Engage, Listen, Act: How to Meet the Needs of People with Learning Disabilities in the New Forest and Surrounding Area

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University of Winchester, January 2024

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Executive Summary:

This document reports the findings and suggestions made by researchers at The University of Winchester regarding current and future practice at New Forest Mencap. The research explored the needs, wants and aspirations of people with learning disabilities who live in the New Forest and the surrounding areas in Hampshire, England with regard to their access to activities.

New Forest Mencap were keen to evaluate the needs of people with learning disabilities in the New Forest and surrounding area regarding their activities and support. New Forest Mencap wished to better understand the needs, wants and aspirations of people in this under-served community to create evidence-based strategic aims and operational outcomes. Evidence-based funding bids

will then be created by New Forest Mencap to better meet the stated needs of people with learning disabilities living in the New Forest and surrounding areas.

Summary of Key Findings

We reviewed academic and practice literature. We then interviewed people with learning disabilities in a range of activity settings across the New Forest and surrounding area.

Areas of strength were found in the activities that New Forest Mencap currently offer, above and beyond the skills those activities aimed to develop. Suggestions are made for future activities and for future practice.

Overall, New Forest Mencap delivered vibrant, attractive experiences to a diverse range of people. A range of activities were offered, the content of which were found to positively impact wellbeing, specifically regarding the building, maintaining and developing of confidence through positive relationships with others.

People with learning disabilities were able to communicate clearly what different activities meant for them and what other activities and support they would like to have the opportunity to access. They were able to evaluate whether they had enough to do in a week or would like to do more. They also identified barriers to accessing activities, including lack of transport, and time from support workers being used up by practical activities rather than promoting the building and maintenance of social skills that the research participants wanted to develop.

Volunteering or engaging in paid employment was much valued by those participants who were currently volunteering or working or had done so in the past. However, such opportunities were often short-lived, and some participants had not thought of work as a possibility for them.

Alongside the activities that New Forest Mencap provides, the ways in which people with learning disabilities were encouraged by staff and volunteers to make choices, try out new things, question how barriers could be overcome and express their opinions were observed as genuinely empowering.

The activity sessions provided opportunities for parents and family members of people with learning disabilities to access advice and support from New Forest Mencap staff and volunteers.

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Acknowledgements:

This research and final report would not have been possible without the willingness of those who went out of their way to organise and take part in interviews and those who shared their thoughts and experiences so fully and frankly. We offer thanks to the following people:

> Jackie Lillywhite, New Forest Mencap
>
> All the New Forest Mencap staff and volunteers who ran the activities groups we visited.
>
> We would like to offer particular thanks to the many people with learning disabilities who agreed to take part for their contributions to the research and to this report.

Purpose of the research

This research project sought to provide an evidence-based approach to understanding the needs, wants and aspirations of people with learning disabilities in terms of the activities they currently undertake, or would like to undertake in the future. The research focused on the following two key areas for consideration, which were the research aims:

1. To identify the unmet needs of people with learning disabilities in the New Forest and surrounding area.

2. To identify ways in which New Forest Mencap could meet those needs.

This report provides practical suggestions for strategic and operational planning. New Forest Mencap intend that findings from the research will inform delivery of best practice and be used to influence policy and priorities for funding applications for people with learning disabilities to enable them to live their best life.

New Forest Mencap intend to use the findings in the following ways:

- To better understand the needs of the current under-served community of people with learning disabilities and to broaden New Forest Mencap's reach.

- Through better understanding of the barriers and hurdles associated with this under-served community, New Forest Mencap will be better able to meet the needs of other people with learning disabilities, particularly those who are traditionally considered to be 'hard to reach'.

- To ensure that the organisational culture is embedded in valuing the aspirations and lived experience of people with learning disabilities themselves.

As a result of the participatory approach used in this research, it is hoped that New Forest Mencap staff, support workers and people with learning disabilities themselves will become interested in undertaking their own research. It is also hoped that the wider dissemination of this report will engage a range of charities, organisations, social care commissioners, social care workers and educators in considering their own cultures and future directions for policy and practice in services.

New Forest Mencap's Mission

New Forest Mencap is a stand-alone charity which is part of the Mencap family. New Forest Mencap supports people in the New Forest and surrounding area with learning disabilities (of all ages) and their families. They do this through the provision of a range of time limited grant funded services, including an Information, Advice and Guidance service, a Life-skills project, an employment and volunteering project and various social opportunities which include activities and groups and Gateway Clubs which are essential for mental and physical wellbeing. New Forest Mencap is responsible for achieving all its own income which is a large task for a relatively small organisation (in 2022/23 income was £170K) but which is providing a large amount of front facing services – circa 2,700 attendances by circa 150 people with learning disabilities and also support/information to circa 40 parent carers/family members. They currently employ circa 3.5 FTE staff.

