



Mencap Northern Ireland

Elevate Mentoring and Grants Programme

‘Treat me well’ – reducing health inequalities for people with a learning disability

Project report

July 2021



About Mencap NI

Mencap NI is part of the Royal Mencap Society, which delivers services and provides a voice for people with a learning disability across Northern Ireland, England and Wales. Mencap was established in Northern Ireland in 1964.

We are a recognised provider of traditional core services such as children's, housing and employment, and more recently youth and community work. Each year we support over **2000** people with a learning disability, families & professionals through a combination of services and training opportunities. We also influence decision-makers to improve policy and practice within several strategic priority areas. These include health; social care; and reducing stigma and discrimination.

Throughout the Covid-19 pandemic we have utilised a blended approach via direct provision and online platforms to continue delivering vital services and inform government about priority issues for the people we support.

Introduction

Mencap's vision is a future where the health inequalities faced by people with a learning disability are eliminated, and individuals have access to the same quality of physical and mental healthcare as everybody else. This future would see an end to avoidable deaths¹ of people with a learning disability, and the creation of a health system that fully meets their needs.

People with a learning disability face many health inequalities, including avoidable deaths, long-term health conditions and an average life expectancy which is 16 years lower than the rest of the population (NHS Digital 2019). This has been further compounded by the disproportionate impact of the Covid-19 pandemic on those with a learning disability, including greater risk of death, increased isolation and loneliness, and reduced access to vital day services.

One of the primary ways to address health inequalities is to provide healthcare professionals with more training around learning disability. Likewise, people with a learning disability and their families, carers and support staff can be given information about their equal right to access good quality healthcare, and how to speak up if they do not receive appropriate support.

Advocating for this type of awareness and training are core components of Mencap NI's '**Treat me well**' campaign aimed at ensuring people with a learning disability get the reasonable adjustments they need in hospital. This can include using simple language, allowing extra time in appointments, and providing easy read information.

In 2019 Mencap NI were awarded funding through the Public Health Agency (PHA) 'Elevate Mentoring and Grants Programme' to deliver a series of 'Treat me well' workshops focused on reducing health inequalities amongst local people with a learning disability. The key learning points from these initial sessions can be found at Appendix One. A further grant was awarded in 2020, enabling us to build on this learning and adapt the original workshops for online delivery during the pandemic, including some focus on Covid-19.

¹ Mencap uses the term avoidable death for deaths that could have been avoided by the provision of good quality healthcare.

About this paper

This paper provides a summary overview of the **Treat me well** project Mencap NI delivered through the PHA Elevate Programme in 2020/21. In doing so, it presents key outcomes from the workshops delivered to healthcare professionals and people with a learning disability, family members / carers, and support staff.

1. Methodology

Informed by key learning from training we previously delivered through the Elevate programme, Mencap NI provided further workshops aimed at raising awareness about healthcare and learning disability to help tackle health inequalities in local communities.

In response to the ongoing Covid-19 pandemic, all workshops were delivered virtually using Zoom or Microsoft Teams. Sessions typically lasted up to two hours, and were specifically tailored to participants' needs and preferences. The workshops were co-facilitated by at least one person with lived experience.

15 workshops were attended by a total of 200+ participants

- **Treat me well: 7 workshops for health and social care professionals**
- **Know Your Rights: 8 workshops for people with a learning disability, parents / carers, and support workers**

• Evaluation

All workshop participants were invited to complete an online **evaluation** form. The purpose of the evaluation was to examine the effectiveness of both Treat Me Well and Know Your Rights workshops in providing information to participants and to identify areas for improvement. An online survey for each workshop was developed, and a link was provided to participants at the end of each workshop and also sent to all participants via a follow up email to ensure a good response rate. Each survey was anonymous and designed to be completed in under 10 minutes:

Treat Me Well: This survey had 38 items and focussed on healthcare professionals. A total of **41** participants completed this survey. A retrospective pre and post design was used to capture knowledge of key areas such as learning disability awareness, reasonable adjustments and consent and capacity before and after the workshop. Other areas covered in the evaluation included awareness of health inequalities and the impact of COVID-19 on people with a learning disability.

