

Older people with a learning disability experience many health and social inequalities which make it particularly difficult for them to participate in community life. Reduced social networks put them at greater risk of social isolation, exclusion, depression and ill-health.³ The Link Me project sought to address this through a programme of tailored support which promoted their inclusion in local activities.

This report provides an overview of the key achievements and learning from Link Me and makes some recommendations for policy and practice. Participants' voices are highlighted throughout in stories and quotes.

A **learning disability** is a reduced intellectual ability and difficulty with everyday activities which affects someone for their whole life. The level of support someone needs, depends on the individual person and the extent of their learning disability. With the right support, most people with a learning disability can lead independent lives.¹

In the UK, 2.16% of adults are believed to have a learning disability.

In Northern Ireland, there are 42,000 people with a learning disability, including 31,000 adults.²

About Link Me

The Link Me project was developed to address the complex and ingrained issue of isolation and loneliness amongst adults aged 55 and over with a learning disability.

By supporting them to participate in local activities, the project aimed to ensure that older people were enabled and empowered to lead fuller, connected lives as valued members of their local community.

The project ran for just over 4 years, from July 2013 to December 2017. It was delivered in Omagh, Strabane Carrickfergus, Larne, Newtownabbey and Kesh areas.

Link Me was funded by the Big Lottery Fund and delivered in partnership with Volunteer Now and Omagh and Carrickfergus Senior Gateway Clubs.

Volunteer Now is the lead organisation which works to promote, develop and support volunteering across Northern Ireland. The Senior **Gateway Clubs** provide social and leisure opportunities for adults with a learning disability, and promote their social inclusion in local communities.

Link Me - Key Features

- Taster sessions provided participants with information about the range of activities available in their local community.
- Support and activities were individually tailored, based on needs and interests.
- Participants set personal goals that they would like to achieve, for example, to be more confident; make new friends; get out and about more; feel healthier; or not to be so lonely.
- Trained volunteers supported participants to connect with their chosen social and recreational activities across various settings such as libraries, community centres, leisure centres, churches and many other community settings.
- Participants were encouraged to continue with activities independently; and supported to register with community transport providers.
- Graduation events throughout the project celebrated participants' achievements.

‘Older men and women with a learning disability have few opportunities to take part in leisure pursuits. This is due to the health problems they face, perceptions of them as a lower social status group, exclusion rather than inclusion within their community and lack of support to access leisure activities.’ (Bamford, 2005)⁴