Background to the research

Cuts to services have meant that services to meet the needs of people with learning disabilities have been cut and are under continued threat of further cuts. In October 2023, Hampshire County Council announced plans to cut its budget by another £132 million by April 2025, with further cuts planned after this time. They are among many councils which are planning to have to move to providing only services which they are legally obliged to fund, to minimum levels. This is due to lack of funds, raised

costs of services and greater numbers of people in need of services (Hampshire County Council, 2023). A recent consultation by Hampshire County Council highlighted the ways in which people with learning disabilities could be particularly disadvantaged by further cuts. Issues of concern included an inability to be able to afford to socialise or go out of their own homes, thus experiencing greater social isolation and worsening wellbeing (Hampshire County Council, 2023). Providing services which are demonstrated to be needed, to provide value for money and which make a meaningful and demonstrable difference in people's lives is therefore of fundamental importance.

In addition, people with learning disabilities are less likely to be visible, active, vocal or involved in their communities. They are often exposed to negative attitudes and behaviours from others which results a lack of confidence in engagement with mainstream activities, and, unless a discrete, pro-active, accessible and meaningful provision (such as New Forest Mencap) is available, social isolation and poorer mental wellbeing may be the result. This is particularly the case for people with learning disabilities who have been shown to often experience stigma in all areas of their lives (Harrison et al, 2021). Discovering what people with learning disabilities want for themselves and from their lives will always be more time consuming and 'resource hungry' than with the typical population. For this project, differentiated resources were required, significant time was needed to build rapport and getting into contact with local people with learning disabilities was more difficult due to a lower usage of current communication methods e.g. social media, surveys and digital methods. All these barriers have traditionally led to a lower level of research participation for this community and thus less understanding and awareness than for one without these needs and barriers. In addition, researching with people whose voices are seldom heard who live in relatively remote or isolated locations (such as some areas of The New Forest and surrounding areas) presents its own difficulties for researchers in terms of time taken to travel to and from these locations within often quite short timeframes.

The research focused on the following two key areas for consideration, which were the research aims:

1. To identify the unmet needs of people with learning disabilities in the New Forest and surrounding area.

2. To identify ways in which New Forest Mencap could meet those needs.

The research questions to meet those aims were:

- What are the needs, wants and aspirations of people with learning disabilities in the New Forest and surrounding area?

- What gaps could New Forest Mencap could fill and in what ways?

This report now provides a background literature review, information regarding the methods chosen, the findings of the research, a research summary, recommendations, feedback from New Forest Mencap regarding the research project and a conclusion. Useful references are provided, as is a copy of the adapted SONES measure used in this study.

Background Literature Review

Harrison et al. (2021) undertook a systematic review and synthesis of all the available academic literature related to the social networks and activities of people with learning disabilities. Relevant background literature from that review and synthesis is provided below:

Social networks can be defined as 'opportunity structures' (Forrester-Jones and Grant, 1997, p. 7) or interpersonal relationships (Sullivan et al., 2016). Social networks can contain a range of people, including partners, family, friends, acquaintances, professionals and neighbours.

Hill and Dunbar (2003) reported typical network size for non-disabled adults as over 100 contacts dispersed across different areas of life. Social network size for adults with learning disabilities however is smaller and more restricted; Forrester-Jones et al. (2006) in their study of 213 individuals, found an average network size of just 22 contacts and 'dense' network membership restricted mainly to other adults using learning disability services.

Social networks are key to social identity for adults with learning disabilities (Heyman et al., 1997) and social networks are vital for social functioning, self-esteem and quality of life (Bhardwaj, Forrester-Jones and Murphy, 2018). Social networks are also associated with happiness, self-confidence, mental health and leisure activities (Forrester-Jones et al., 2006) and are deemed crucial for facilitating social inclusion (van Asselt-Goverts et al., 2013; White and Forrester-Jones, 2019). Strong, supported social networks can build people's skills and positively impact on the identities of adults with learning disabilities (Beadle-Brown et al., 2016). Adults can find their relationships are enhanced through much-needed supportive networks (Hall and Kramer, 2009) in diverse situations such as living on locked wards (Fish, 2016); being mothers (Stenfert Kroese et al., 2002); or experiences of older age (McCausland et al., 2018). Social networks can also combat loneliness (Callus, 2017), which itself can have a detrimental effect on health and wellbeing. For adults with learning disabilities and their families, the importance of social networks for positive health, wellbeing, social inclusion and tackling disadvantage across the life-course cannot be understated

(Bele and Kvalsund, 2016). Despite this, non-disabled people rarely consider the importance of social networks for adults with learning disabilities (Dunbar, 2015; Emerson and McVilly, 2004; Hall, 2005).