Know Your Rights: This survey had 19 items and was aimed at people with a learning disability, their parents and/carers. A total of **43** participants completed this survey. Key themes covered in the evaluation included the rights of people with a learning disability when accessing healthcare, COVID-19 and awareness of keeping healthy and well.

Additionally, participants of both workshops were asked their views regarding the online nature of the workshop, in order to ascertain the suitability of this format in the future. All quotations used throughout this report have been taken unchanged from participants comments which may include typing errors.

A focus group was held with three Inclusion Consultants who co-facilitated the sessions to capture their experiences of participating in the workshop. Participants were asked about their involvement in this project, what they enjoyed and what could have supported them better to do this type of work. This focus group was also held online and the sessions were recorded, with participants' consent, for the purposes of conducting thematic analysis.

2. About the workshops

Workshop Objectives

- 1) Understand what a learning disability is**
- 2) Be aware of the health inequalities and barriers people with a learning disability experience, especially during COVID-19**
- 3) Feel more confident supporting people with a learning disability when they are accessing healthcare services.**

Workshop Content

Treat me well

Learning disability awareness

- Introduction to Treat Me Well
- What is a learning disability?
- Recognising learning disability
- Communication.

Health inequalities and barriers to accessing services

- Ease and frequency of access to services
- Health inequalities and exacerbating issues in healthcare provision
- Increased risk of health problems
- Consent and capacity
- Impact of Covid-19.

Reasonable adjustments

- Definition and legal duty to ensure they are provided
- 10 most common reasonable adjustments / case study
- Hospital Passports
- Improving accessibility.

Know your rights

Workshops included health literacy (why health is important, who helps look after our health, how to find information about health, how to choose services for healthcare). The focus was on the role of hospital passports and how to complete them appropriately, and to increase confidence of service users to be assertive if their needs are not being met, including how to make a complaint or compliment to healthcare services.

Four key rights were covered during the workshop:

- (i) The right to be treated equally

- (ii) The right to accessible information
- (iii) The right to have reasonable adjustments
- (iv) The right to have support to make decisions.

3. Project Outcomes

Treat Me Well Workshops

“Treat Me Well is important because we want everybody to be treated well in hospital. I care about people with a learning disability and I care about the NHS. Treat Me Well provides lots of support and guidance to people with a learning disability so that they feel more safe, relaxed and able to go into hospital because staff will know how to support them better.”
(Inclusion Consultant)

Key Findings

- 100% of participants reported that their knowledge of learning disability increased after attending the Treat Me Well workshop
- 100% of participants rated their knowledge of health inequalities faced by people with a learning disability as excellent after the workshop
- The topic healthcare professionals were least knowledgeable about was reasonable adjustments, with over thirty percent of participants rating their understanding of the types of reasonable adjustments available as low (27%) or none (5%) before the training
- Results show over a 40% increase in participants rating their knowledge of reasonable adjustments as excellent after the workshop
- Healthcare professionals identified three key areas to reduce health inequalities for people with a learning disability as: (i) better communication; (ii) making reasonable adjustments and (iii) having greater awareness of learning disability
- Overall, 76% of participants rated the training as excellent and 24% of participants rated the training as good
- 100% of participants reported that they would recommend the Treat Me Well session to their colleagues.

Who responded?

A total of 41 participants completed the evaluation survey which accompanied the online Treat Me Well workshops.