Link Me - Achievements and Learning

About the participants

Figure 1: Link Me participants by gender

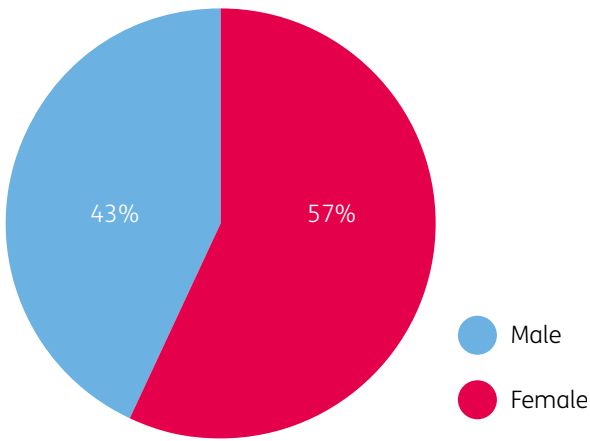


Figure 2: Link Me participants by area

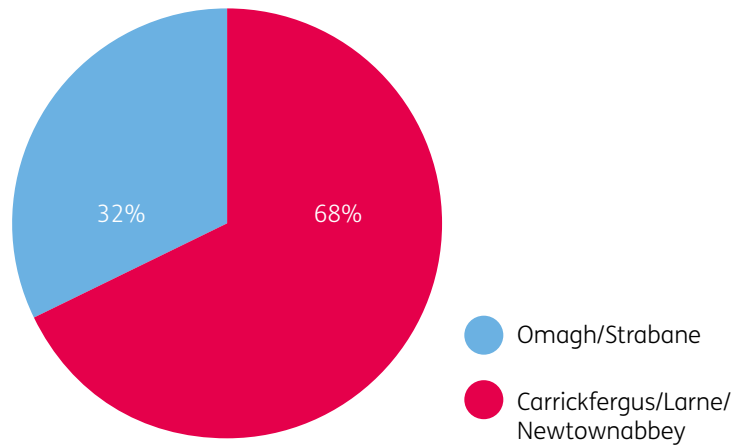
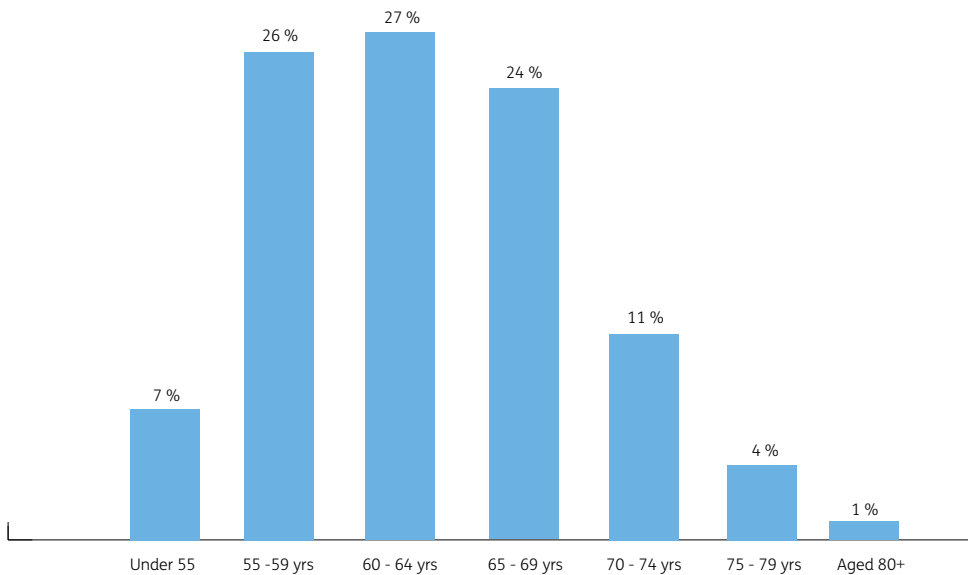


Figure 3: Link Me participants by age



- The Link Me project supported 81 people, of which 43% (35) were male and 57% (46) were female (Fig 1).
- With regards participants across the two programme delivery areas, 32% (26) were supported in the Omagh / Strabane area; and 68% (55) in the Carrickfergus / Larne / Newtownabbey area (Fig 2).
- Participants ranged in age from 51 to 88 years;⁵ with the majority (84%) aged in their fifties (33%) and sixties (51%) (Fig 3).

1. Increasing confidence and reducing isolation

- 94% participated in activities in their local Gateway Club
- 88% participated in activities in their local community
- 53% can now access activities in their community independently of Link Me
- 52% feel less lonely and isolated than when they joined the project
- 64% feel more confident than when they joined the project.

All the Link Me participants attended at least one form of activity, either in their local Gateway Club or in the wider community. In terms of recognising achievement and goal setting, everyone achieved based on their individual capacity to do so. Activities were wide ranging and included arts and crafts, exercise / dance classes, book clubs and church groups. For participants, key factors related to improved confidence included:

Being outside the house

For many of the participants, their home environment is where they spent the majority of their time. Taking part in Link Me initiated a fundamental change to individuals' lives in enabling them to leave their homes, try new activities and meet new people.

'I am out'

Making new friends - with and without a learning disability

Being able to meet with other adults who had a learning disability was particularly welcome, especially when taking part in activities for the first time. Significantly, in accessing mainstream activities across a range of settings, many were also able to positively engage with members of the community beyond learning disability circles.

'I met people like me'



'I made new friends'

'We knit and we natter'

'It's been enlightening to witness the interaction between older people with a learning disability and their peers in the community. For many of their peers they simply have no experience of encountering disability never mind older people with a learning disability.'
(Library staff member)

'...participation in the Knit and Natter improved confidence and increased the number of friends around. The end of the programme means she will struggle to maintain the friendships and that is sad.'
(Manager, residential home)

Using transport

In addition to supporting participants to walk to venues in close proximity to their home, a key element of the project was introducing people to a mix of public and private transport options. In doing so, it is anticipated that many will continue to attend events and take part in new activities, both in their immediate community and further afield.



'One of the great things to come out of the Link Me Programme is the fact that Heather is less nervous now about going to her respite centre. The programme has made her much more confident and she looked forward to every single session. I would go as far as to say that it brightened her day'.
(Iris, Heather's sister)

John's story

Hello, my name is John and I live in my own home with my mother. I started the Link Me project in October 2016 and since then I have made great progress accessing my community. Before the Link Me project I was not part of any group within my local community and wasn't sure what was available.



The Link Me project officer asked me what kind of activities I would like to do. I told her that I liked bowls. When I was younger and lived in England this was my favourite past time. Since I moved here I have not been able to find or join any clubs to keep up my hobby.

The project officer found an activity called boccia⁶ which was quite close to my home. She helped me access the Disability Action Transport Scheme, which me or my family had not heard of and supported me from my home to the activity, during the activity and back again. I really enjoyed the activity and decided to join the group. I now go to the boccia group independently, twice a month and I really enjoy it.