An examination of relevant theories can aid our understanding of the lack of inclusion adults with learning disabilities experience. Goffman (1990, p. 15), for example defined stigma as, 'an attribute that is deeply discrediting', and pointed out that when considering the ways in which the self can be presented in society and the social 'norms' that are created in relation to a sense of 'usual' self, identity, institutions and societies, 'it should be seen that a language of relationships, not attributes, is really needed'. In his consideration of human relationships, broadly from the perspective of symbolic interaction, he showed that the power inherent within stigma and labelling can be dynamic and have significant negative impacts on the lives of those who are stigmatised (Goffman, 1991). One critique of Goffman's work is the need to focus not only on what causes this situation, but also on how it can be overcome, in particular when social networks and relationships which, 'emphasise acceptance of differences' are formed between disabled and non-disabled adults (Bogdan and Taylor, 1987, p. 33). One such principle which is used to try to develop positive relationships with self and others is normalisation, developed by Wolfensberger et al. (1972). They suggested that perceived social deviance identified adults with learning disabilities in several specific ways: as sub-human organisms; as threatening; as menacing; as objects of pity; as holy innocents; and as eternal children. They proposed that a focus on supporting adults with learning disabilities in 'ordinary' day-to-day places, with 'ordinary' adults was more likely to succeed in reducing stigma and tackling the perceived social deviance of adults with learning disabilities. This in turn would lead to the opening up of possibilities for adults with learning disabilities to build and maintain wider, reciprocal social networks, with a broader range of people, thereby increasing the wellbeing of people with learning disabilities and enabling them to take part in and contribute to, their wider communities. Critiques of normalisation suggest that its absence from sociological and ideological agendas render it inadequate. Challenges include possible gender-bias (Williams and Nind, 1999) and that disability-

specific spaces can be used to celebrate disabled identities and resist social discourse around what constitutes ordinary vs stigmatised locations. Chappell (1992) suggested normalisation reflects the views of powerful (non-disabled) professionals and their understanding of typical ways of behaving rather than the views of disempowered and impoverished people with learning disabilities. A lack of clarity of concept among policymakers and practitioners and of empirical evidence are important concerns, though could be argued to be less important than understanding inclusion as a human rights issue (Culham and Nind, 2003). Despite their flaws, using the concepts of normalisation and stigma highlights that social networks can therefore either <u>protect against or entrench</u> the effects of stigma and segregation for adults with learning disabilities. Using these theories adds to our understanding of the possible reasons for a lack of focus on the social networks of adults with learning disabilities.

While previous research has considered the effects of poor social networks on the health and wellbeing of groups of adults with learning disabilities, institutional closures in the 1980s and 1990s, day services closures in the 2000s and austerity policies since 2008 have impacted the nature of social networks and their related activities for adults with learning disabilities.

Key Findings from the Literature Review:

1. **Networks and Activities**

Over the timeframe of these studies, it was suggested that public spaces where friendship activities were found to be more likely to occur (Emerson and McVilly, 2004). Forrester-Jones et al.'s (2004) findings concurred; they concluded that being employed was a significant factor in increasing wellbeing, social network size and diversity. Day services, where these were available and accessed, were spaces where adults with learning disabilities could engage with others outside their home environment, but networks remained small overall (Bhardwaj et al., 2018; Cooper, 1998). Many

studies highlighted that even though policies with their basis in normalisation principles, such as community care and person-centred planning, had a beneficial impact on the lives and networks of adults with learning disabilities, the aim of full inclusion in terms of community presence and relationships that early authors had argued for had yet to be achieved (Cooper, 1998; Donnelly et al., 1997; Robertson et al., 2001, 2007). They found that although activities had shifted location from institutional to community settings, these were still segregated from 'ordinary' activities enjoyed by non-disabled people. Activities often took place as a group of adults with one staff member all undertaking the same necessary household activity such as shopping or took place in day service settings. Both these types of activity, while important, provided adults with limited opportunity to create relationships or build networks as they were unlikely to either meet new people, or to meet a diverse range of people (Lippold and Burns, 2009). Contacts with new neighbours did not necessarily lead to inclusion (Perry et al. 2011); and adults with learning disabilities remained criticised by others across settings and by different network members (Forrester-Jones et al., 2004, 2006; Hulbert-Williams et al., 2011). Where networks increased significantly and included higher numbers of non-disabled members, this was in a workplace setting and networks took time to develop as familiarity grew (Forrester- Jones et al., 2004).

