

Building Bridges - Social Prescribing with people with learning disabilities and autistic people

"Often the role of social prescriber is a bridging role – helping people or encouraging people to join this thing happening here."

About the project

In recent years, since the advent of NHS England's [Universal Personalised Care](#), social prescribing has become well-embedded in local areas. The role of link workers was developed and recruited to, and they now play a key role in local systems, based in Primary Care or hosted in the Voluntary Sector. The role and approach has its roots in community connecting and [asset-based community development](#). Often people reach out to their GP for help with concerns that have social causes or can be better supported in their community than through medical interventions. A GP or other person in primary care can refer a patient to a link worker. The link worker's role is to get to understand what is important to the person and what health or wellbeing issues they want to address and connect them with opportunities or groups in their local communities that will make a difference to them.

Social prescribing has the potential to reduce health inequalities and build social capital by connecting people to community groups, and support services in their area, to help with both mental and physical wellbeing. People with learning disabilities and autistic people experience huge health inequalities compared to the general population. Given the potential of social prescribing, we wanted to understand whether people with learning disabilities and autistic people have access to social prescribing, and, when they do, what makes it work well.

About the Valuing People Alliance and the Health and Wellbeing Alliance

The Valuing People Alliance is one group that make up the [Health and Wellbeing Alliance](#). We are made up of 6 organisations - Learning Disability England LDE, BILD, NDTi, VODG, Paradigm, Respond and the Foundation for People with Learning Disabilities (FPLD). We work together, and with our wider networks of people with lived experience and work roles, to ensure that the voices of people with learning disabilities and autistic people, and those who know or support them are heard, and considered across health, social care and community sectors. This project is one of 3 we did during 2022-23 as part of our work with the HWA.

What we did

Research and Reading

Reading about what others had done helped give us some context and led to contacts to speak to about more work. We did the following:

Looked online for services available and reports written about social prescribing for people with learning disabilities or autistic people.

Looked online



Gathered a range of reports which were about social prescribing for specific groups or inclusion and diversity.

Gathered a range of reports



Looked at resources aimed at link workers and GPs about including people with learning disabilities and autistic people in social prescribing.

Looked at resources



This showed us that not much is written about people with a learning disability or autistic people and their experiences of social prescribing. Some of the reports that looked at inclusion and equalities in social prescribing mentioned that more needed to be done to make sure these groups had access to social prescribing and that reasonable adjustments were made. Some research has been done into the experience of autistic people, and recent papers include exploring how people define wellbeing, and how community connections can be built to support this for autistic people. Some areas have done pilots and projects to give people with learning disabilities access to social prescribing and developed resources for other link workers.

The documents and websites we read are collated in the Bibliography at the end of this report.

Surveys

We ran two surveys to call for evidence and to hear the experiences of different people.



Survey for link workers and social prescribing services. This was completed by 16 people.

- 8 social prescribing link workers
- 1 Occupational Therapist working in a social prescribing service
- 6 people in different voluntary sector roles
- 1 person who has had a social prescription
- 10 people who completed the survey said they had supported someone with a learning disability, and 8 said they had supported an autistic person with social prescribing. The others said they hadn't experienced supporting these groups.



Survey for people with lived experience and their families or supporters. This was completed by 37 people:

- 8 people who had a learning disability
- 10 autistic people
- 14 Family members
- 5 other friends or supporters
- 20 of this group said they knew what social prescribing was (the other 17 said no, or didn't answer)
- 7 out of the 37 said they had had experience of social prescribing themselves.

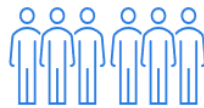
We have included the responses from people who completed the surveys in our learning below, about what works and what doesn't work well.

Conversations and focus groups

We spoke to 25 people with different roles and experiences 1:1 or in small groups.



3 people with lived experience who had experienced social prescribing



6 people from community groups or places who have social prescribing referrals



3 people who manage or run social prescribing link working services



7 link workers



3 people looking into or doing research about social prescribing



3 people from NHS England involved in social prescribing and personalised care

A note on the limitations of this project

This was a small research project with limited time and resources. We did not have the capacity for an exhaustive literature search, and whilst we circulated our call for evidence widely through our networks, on social media, and through social prescribing online networks, the participants are those who chose to respond, rather than those we sampled and approached. The numbers we heard from are, therefore, quite a small sample of those who might work in or have experienced social prescribing. We cannot estimate how many or what proportion of people have these particular experiences, whether it is working well for more or less people. We also cannot guess how many people who have learning disabilities or are autistic are given the opportunities that social prescribing can provide. However, the messages we heard about what helps and what hinders people with learning disabilities and autistic people from having a good experience and positive impact from social prescribing were clear, and the messages were repeated across different groups of people.

What we heard about what works well

“Talking to my link worker helped me to understand the difficulties I had been having, especially with executive functioning and look for ways to support me with these, rather than continuing my struggle alone. Finally, someone else was doing the hunting for solutions for me rather than me struggling to make myself heard! (an autistic person describing the positive impact after autistic burnout from living in a neurotypical world)



Person-centred conversations about what mattered to people, and what their interests and wishes were key to getting the support and matching people to the right activities.