Area: Participants of the Treat Me Well workshops were drawn from all Trust areas in Northern Ireland, with most working in Belfast HSCT (22.5%), Western HSCT (20.0%) and South Eastern HSCT (17.5%). Fewer participants were drawn from Southern HSCT (10.0%)

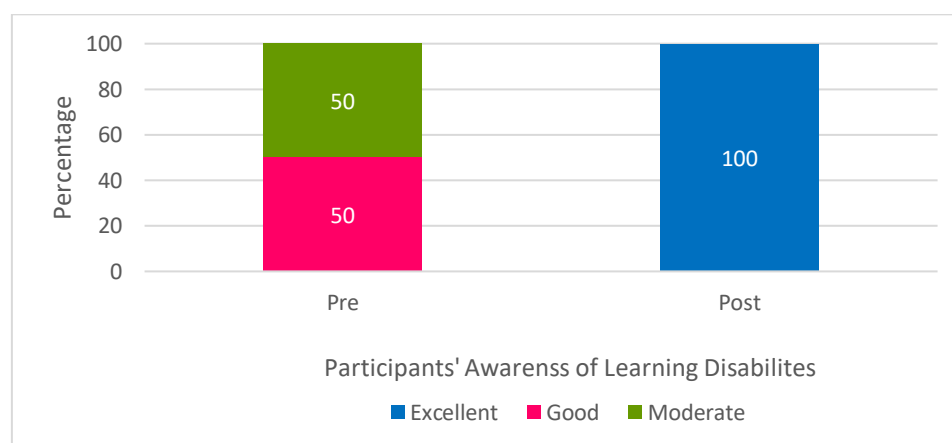
and Northern HSCT (7.5%) areas. Interestingly, 12.5% of participants worked outside Northern Ireland,² while 10.0% worked across NI.

Profession: Most participants were health and social work practitioners drawn from nursing, dentistry, general practice and social work. Other participants who attended included support workers, youth workers and administrative staff working in health and social care.

- **Awareness of Learning Disability**

Participants were asked to rate their knowledge of what a learning disability is. All participants reported that their knowledge of learning disability increased after attending the Treat Me Well workshop as shown in Figure 1.

Figure 1: Participants' knowledge of learning disabilities pre and post Treat Me Well Workshop



N = 41

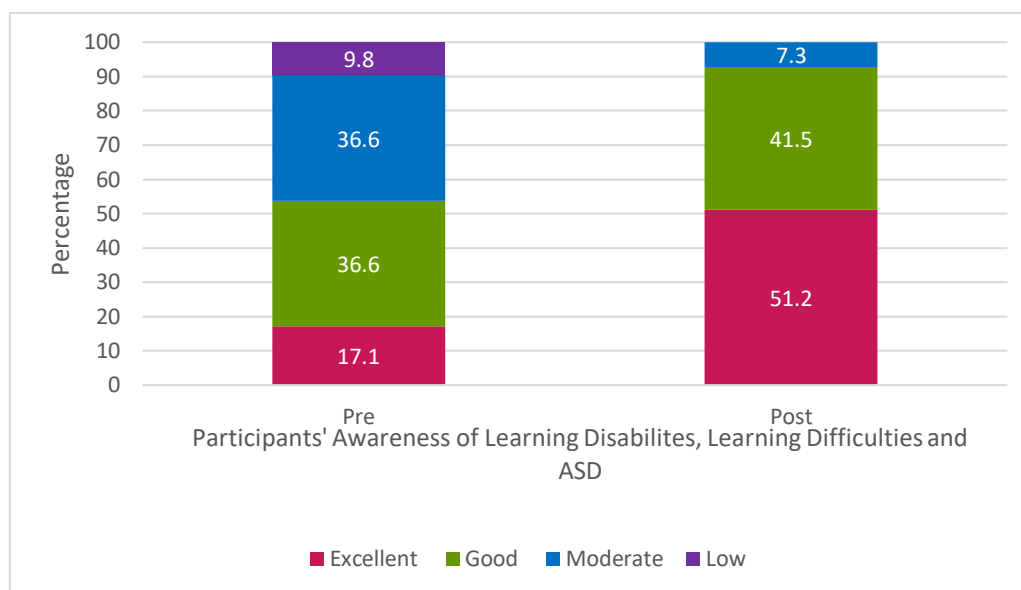
Similarly, results show that all participants' awareness of health inequalities faced by people with a learning disability increased by the same proportion with 100% of participants rating their awareness as excellent after the workshop.