2. Friendship and Activities

Forrester-Jones et al. (2006) highlight the importance of allowing individuals with learning disabilities to report on their own social lives, rather than relying on staff accounts; individuals being the best judge of who is included in their social network. Gregory et al.'s (2001) study found participants valued relationships which were friendly, where people got on with one another and did 'ordinary' activities together, such as shopping, working and conversing with neighbours. In that vein, supportive relationships, where they existed, were recognised and valued by people with learning disabilities (Bhardwaj et al., 2018). This could be seen in people with learning disabilities' definitions of friendships particularly. For example,

> *We say that a friend is someone who is there for you when you are stuck, and someone who is gentle, kind and helpful. You can tell your friends things you do not want other people to know. It is also about having people to spend time with and do things together.* (The Money, Friends and Making Ends Meet Research Group, 2012, p. 130)

3. Activities and power

People reported finding a range of systems difficult or impossible to negotiate (Power and Bartlett, 2019). Many people did not have access to digital systems, and many could not read or write, so needed support from people in their networks without learning disabilities in order to access and negotiate systems which are vital for wellbeing (such as welfare benefits, housing and finances). When this was lacking, people could easily experience a slide into debt and crisis without the social networks and relationships which could slow or stop the slide into powerlessness (The Money, Friends, and Making Ends Meet Research Group c/o Liz Tilly, 2012).

Policies introduced to promote adults with learning disabilities as employers of their own staff, in principle appeared to afford the opportunity to move into more powerful roles. Yet people still experienced stigma and powerlessness even in these relationships (Hamilton et al., 2017), thereby thwarting possible opportunities for social network development.

4. Activities and the Importance of the Role of Support Services

Where Local Authorities had reduced or removed the services they provided, often voluntary sector groups had been a <u>vital source of support</u>. Despite positive policy developments, when experiencing cuts to their services, people with learning disabilities appeared thwarted in their lives and opportunities for relationships without significant additional support from others (Power and Bartlett, 2019; The Money, Friends, and Making Ends Meet Research Group c/o Liz Tilly, 2012). Adults with learning disabilities needed support not only to access social activities and networks but also to access a range of support services (Sango and Forrester-Jones, 2018).

Negative impacts of cuts to services on existing networks were reported. Lack of money and irregular hours of support led to reports of boredom (Power and Bartlett, 2019; The Money, Friends, and Making Ends Meet Research Group c/o Liz Tilly, 2012), isolation and harassment by strangers or neighbours. Hamilton et al. (2017) and The Money Friends and Making Ends Meet Research Group c/o Liz Tilly (2012) suggested that any positives of the Personalisation agenda were greatly diminished by significant cuts to social care budgets. As Michael explained, 'they're trying to stretch people as far as they can without spending any money to give people support' (Hamilton et al., 2017, p. 294).

Proactive support and reciprocal social network relationships were required to prevent problems occurring in the first instance, with for example reading letters, paying essential bills, shopping, accessing food banks and budgeting on very limited or zero finances until benefits were available (The Money, Friends, and Making Ends Meet Research Group c/o Liz Tilly, 2012).

As austerity policies continued, relationships and meaningful networks were perceived as being unimportant in the eyes of funders (Hamilton et al., 2017, p. 301). It was therefore unsurprising that people with learning disabilities could feel, 'Sometimes it seems like we are always in a battle' (The Money, Friends, and Making Ends Meet Research Group c/o Liz Tilly, 2012, p. 131).

Conclusion to the Background Literature Review

The literature suggests that there is a clear link between undertaking meaningful activities, building and maintaining social networks, positive identity, wellbeing, confidence and inclusion. In times of cuts to services, welfare, support and care, the importance of the role of support services, including charities such as New Forest Mencap, cannot be understated.

The Research

Sampling

Posters were produced and people with learning disabilities and their families were invited to take part in this project. As is good practice in research with people with learning disabilities, straightforward images and photos of the researchers were included. Information about the project which included easy-read images and symbols was provided. Participants were all engaging with at least one activity group offered by New Forest Mencap.

Method

Face-to-face interviews with people with learning disabilities were considered to be the best way to collect and analyse quantitative and qualitative data in order to meet the research aims. Four sites and seven different activity groups were visited 12 times by one or both researchers between September 2023 and January 2024. Interviews typically lasted one hour. People with learning disabilities could choose the place and time of the interview. Most people with learning disabilities were interviewed individually in a quiet space at the activity they were attending. Some chose to be accompanied by a friend or colleague, family member, staff member or volunteer. One person was interviewed using a family member as a sign language interpreter. One person was interviewed online using a connection set up by the New Forest Mencap Development Officer during a group activity session.