“There is, at least in my case, a person centred approach. That being the environment and activities reflected interests and positive experiences that I already had and so could engage in with ease. Also I think social prescribing works well in the city where there are lots of activities and organisations, and a culture of diversity” (autistic person who had experienced social prescribing)

- Where people needed support to try something new, the link worker could go with them the first few times.
- If people needed support to keep up an activity, it worked best when they already had support in place day to day.
- People with learning disabilities were able to benefit and thrive when they were connected with the right activities or groups consistently.

A young autistic man was referred to join a local men’s shed. He was in school but showed a keen interest in woodwork above all. The man running the men’s shed asked about what he would need to stay safe with all the tools and helped the young man and his supporter to use things. For the first months, the young man was quiet and hardly spoke. But gradually he got more confident and now regularly has conversations with the other members and is proud of the things he’s made such as a bird box. (From a participant who has people referred to his men’s shed in a focus group)



It worked best when the link worker or supporter shared with the group the person joins as much about them as possible- what they love, what they are good at, what they want to try, and what support they need. This is especially important if there are health and safety issues to consider.

Preparing the group to welcome the person, and using a buddy for them in the group helps people settle in well.

The shadowing and making introductions is important and helps establish a connection. It is by chance sometimes that you find a right fit – for example, one young woman I linked and accompanied to a mainstream art club and the person running it just happened to be a specialist learning disability teacher, so the young woman fitted in really well through this knowledge from the art club’s lead. In other successes it is just the club willing to learn how to include people with a learning disability into the club. (link worker in a focus group)

- Several projects link up social prescribing with Annual Health Checks for people with learning disabilities. People have a chance to meet a link worker after their AHC, or even that day in the surgery.
- We heard how much getting connected to a new group of people with similar interests, built people’s confidence and improved their mental wellbeing.

One man shared how he had been going through a difficult separation situation and trying to establish shared parenting arrangements. He went to his GP feeling depressed and stressed. ‘The GP said you shouldn’t have to go through this alone and referred me to social prescribing.’ The link worker helped to find and connect him with family advocacy support through the process and ensured he had the tools and connections to manage. His mental wellbeing improved dramatically after that. (Person with learning disability in focus group)



Keeping it local helped people get to and sustain involvement.

Link workers shared how sometimes they would “travel train” someone; helping them learn the bus or train route to an activity helped people gain confidence, skills and independence.

What we heard about the challenges

“I spoke to a link worker on behalf of my son, however we were offered activities that were either not local, or which we have yet to find out more about before trying them, given that my son has challenging behaviour and group activities can be too overwhelming or unpredictable for him.” (Mother sharing experience about social prescribing for her son)

- Suitable local activities aren't always available
- Some people who needed support to stay involved in an activity didn't have someone to support them - either families were already busy, or they couldn't get paid or volunteer support
- The challenge for link workers was connecting people to services that can continue supporting them and sustaining these positive connections.
- Link workers found themselves having to help people apply for a personal health/personal budget or for social care support directly. Sometimes this process took a long time or didn't result in support.
- Many link workers had limited fixed times or numbers of appointments they could spend with each person. Often this wasn't enough time when someone needed more support to get to know them and support them to try and engage in new things.

“I have high functioning Autism and it should be tailored to that person's interests, not used as a way to fill voluntary positions that you can't fill, also I have physically disabled so it should be tailored for that, it's also about attitude” (autistic person who shared experiences in our survey)

- Reasonable adjustments are key. For instance, if someone is referred to a gym, they might need extra support to get to know the equipment to use it confidently. We heard this doesn't always happen.
- Sometimes it is hard to motivate people, especially as people got more used to staying at home during covid. Some people have lost the confidence to go out and be with others. Having the time to build rapport and help people build confidence to go out one step at a time takes longer than a usual link worker referral.

A young man who has learning disabilities, who had a great time at the college he attended but missed out on his last year due to Covid. Now he is an adult – in his early 20s, but he is stuck and isolated. Again, there is tension at home. He is not in touch with any service/around supporting him, there doesn't seem to be any social care out there. (Shared by a link worker in a focus group)

- In some cases, community groups that used to run have closed due to lack of attendance. This is in part down to Covid where people have been isolated for so long that they have 'fallen off the radar' and lost their connections.
- Community groups and activities that work well can reach capacity and don't have the investment to grow, or to build in more support for more people to be referred.
- There can be particular challenges in rural settings where there are fewer things going on which might be further away from where people live or harder to travel to.
- Travel to places could be a real barrier.
- Sometimes activities had a cost, and many people or families could not afford the cost of the activity or the travel.

Discussion points

General or specialist link worker roles

It doesn't seem to matter whether the link worker is there for the whole local population, or specialist – if they are person-centred and can make reasonable adjustments around the person. Those who had more flexible time or number of appointments with people could adapt their approaches and support. It was often the case that specialist link workers who were funded to support people with learning disabilities or autistic people had more flexibility in how they were able to work. But the mainstream link workers we spoke to also found ways to support people and were incredibly person-centred and could work with people just as well.