2. Improving health and wellbeing

- 59% of participants took part in more physical activities
- 64% of participants reported an improvement in their health and wellbeing

Many participants described themselves as feeling happier, healthier and more independent after taking part in Link Me. Feeling more included and able to voice their thoughts and opinions contributed to their overall sense of wellbeing. The benefits for participants of accessing a new range of sporting and recreational activities (and making new friends) were also evident to those closest to them.

‘All of them demonstrated greater levels of independence and confidence, enjoyed a greater scope and number of friends and all enjoyed positive physical and mental health benefits’. (Manager, residential home)

‘Participants generally felt stronger, fitter and more independent’. (Staff member, leisure centre)

‘Gerard has enjoyed both the bowling and the boccia events; and his physical and mental health has improved as a result of the activities and the friends he has made’. (Gerard’s mother)

Since joining the Link Me project I am happier, healthier and I have noticed a change in my mood....I am happier more often now!



Bridget's story

I live in a supported living house and attend a day centre five days per week. Before the Link Me project I did not attend any activities outside in the community where I live and so my goal was to get out and about in my community more!

I took part in a lot of group activities with the Link Me project so that I got to know the staff and volunteers better. I enjoyed all the activities but especially liked the arts and crafts and dancing.

When Link Me found a knitting class for me to go to I was very happy, but worried how I was going to get there by myself. Link Me staff supported me to walk to the knitting class and helped me to cross the road. I met new friends at the knitting group and sometimes I brought my jigsaws or colouring to show my friends too! Link Me helped me to get access to a bus (community transport) to help me get to and from my knitting group and now I go every week by myself. The bit I enjoy the most is talking to my new friends.

I also now attend boccia every week, and meet with my new friends for tea and biscuits afterwards as well. I have learnt to play boccia well and even passed a test to help me teach other people boccia too.



3. Involving volunteers in supporting older people

- 60 volunteers were recruited and trained to support older people with a learning disability
- 88% of participants accessed new community based activities with support from volunteers

Trained volunteers were critical to the success of the Link Me project in supporting the integration of older people with a learning disability into their local community. While also supporting participants to choose their own activities and take control over access to leisure opportunities, the volunteers themselves gained a great deal from the experience.

The general consensus across participants was that the volunteers had made an enormous difference in enabling them to join in activities, learn new skills and make new friends. Their support was particularly important when participants were going somewhere new for the first time, and in helping them progress to attending activities independently.

'In order that the project was able to be fully inclusive, relief staff were employed on occasion to support participants' with additional or more complex needs.'

Personal care and administration of medication were not relevant to Link Me and Challenging Behavior now termed Behavior of Concern. (PBS) .

'Volunteer Now has been delighted to be involved in the Link Me project. Training staff, assisting with recruiting volunteers, developing the accredited volunteer training and being on the Project Board, has meant we have seen first-hand the importance of the role of volunteers in the project. The highlight for us has been carrying out a Volunteer Impact Assessment towards the end of the project where we gathered evidence of the huge impact that the volunteering has had on the Link Me participants as well as on the volunteers themselves. Summed up by one participant - 'It's a good idea to have a volunteer, they are able to support you to go places and to explain things to you.' (Sandra Adair, Director, Volunteer Now)



Breda's story

I used to see people out and about helping people with learning disabilities and I thought I would always love to do that. I have a daughter who has a learning disability and I would love to work with adults with a learning disability. I like to meet new people and also see what's out there in the community that my daughter might be interested in. That is what inspired me to volunteer with the Link Me project.

When I first started with Link Me I supported older people with a learning disability in a group setting. I then moved onto one-to-one support with a gentleman called Stephen. I was responsible for teaching Stephen how to walk from his home to a local leisure facility in the Omagh area.

After gradually reducing my support, I am very pleased to say that he is now walking to and from there independently. I have to say that I was a bit nervous when I knew he was going on his own but he did really great! I communicated to him using Makaton to say well done and that I was very proud of him. He smiled and signed back that he was also very happy that he walked by himself!

Now that Stephen is independent I hope to support some ladies to attend their knitting class on a Tuesday evening in the local library, with the aim of reducing my support until they become independent.

The training that I received was really good and it really helps! It gave me a good insight into different things such as if circumstances arise, how to manage.

Volunteering gives you such a good feeling and volunteering for Link Me is great to be part of.



4. Engaging local communities

- 94 community-based organisations included older people with a learning disability in their activities

While some parents and carers were initially reluctant for their loved ones to engage more widely with services other than Link Me staff and volunteers, much progress was made in terms of participants' level of engagement. A significant number of organisations in the local community liaised with Link Me across all sites to include older people with a learning disability in their activities.