The Social Network and Employment Scale (SONES) (Forrester-Jones et al., 2006), provided in Appendix 1, was used as a recognised, well-established and validated measure for recording details of each person's activities and networks. The SONES was used with participants regarding details of their daily lives, including their activities and social networks. This was used as it included asking participants how many people they knew across a wide range of personal, casual and professional

areas of their network and how often participants saw those network members. It also included questions on what activities were undertaken by participants at what days and times throughout the week, and questions on employment. Questions on how many people supported participants with different aspects of their care and qualitative questions regarding each part of the SONES were also included.

In addition, people with learning disabilities were shown 26 cards each depicting a different activity (see Table 1). Each activity was represented in both pictorial and word form and was explained by researchers where required. Interviewees were asked whether an activity was important or not important to them, something they currently did or would like to have the opportunity to do in the future.

Analysis

The quantitative data was inputted into SPSS, a well-respected computer programme which provides reliable statistical analysis of quantitative data. Data were analysed using descriptive statistical analysis (Pyrczak and Oh, 2018). This analysis provided a range of information regarding the activities people with learning disabilities enjoyed currently and those they would like to undertake in the future.

Qualitative data was analysed using thematic analysis (Braun and Clarke, 2022) to create themes related to the activities people undertook and what they valued from taking part in activities.

All statements in quotations marks "" are direct quotes from research participants.

Findings

40 people with learning disabilities were interviewed between September 2023 and January 2024. 19 people were male, 21 were female. One male participant did not complete the entire questionnaire. These research participants lived across the New Forest and surrounding areas and in a range of different accommodation types. 15 participants lived with a parent or parents and sometimes siblings as well; 14 lived in supported living situations; 9 in residential care; 1 participant lived with their partner and 1 lived alone with no formal support. This fits within a national picture where around half of 1.5 million adults with learning disabilities live with their families (Foundation for People with Learning Disabilities, 2023).

Activities

People with learning disabilities indicated their preferences for a range of activities. The following results in Table 1 indicate responses where people with learning disabilities stated they would like to undertake a given activity out of the 26 possible activities presented on the cards.

Table 1: Activities Positively Indicated by Research Participants

Activity	Number of research participants choosing this activity (N=39)	Percentage of overall research participants indicating positive response
Confidence building	30	77%
Learning how to stay healthy	28	72%
Learning how to make new friends	27	69%
Spending time with friends I know	27	69%
Learning how my money works	27	69%
Learning how to give my opinion	26	67%
Learning new things	26	67%
Cooking	24	62%

Going out in the evening	24	62%
Dancing	23	59%
Learning how to make choices	23	59%
Arts and crafts	22	56%
Learning Digital Skills	22	56%
Learning how to get information I need	22	56%
Understanding maths and numbers	22	56%
Improving reading/writing	22	56%
Learning how my support works	22	56%
Making or playing music	21	54%
Having a boyfriend/girlfriend	20	51%
Singing	18	46%
Keep Fit	17	44%
Doing drama/ acting	16	41%
Working/volunteering	15	38%
Gardening	13	33%
Spirituality	13	33%
Yoga	6	15%

For some activities, between 1 and 3 participants indicated they 'did not know' or would like to undertake activities 'sometimes'. Most often research participants who responded positively to an activity had undertaken that activity previously and would like to undertake it again or were currently undertaking that activity and wanted to continue with it beyond the current provision.

There was no significant difference between whether activities were positively indicated by men or by women.

Some participants attended day opportunities that provided a range of activities or had parents with the time and resources to put together a varied programme of activities. But for most participants the sessions and activities run by New Forest Mencap, two affiliated Gateway Clubs and other

voluntary organisations were a significant event in their week and sometimes the only external activity they engaged in.

Additional activities not represented on the cards that participants mentioned as enjoyable or important to them involved:

- walking dogs / looking after pets
- horse-riding
- sport / football
- Zumba
- playing pool
- bowling
- going to the pub
- attending parties
- cinema trips
- musical theatre
- going to the pantomime
- going on holiday
- food
- making cakes
- playing digital games
- clay model-making
- crochet
- understanding the dangers of the internet.

Each of these activities was mentioned by up to three participants. These activities were not specifically included in the standard questions regarding activities, but all participants were asked about their current activities, desires for possible activities as well as being asked to rate the activity cards used in this research. It may be that if these additional activities had been included in the set of cards, more participants would have indicated they would like to undertake them.