Participants also reported that their knowledge of the differences between learning disability, learning difficulty, and autism spectrum disorders (ASD) had increased.

As displayed in Figure 2, 68% rated their own knowledge as excellent or good before the workshop which increased to 93% after the workshop.

² While intended for professionals living in NI, the open nature of the online recruitment led to registrations from outside NI.

Figure 2: Participants' knowledge of differences between learning disability, learning difficulty and ASD pre and post Treat Me Well Workshop



N = 41

• Specific Healthcare Issues

In terms of more specific issues relating to how people with a learning disability access healthcare, results indicate that participants' knowledge had increased after the workshop. Two examples of this can be demonstrated by these results:

1. Over a fifth (22.2%) of participants described their knowledge of reasonable adjustments as low, with only 14.6% rating their knowledge as excellent before the training. After the training, participants' understanding of what is meant as a 'reasonable adjustment' increased as all participants rated their awareness of reasonable adjustments between excellent (56.1%), good (36.6%) or moderate (7.3%).
2. 19.5% of participants reported that they had low or no understanding of issues related to consent and capacity for people with a learning disability before the training. After the training, the majority of participants reported an increase in understanding of consent and capacity with 48.8% rating their understanding as excellent, 43.9% rating their understanding as good and 7.3% rating their understanding as moderate.

• Actions to Reduce Health Inequalities

Participants were asked to reflect on what they had learnt from the Treat Me Well workshop that would help them in their work, and to consider examples of how they could reduce health inequalities for people with a learning disability. Three key themes were drawn from a thematic analysis of participants' responses as outlined below.

Better Communication: Participants identified that they had an increased understanding of the importance of communicating effectively with people with a learning disability. Participants were able to identify a range of examples of how to improve communication, including engaging directly with the person with a learning disability,

greater use of visual aids and easy read documents and the need for further staff training to focus on effective communication.

“Allowing people with learning disabilities to speak for themselves and make informed choices.”

“Treating person with respect and helping them understand what you telling them by finding a way to communicate so they can understand.”

Reasonable Adjustments: Participants also reported gaining a greater understanding of what reasonable adjustments are available for people with a learning disability. Greater use of the hospital passport was identified as a practical example of how practitioners could reduce health inequalities. Participants also provided other examples, such as booking double appointments to provide more time and consideration of the waiting environment as reasonable adjustments that would be beneficial in supporting people with a learning disability access healthcare:

“A hospital passport is a good resource in breaking down health inequalities for people with learning disabilities and booking a double appointment so the person with a learning disability has a longer time to listen and learn the information in the appointment.”

“Ensuring that you provide reasonable adjustments, like thinking about appointment time, routine, access, waiting room environment versus a side room environment to facilitate access to healthcare environments.”

Awareness of Barriers to Healthcare: Related to reasonable adjustments was the greater recognition by participants of the major barriers people with a learning disability can face when accessing healthcare.

- **Mode and Format of Workshop Delivery**

Due to the COVID-19 pandemic, all workshops were delivered online. This provided the opportunity to capture participants’ feedback about the online delivery of training generally, with specific reference to evaluating elements of this workshop such as the length of workshop, pace and quality of material. The top **three** elements of the training that participants reported being very satisfied with were:



85% were very satisfied with the presenter communication style



76% were very satisfied with the quality of the content



65% were very satisfied with the videos used in the workshop³

³ Due to technical issues online, not all sessions included any/all videos.

A total of 63% of participants reported they were very satisfied with the input from Inclusion Consultants. This was underlined through the positive qualitative feedback, as the majority of participants reported that listening to the lived experiences of the Inclusion Consultants was what they enjoyed most about the online training. Participants found their input particularly beneficial, as the Inclusion Consultants related their own experiences of accessing healthcare to the issues being presented in the workshop. Comments included:

“I love the co-productive approach. I found it really insightful to learn from the lived experience of individuals with learning disabilities within healthcare environments and society. I thought that was a great way to show the benefits of co-production and how to improve service provision according to the lived experience of these services.”