Activities attended were wide-ranging in nature. They typically included music, dance / exercise classes, bowling, swimming, pottery and knitting. Participants also went to coffee mornings, lunch clubs and social evenings, as well as trips to the cinema, art exhibitions and the Christmas market.

Local libraries, Gateway Clubs, churches and leisure centres were key, accessible venues for participants. In particular, many continue to attend Gateway Clubs and activities in the library like 'Knit and Natter' and 'Mindful Colouring' groups.

'Omagh Gateway club was delighted to be part of the Link me project. It has been great in supporting older people with a learning disability to get out and about and be more included in their local community. In regards to the extra support offered to the club in terms of volunteers and activities, it really couldn't have come at a better time for us and has been invaluable. Not only are older people with a learning disability more included and visible in our club but it has supported the sustainability of the club for years to come.' (Ruth Patterson, Treasurer Omagh Senior Gateway Club)



'It has been a privilege for Carrickfergus & District Senior Gateway Club to be involved in Link Me. This project has enabled older members of our surrounding areas to participate and integrate within Gateway and the community. Without the project these members would have been less involved and isolated. The project has been very positive for all involved.'

'The support the Link Me project has given Gateway has been outstanding. Our members that are the beneficiaries of the project are now fully involved in all aspects of our club and community. We hope that the great work that has started with them will continue to grow.' (Thomas Haighton - Leader, Gateway Club)

Many of the community groups spoke positively about how their own lives had been enriched and simply 'made better' by their engagement with the Link Me project. A particular highlight was the Carrickfergus Learning Disability Pride event in May 2017. It demonstrated that there is growing recognition that people with or without a disability are individuals and should not be defined by their disability.

Learning Disability Pride

In autumn 2016, Carrickfergus Senior Gateway Club was awarded £5,000 from the Big Lottery Fund's Celebrate programme to hold Northern Ireland's first ever Learning Disability Pride event.

They worked in partnership with Mencap and Mid and East Antrim Borough Council to organise and deliver the event in Carrickfergus in May 2017. Local businesses, community and voluntary organisations all rallied round to ensure the day was a great success.

Link Me participants, staff and volunteers were among the 5,000 plus people from across Northern Ireland who took part in the parade and enjoyed the range of activities provided in the Castle car park afterwards.



Project Learning

- While more than half of the participants will continue to successfully access activities in the local community after taking part in Link Me, this will not be possible for everyone. Many of the older people have multiple and complex needs which require ongoing support; and often family members are not able to provide the support offered by the Link Me project, including travel costs.
- The Link Me model will provide useful learning for wider practice, especially for volunteer-led work in the community with adults who have a learning disability. However, given the complex nature of many older peoples' needs, without some dedicated resource the capacity to roll-out / replicate the Link Me project is limited.
- The complexity and range of participants' needs and consequential supports was perhaps under-estimated. This proved to be a particular challenge in involving and retaining volunteers. Volunteer Now have explored how best to support volunteers working with complex needs. This has included a series of seminars involving a range of voluntary organisations, with a view to identifying best practice guidelines.
- Beyond Link Me, for many of the participants their local Gateway Club will continue to be their chosen leisure opportunity of choice. Maintaining this without additional investment will likely prove challenging.



Recommendations

- Older people with a learning disability should be identified as a priority group in policy related to promoting social inclusion and emotional well-being, particularly those with multiple and complex needs.
- More investment is needed by government on local initiatives which help prevent isolation and loneliness amongst older people with a learning disability by supporting them to develop social networks and access community activities.
- Local agencies should be supported through the Community Planning process to work together to share learning and adopt strategies and interventions that effectively tackle isolation amongst older people with a learning disability.
- Local councils should ensure that information about community services, activities and events is routinely available in formats accessible to older people with a learning disability.
- There needs to be improved data collection about the local population of people with a learning disability, including by age range, so that information and services can be targeted appropriately.



¹ www.mencap.org.uk/learning-disability-explained/what-learning-disability

² These approximate figures have been calculated using learning disability prevalence rates from Public Health England (2016) and population data from the Office for National Statistics (2017).

³ British Institute of Learning Disabilities (BILD) (2014) Supporting Older People with Learning Disabilities: A Toolkit for Health and Social Care Commissioners. BILD, Birmingham.

⁴ Bamford (2005) Equal lives: Review of policy and services for people with a learning disability in Northern Ireland. Department of Health, Belfast.

⁵ Based on 74 participants whose age was recorded.

⁶ Boccia is a disability sport that tests muscle control and accuracy. Players propel balls to land close to a target ball.



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