Spending Time with Other People and Building Social Confidence

Many participants said that they valued activities where they could spend time with other people.

"I like Gateway Club a lot. I like having lots of people around, it makes me happy."

[Researcher: What is the best part of your week and why?] "Getting out and meeting other people, making new friends. That's why I like digital skills and life skills."

Participants frequently highlighted that the desire to build their own confidence was related to knowing how to start conversations with people they did not know or in circumstances they couldn't control. One participant talked about freezing up when a taxi driver asked him a question:

"I feel I know too much about computers to come here (digital skills group) but I'm desperate for some sort of social life. I find it hard to have conversations unless it's controlled. [...] I can't do social skills. I need to learn and I need help with these."

For many participants, crowded places were particularly difficult places in which to try to start conversations with other people. This meant that they might need additional support from someone who understood them in such settings:

> "When I go wobbly, it's hard for other people to be with me. […] If people understood, it would be much easier for me."

Some participants who were new to an activity group had difficulty with entering the building or room because they lacked confidence in new settings and with new people. Staff and volunteers had worked for several weeks with one person attending an employment and volunteering workshop for example, so that after 6 weeks he felt comfortable enough to enter the room and stand by the door, engaging with activities from this 'safe space'.

Having a Boyfriend/girlfriend

For some participants the desire to be able to converse confidently with others they did not know was related to the desire to have a boyfriend/girlfriend. Table 2 indicates the number of people who told us they wanted a boy/girlfriend (Note: not everyone answered that question). Table 3 presents the number of participants who said they had a boy/girlfriend.

Table 2: Number of Participants Wanting a Boy/Girlfriend (N=38)

Gender	Wanting a boyfriend/girlfriend	Not wanting a boyfriend/girlfriend	Total
Male	10	7	17
Female	10	11	21

Table 3: Number of Participants who had a Boy/Girlfriend (N=39)

Gender	Has a boyfriend/girlfriend	Does not have a boyfriend/girlfriend	Total
Male	6	13	19
Female	10	10	20

Volunteering and Paid Employment

Fifteen participants (38%) said that the opportunity to volunteer or engage in paid employment was important to them. Volunteering and paid employment provided a structure to the day or week, the opportunity to use and develop skills, social interaction and the potential for expanding social connections beyond family, support staff and other service users. It is well established that people with a disability are less likely to be employed and that rates of employment among adults with a learning disability are particularly low. 6.6% of people with a learning disability living in South-East England and 5.5% of those living in the South-West were in paid work in 2022/23.

Ten of the people interviewed for this research (25%) were doing some voluntary work at the time of interview and 4 (10%) had a paid job. Volunteering most commonly took place in charity shops or cafes/food outlets either serving customers or more often washing up. One participant volunteered doing gardening and another did voluntary work on a farm. Two participants had previously

volunteered in charity shops, which they had enjoyed, but the shops had closed down. One advantage of volunteering was that it could be tailored to what the person felt comfortable doing:

> "I used to volunteer at a charity shop but it closed. I put the clothes out, not the till. I'm not very good with money. […] It was Monday mornings and mum stayed in town in case there were any problems."

Some participants said that they had done a lot of volunteering but wanted to be paid for their work. One participant worked 4 hours on one day every week doing kitchen and laundry work at a hotel but was not paid. Another participant who worked 4 hours on one day every week in a pub washing pots was paid but said others kept being promoted instead of him because, he was told, he was 'too slow' to be promoted. Other participants mentioned 'things happening' at previous places where they had worked but did not provide details, or applying for a job and not being told why they were unsuccessful. Some participants said that they had never thought of work as a possibility.

Barriers to Participation in Activities

Transport was an issue for many participants and the importance of having accessible and affordable transport was all too apparent within this study. Issues included a lack of public transport in the New Forest and surrounding areas, a lack of staff time available to support participants using public transport or drive them to activities and a lack of affordable alternatives such as taxis.

This meant friendships previously developed were no longer maintained. Without proactive support by others to use technology, friendships and social networks built over time simply drifted and were lost. Participants felt this negatively impacted their wellbeing and confidence. Activity groups were often only accessed with the support of parents willing and able to drive their adult sons/daughters to and from activity groups. New Forest Mencap provided taxis for some participants who live in parts of the New Forest and surrounding area which are particularly isolated, in order that

participants do undertake some meaningful activity. For the 2023 Life-skills group for example, slightly over 1/3 of the total number of attendees (27 out of 67) were provided with a funded taxi (i.e. free to them) to enable attendance. The distances ranged from a round trip of 3 miles up to a round trip of 30 miles and that course ran for 24 weeks. Without this essential funding for transport, these attendees would be unable to attend this Life-skills group.