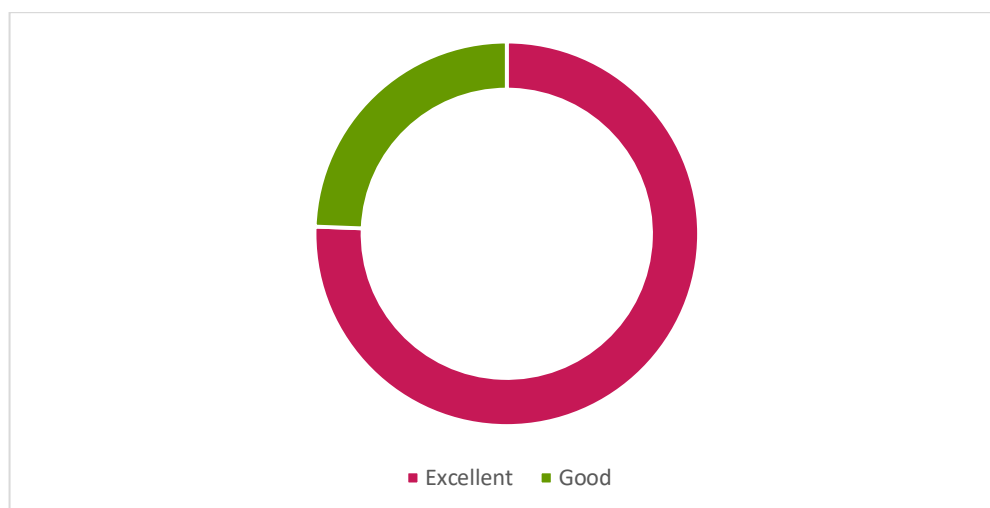
“The layout of the presentation was great. I thoroughly enjoyed listening to all three presenters. The ladies who had a learning disability, brought a personal approach which was fabulous!”

Participants also commented that this approach demonstrated how co-production can work well in practice. Other comments about what they enjoyed about the online training included the mixed media used and the use of polls to gauge awareness throughout the session.

- **Learning for the Future**

Participants reported high levels of satisfaction with the training overall, with all participants reporting that they would recommend the Treat Me Well session to their colleagues. As shown in Figure 3, 75.6% of participants rated the training as excellent and 24.4% of participants rated the training as good.

Figure 3: Participants’ rating of the Treat Me Well Workshop



N = 41

Although there were high levels of satisfaction with the workshop, participants were asked what they enjoyed least about the workshop in order to gain insight into any improvements that could be made for the future. Thematic analysis of the qualitative comments found that, in addition to experiencing technical difficulties, participants did experience three main challenges with the online training:

- **Adapting to online training:** Some participants indicated that they did not enjoy online training in general and reported a strong preference for face to face training
- **Greater Interaction:** Participants reported that more discussion within the session would have been beneficial, with suggestions of using breakout rooms or more planned time for discussion
- **Time Management:** Participants acknowledged there was a lot of content to take in within the session and suggested that this made the session feel too long, or that it would be beneficial to hold the workshop over two sessions.

Co-Facilitator – Case Study



My name is Aine Owens and I am 24 years old. I have been working on the Treat Me Well Elevate project as a co-facilitator. As well as having a learning disability, I have a rare chromosome disorder. I have a job and am supported by Mencap on the EmployAbility2 project. I go to a day opportunities service, and am also involved in some drama and other social and support groups, including ones I have helped to set up to support people with rare chromosome disorders.

I am proud of who I am and I wouldn't change anything. For me, having a learning disability means I just need to process information a little longer and that I may need some extra support with some tasks. My learning disability has never stopped me from reaching my goals. The negative side of having a learning disability is other people's negative attitudes or lack of awareness, and I have previously been treated unfairly. But these experiences have made me very passionate about speaking up for people with a learning disability especially those who may be scared or non-verbal.