Specialist or mainstream community activities

We heard that link workers refer people to both services specific to their support need, as well as mainstream services and groups there for everyone. It depends on what is available locally to meet the person's interests, and their preferences and what they want to achieve through their social prescription. Mainstream opportunities work just as well as specialist. Link workers that get to know the person, and then connect and get to know the group and environment, can make the joining process go smoother. Depending on the person's support need and the capacity of the group, the person might need to have a supporter with them.

"Finding out about what matters to them, what interests and skills they have, matching them to activities in their community which are inclusive, but not exclusive to people with a learning disability and or/ Autistic. Contacting service providers or visiting them in person to make sure the activities are suitable, accessible and discuss with the activity provider whether any reasonable adjustments can be made." (Linkworker- about what helps things work well)

Social prescribing services need the right information about, and introduction to the person. They also need investment, e.g. for adaptations, or to build capacity to include people. Some get overwhelmed with referrals when social prescribing is working well in the area.

Social Prescribing as part of a local system

Social prescribing seems to work best where other services in the system are also working well. Many link workers we spoke to shared examples of referrals to them from people in acute distress, or needing much more intense support than they could offer. They described having to act as a social worker, an advocate, and a support broker all in one. This meant sometimes referring someone to a social worker and helping them get a personal budget or personal health budget. And sometimes the voluntary sector community groups they wanted to refer people to were at capacity and didn't have funding to include more people.

Some important messages about making sure social prescribing works for people with learning disabilities and autistic people

What Link workers and social prescribing services can do



Work flexibly within their boundaries e.g. on the time spent and ways of connecting with people.



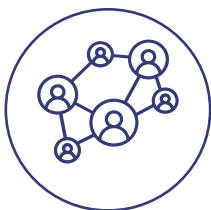
Person-centered approaches to wellbeing they are already using is key to getting to know and supporting people well



Strengths-based approaches and understanding what matters works brilliantly for people with learning disabilities and autistic people



Engage with people's families or other supporters



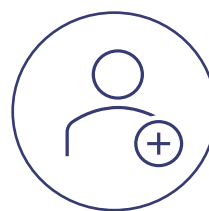
Spend time with community groups to check they can make the adaptations needed



Find training or support if link workers want to learn more about learning disabilities or autism



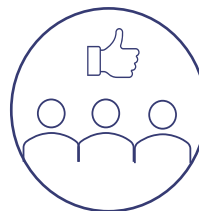
Explore mainstream as well as specialist groups and activities or services for people



Draw in support from volunteers or paid support to help the person sustain their involvement if they need that



Consider peer support- link up 2 people interested in the same kind of thing, so they have someone to go with

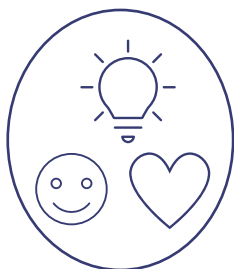


Buddy people up with another member of the group



Ask for specialist input if you need to know more

What people and their supporters can do



Think about **what you really love to do** or are interested in



Tell the link worker and community groups as much as you can about what matters to you and any support you need



Try to get support to go to things if needed – this might be from a family member, friend, volunteer, or paid supporter



Ask the link worker to **keep things local**
Or for help to learn a new route



Be brave to take
new steps and
try new things



Supporters -
keep things
consistent so the
person can make
friends and
connections in
the place they go.



**Supporters can
help by
motivating** the
person and
helping them feel
brave if they get
cold feet, trying
new things can be
scary

What community groups can do



**Be curious and
ask as much as
you can about
the person**, what
they love and
what they need
support with



**Let the person
visit first** when
the group isn't
there so they can
get a feel for the
place and space



Get a buddy in
place to help
them be
**welcome in the
group**



**Be brave and
welcoming** and
people will
become as much
part of the group
or activities as
anyone else



Link people up with someone else in the group if it's possible for them **to travel together**



Apply for **local grants** if you need to make **reasonable adjustments** or adaptations to the environment or equipment

What commissioners and funders can do



Build flexibility into the contracts for link workers so they can offer more time or appointments if needed



Make grants or investments available to **community groups** so they can **build capacity** and put in place **reasonable adjustments** for people to be part of them

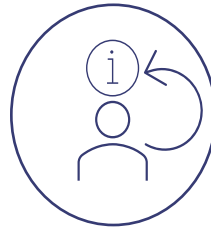


Either commission some **link workers with expertise in learning disabilities or autism**, or **fund local advocacy or self-advocacy groups** to support local link workers if they need any specialist input

What GPs can do



Use **Annual Health Checks** as an opportunity to tell people with learning disabilities about social prescribing and **connect them to a linkworker**



Make social prescribing available to people **awaiting an autism assessment** or other diagnosis



Tell families and carers about social prescribing. A link worker may be able to connect them up with peer support or other support, whatever age their child is who has a learning disability or is autistic

Acknowledgements

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