The majority of participants in this research told us that on days and evenings when a New Forest Mencap activity was not taking place, they sat at home and were 'bored'.

Another barrier described by some participants was that allocated support worker time was not always spent on activities that the person with learning disabilities wanted to engage with. One person had selected 'Learning how to stay healthy' as something that was important to him. However, he had been advised not to take home fresh vegetables from a local food bank because his support workers would not have time within his allocated hours to help him prepare them. A New Forest Mencap member of staff helped him to think about challenging that and asking for his support time to be spent on the activity he wanted to do.

Other interviewees said that support worker time was taken up with practical tasks but not in helping them build the social and communication skills the person with learning disabilities wanted to develop.

Encouragement to Say What you Want and Need

Many research participants came across as confident in expressing their views and describing their experiences. For example, this participant had clear views on the adequacy of local provision of 'disability-friendly' spaces:

> "All the playparks are for children but are really lame. A park near me said it would be sensory and disability-friendly but it's not. I can't even access it. I would like the Council to do something around people who are disabled. [We need] adult disability-friendly."

Such confidence may have come partly from the interviews taking place in a familiar space and the approach being orientated towards ensuring the participant felt comfortable. But there were also many instances where a participant reported or the researchers observed New Forest Mencap staff and volunteers encouraging people with learning disabilities to communicate what they wanted or needed, as with the example cited on page 28 of the participant who wanted time with his support worker to be used to help him prepare fresh vegetables.

Supporting Families

Researchers observed parents and other family members asking for and gaining advice from the New Forest Development Officer at every group activity. This was a vital service for parents and the time and expertise taken to provide this advice should not be underestimated. Parents were often observed to need specialist support after being unsuccessful in their search for support elsewhere, or to simply not know where to turn when an issue with any aspect of their lives related to their adult sons/daughters had arisen.

Summary of Research with People with Learning Disabilities

New Forest Mencap was found to provide a range of opportunities for people with learning disabilities, many of whom were living in remote or isolated areas, to undertake activities of interest to them. Some activities focused on employability skills, others on gaining vital life-skills, some on gaining new skills and others on recreational activities undertaken with others. It was clear that participants in this study very much valued the skills they gained which had enabled some people to undertake voluntary or paid work, others to learn online safety and others to undertake new or favourite hobbies and interests. A key finding was the high value participants placed on having the opportunity to mix with other people who were friends and with staff and volunteers who could help them with daily problems of life. The desire of people with intellectual disabilities in this study to gain confidence so they that could extend their own friendship groups and social networks even further was clear.

New Forest Mencap were found to be providing a range of vital services which were filling in some of the gaps in people's lives: both of people with learning disabilities and their parents. These gaps included gaps in service provision, in meaningful activities, in missing knowledge and skills and in advice and advocacy.

New Forest Mencap provided a broad range of meaningful services which went beyond their funded duties. The input of volunteers and advisors meant that people with learning disabilities were gaining far more than the opportunity to gain new life skills or employment skills or to maintain skills in a hobby. Time taken by staff and volunteers to get to know people with intellectual disabilities, as individuals with individual interests and individual dreams, wishes, needs and concerns, was unfunded but vital. Taking the time to listen, engage and value individuals, and to build trusting relationships, enabled people with intellectual disabilities to have the confidence to learn and develop skills in communication, to build their confidence, to make choices, to advocate for themselves and to identify their own solutions to issues. Knowing they would be supported by New Forest Mencap workers in a range of areas in their lives was important to people with intellectual disabilities. New Forest Mencap was found to provide a platform for growth and wellbeing, working with individuals and groups to build their skills in social interaction in order that their lives were richer and more varied.

Recommendations

In relation to this study we recommend:

- New Forest Mencap are already doing meaningful work meeting needs of people with intellectual disabilities in the New Forest and surrounding areas. They need funding to maintain what they are currently doing before then expanding to consider the unmet needs of people with learning disabilities in the area who are not yet known to New Forest Mencap. The additional (and often unfunded) value New Forest Mencap adds to the lives of people with learning disabilities and their families has been highlighted by this research.

- New Forest Mencap provides further activity groups based on the stated desires of the participants in this study.

- New and current groups should include a strong element of confidence-building with regard to starting conversations and mixing with others.

- Groups which teach skills regarding how to develop and maintain relationships, including with a romantic partner, are needed. A men's group would also appear to be needed in this area.

- New Forest Mencap should continue to offer support regarding daily life problems for both people with intellectual disabilities and parents.