My role in the Elevate project was:

- Promote the workshops by recording a video to invite people to come along
- Involvement in putting the workshop content together
- Co-facilitate workshops - speaking about my own experiences.

Topics I helped explain in the workshops:

- What a learning disability is and is not
- What reasonable adjustments are and why they are important. For example,
 - having a quiet place to wait for appointments
 - someone coming to tell me that it's time for my appointment instead of my name flashing up on a screen
 - looking at my hospital passport to find out more about me and what matters to me, instead of speaking to my mum or jumping to conclusions.
- The importance of communication and how to make it more accessible, as I can sometimes struggle to find the words and might need extra time. Sometimes people think this is because I don't understand the conversation and they look to my mum instead of me, but I just need healthcare staff to be patient with me.
- I was able to share some of my childhood and adult experiences with parents to offer them hope for the future as their child gets older.

I found it good working online because:

- I didn't need to travel and this helped me not have anxiety about travelling
- I had more time to myself when I was not working

- I had my notes for presenting on my laptop which meant I could look at them instead of a big group of people which made me feel more confident. Sometimes I didn't need the notes and by the last workshop I didn't use any.

Changes to healthcare that I think would really make a difference:

- Staff listening to us as individual people, not assuming what our needs are based on what they know or think they know about learning disability
- I would love to see more training in healthcare settings for learning disability awareness because there are lots of different staff in healthcare and they all play a part in providing care and can all help make experiences better for the patients.

Know Your Rights Workshops

Key Findings

- All participants reported they understood the information about COVID-19 in this session to some extent, with 84.8% of participants reporting that they understood well, and 15.2% stating that they understood some of the information
- 73.8% of participants reported they understood well the healthcare supports available with 23.8% reporting that they understood some of the information
- Three quarters of participants reported that they understood the information well about their rights when accessing healthcare (75.6%), reasonable adjustment in a hospital setting (73.2%) and how to use a hospital passport (70.5%).
- 77.5% of participants indicated that they would tell others to take part in the Know Your Rights Session, with 20% not sure.
- 71.8% of participants rated the workshop as good with 25.6% rating it as ok.

Who Responded?

A total of 43 participants completed the Know Your Rights evaluation drawn from all five Health and Social Care Trusts in Northern Ireland. Over three quarters of participants had self-reported having either a learning disability (47.6%) or a learning difficulty (28.6%), with other participants identifying themselves as staff, parents or carers.

Know Your Rights

The main objective of the workshop was to inform people with a learning disability about their rights when accessing healthcare. Participants were asked to rate their understanding using a three-point scale of:

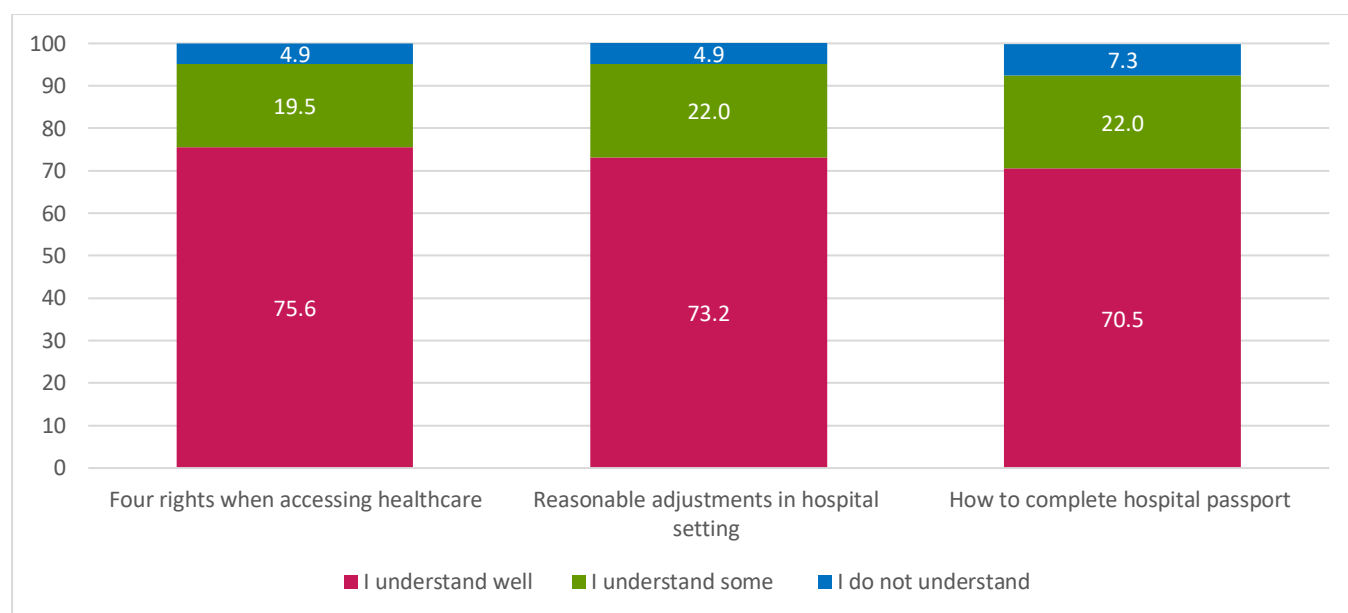
- 1. I understand well**
- 2. I understand some**
- 3. I do not understand**

Participants were asked to rate their knowledge of Northern Ireland's healthcare system generally, with specific reference to the healthcare support that is available for people with learning disabilities.

Most participants reported they understood well the healthcare supports available (73.8%) with 23.8% reporting that they understood some of the information. Similarly, most participants said they understood well the information about the healthcare system in Northern Ireland generally (63.4%), while 31.7% reported they understood some of the information and 4.9% said they did not understand the information.

Three indicators were used to evaluate participants' understanding of their rights related to accessing healthcare after attending the workshop as shown in Figure 4. On average, three quarters of participants reported that they understood the information well, while a fifth reported that they had some understanding of their rights. The remaining proportion of participants (5.7%) did not understand the information across the three indicators.

Figure 4: Participants' understanding of rights when accessing healthcare after the workshop



N= 43

The session also focussed on ways in which people with a learning disability can keep healthy, provided information about what help and resources are available to support participants if things go wrong and raised awareness of Mencap's Treat Me Well Campaign. Results show that most participants reported high levels of understanding after the training in the following areas:



90.5% reported good understanding of how to keep healthy



81.0% reported good understanding of available help and resources



81.0% reported good understanding of the Treat Me Well Campaign

- **Delivery and Format of Training**

In the final section, participants were asked to evaluate how much they enjoyed the workshop generally and how they rated the online format. Overall, most participants rated the workshop as good (71.8%) or ok (25.6%) with 2.6% reporting that they did not enjoy it.

All participants described the online format as positive with 67.5% reporting it as good and 32.5% reporting it as ok. Some contrasting views on the online nature of the training did emerge from the qualitative data, in that some participants continue to prefer face to face training. However, most comments related to the benefits of participating online in terms of the convenience, comfort and accessibility:

“All the information was clearly presented and explained so being online was not a disadvantage at all.”

“I find it so accessible to do these online and in the comfort of your own home.”

Most participants indicated that they would tell others to take part in the Know Your Rights Session (77.5%) with 20.0% not sure and 2.5% reporting no.

Inclusion Consultants Focus Group

The focus group with the three Inclusion Consultants was to capture their experiences of being involved in the project.

Types of Involvement: The inclusion consultants were involved in a broad range of activities which supported the training including: promoting the workshops; co-facilitating, and preparing presentations to share their experiences in areas such as using the COVID-19 app; diagnostic overshadowing; and using the hospital passport.