Conclusion

The literature review suggests that there is a clear link between undertaking meaningful activities, building and maintaining social networks, positive identity, wellbeing and inclusion. In times of cuts to services, welfare, support and care, the role of support services, including charities, cannot be understated (Harrison et al., 2021). This research has found that New Forest Mencap plays a vital role in meeting the needs of people with intellectual disabilities regarding their desires to engage with others whilst undertaking meaningful activities. These activities enhance their lives and social networks whilst building skills in a wide range of areas. On the rare occasions that people with learning disabilities are included in research, asking people themselves about their lives is seldom undertaken. This research study has also demonstrated the value to charities and funders of understanding the needs and desires of people with learning disabilities from the perspective of individuals themselves and the vital role that New Forest Mencap plays in valuing and meeting those needs and desires.

Feedback from New Forest Mencap

Mike Snell CBE, Chair of New Forest Mencap said "I was delighted to see the inclusive and imaginative ways in which the University of Winchester (UoW) researchers engaged with our members, leading in turn to significant numbers wanting to be involved. I am looking forward to receiving the report in January, the findings of which will contribute directly to our strategic priorities in the year ahead".

Jackie Lillywhite, Development Officer of New Forest Mencap said "This opportunity to work in partnership with UoW to research into people with a learning disability has been of great significance to us. Often research into this group is focussed on the cognitive development, the impact of therapies or educational interventions but this research is about what is important to local people with a learning disability to help them lives their best lives, straight from their perspective. Our partnership with UoW demonstrates to both people with a learning disability who draw on our services, parent/family carers and a wide range of other stakeholders that we are listening, understanding and ultimately intend to act on the experiences and feedback that is shared with us.   The two researchers we have been working with (Dr Rachel Harrison and Dr Sarah Earthy) have been professional, sensitive, flexible and committed to this research opportunity and in collaborating with us to improve our support for local people with a learning disability."

 New Forest Mencap will use the findings of this research in the following ways:

a. In the creation of a person-centred strategy for New Forest Mencap.

b. To achieve funding for New Forest Mencap to deliver projects and services to enable it to meet the kinds of needs identified and within the aims of the charity.

c. To create partnerships to meet the kinds of needs identified and within the joint aims of the partners.

d. To demonstrate that people with a learning disability want to and can self-advocate about their lives.

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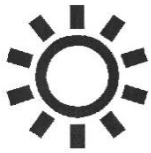
Place   **Date**

Name

Address:

1. **Please tell me about your care**

2. What does a typical week look like for you/what did you do last week? (List the things you do in the timetable below).

	Morning	Afternoon	Evening
Monday			
Tuesday			
Wednesday			
Thursday			
Friday			
Saturday			
Sunday			

3.   **What is the best part of your week and why?**

4.   **What is the worst part of your week and why?**

5.   **Do you have enough things to do?**

6.   **Are there any other things you would like to do?**

7. Employment Process

Which of the following best describes your work situation? (please tick **one** box)

Paid employment ☐   Volunteer work ☐   Primary homemaker ☐

Long-term sick ☐   Unemployed ☐   Student ☐

Training/apprenticeship ☐

If you are in <u>paid employment, training or volunteer work</u> please answer these questions.

What is your job/occupation? ……………………………………………………..

How many hours a week do you usually work in this job?………………………………

If you are a <u>student</u> please answer the remaining questions

How many days do you attend college each week? _____

Do you have any extra help with education? Please tell us what help you get and how often you use

it. _____

_____
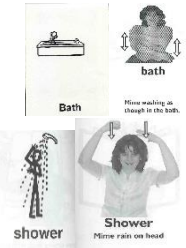
8. Social Networks

How many people do you have contact with from the following groups?

Network Member	Number	How many do you see weekly?
Service-User (LD)		
Paid Carer		
Specialist professional		
Ex- Staff		
Volunteer/Advocate		
Services Contact		
Partner		

Family		
Social Acquaintance		
Other people you know (without LD)		
Employer/Colleague		

9. How many people help you with the following?

	Number	Comments	How many of them do this weekly for you?
Personal			
Household			

Cleaning / Wash clothes Helping to cook			
Material Give money			
Decision Making choose Choose			
Confiding Tell / Worries Upset / Unhappy			
Company Friends			
Invisible			

Work			
Critical of you			

10. **How many of these people do YOU help?** *(write actual names)* **or 'they help you and you help them' (check on understanding of question about reciprocity)**

11. **Who are your close / special friends and why?**

12. **Are you happy with the friends you have or would you like more?**

13. **Does anyone help you / are there opportunities for you to meet new people and spend time with friends?**

14. **Do you feel you are part of the local community (just like the neighbours and other people who live around here)?**