Positive Contribution: All participants reported that they enjoyed being involved this project as it provided an opportunity for them to contribute in positive way and make a difference to others:

“I enjoy talking to healthcare professionals and anybody who joined in so parents and other service users to let them hear, ‘You are not alone’ and also to share something of my experience with healthcare so they know in the future.”

“Sharing my experience, it was good for healthcare professionals to actually listen to us, people with a learning disability.”

“I enjoy making a difference in other people’s lives because with me sharing my experiences, it tends to put a light on other people’s families.”

Participants reported that they were well supported by Mencap staff to participate in this project and had no recommendations about improvements in this area.

Online Format: There were mixed views about participating in an online workshop. While it was recognised working online was necessary during the COVID-19 pandemic, participants felt that in some ways face to face workshops would be more beneficial:

“When you are out doing one to one, out doing it with the people, it has more value.”

“I prefer to have face to face meetings.”

It was also raised that participating in a workshop was made easier online as participants felt more relaxed:

“I like behind the screen. I find it easier to talk rather than in person.”

“You don’t feel pressurised or on the spot to come up with conversation like when you are in a crowd.”

Key Messages: The group was asked to consider additional key messages that healthcare professionals should know about when working with people with a learning disability. The group agreed the following areas should be highlighted to healthcare professionals in future Treat Me Well workshops:

- The use of medical jargon should be kept to a minimum
- There should be a recognised sign of distress for use in a healthcare setting
- Greater range of easy read material related to health should be available.

“Look beyond our disability and don’t always assume we need help with stuff. Explain to us slowly and don’t use jargon when you are talking to us.”

“We are human beings and deserve to be treated equally.”

Conclusion – Project Learning

- Building on the previous Elevate-funded programme, this latest project has assisted us in further developing our organisational capacity to increase awareness around health inequalities and learning disability.
- The programme also gave us a valuable opportunity to incorporate information about Covid-19 and associated resources.
- We further developed our model of co-design and co-facilitation with people who have lived experience; and are currently sharing this with Mencap nationally to inform delivery in England of the Oliver McGowan Mandatory Training in learning disability for health and social care professionals.
- Whereas the previous workshops have always been face-to-face, this project was all successfully delivered online. Having never delivered training in a virtual format before, the process of organising, preparing and delivering sessions online has ensured our staff learn and demonstrate new design and presentation skills.
- There were pros and cons in delivering sessions online. While on the one hand they were more accessible, and enabled us reach a wider range and geographic spread of participants, they had to be shorter to minimise screen time and maintain interest (with some planned content therefore curtailed). In addition, there were occasionally delays and disruption as a result of broadband and other technical difficulties. As illustrated in the case study, for some facilitators, the online format proved very beneficial in helping build their confidence to present.
- Previous learning helped us ensure these sessions were more concise and interactive, to develop suitable resources, and to adapt the length and content to be more appropriate for each group’s interests. We also modified our training and evaluation tools to capture feedback about the effectiveness of the different workshops and to identify areas for improvement. These tools were piloted and adapted for an online audience.

Next Steps

- **Moving forward, our health and well-being programmes (including Treat Me Well) will utilise a blended delivery approach by providing training and awareness in face-to-face settings, and online.**
- **We will continue to build on learning to date, and explore options to:**
 - **Work with community and other partners to expand our programme content and include more specific focus on dentistry, mental health, screening, pharmacy, and sexual health.**
 - **Incorporate more visual tools in our presentations, such as graphics, videos, sound and animation.**
 - **Build a web portal to provide tools, resources and training webinars.**
 - **Enhance the usability and accessibility of easy read online evaluations for people with a learning disability, and improve the mechanisms for collating data when using this format.**
 - **Incorporate some 'Train the Trainer' to upskill local community organisations.**
 - **Provide more opportunities for people with a learning disability to train and become paid co-facilitators.**

For further information about Mencap NI and our health and well-being programmes, please contact:

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