

TOGETHER ALL ARE ABLE: UNDERSTANDINGS OF HEALTH AND WELLBEING FOR PEOPLE WITH LEARNING DISABILITIES AND CONSIDERATIONS FOR FUTURE RESEARCH

Full Report

Qualitative Insight Team, Public Health – Wirral Council

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List of acronyms

QIT	Qualitative Insight Team
TAAA	Together All Are Able

Introduction

Background and methods

The Qualitative Insight Team (QIT) (Researchers: Jamie Halliwell and Jon Roberts, Analyst: Jen New, and Project support officer: Sam Burgess) met with the self-advocacy group Together All Are Able (TAAA) to support the development of the Health and Wellbeing strategy. The council's Health and Wellbeing strategy consists of 5 priorities, and this work contributes to priority 5 which is:

Create a culture of health and wellbeing, listening to residents and working together.

The aim of this priority is to shift the health challenges in Wirral by continuing to work together with local communities and organisations to make a difference for our residents. One way in which this is achieved is by building on the strengths and assets of people and communities to protect health in everything we do. In this work, we have adopted these approaches to explore ways in which the council can conduct research with people with disabilities and what health and wellbeing means to them.

TAAA work with self-advocates, carers, and professionals to make self-advocacy happen and it is run by and for disabled people. The TAAA members who were present throughout the development of the project identify as high-functioning and have a diverse range of disabilities and capacity to take part in this work.

The QIT and TAAA worked together to co-design research questions and methods which also helped to identify accessibility issues to research, and to make reasonable adjustments, where necessary. This will help the QIT on any future research projects with Wirral residents who have disabilities.

Project timeline

The project took place from July to November 2022 and the QIT and TAAA met 5 times over that period. It was agreed that TAAA would be reimbursed for their time and expenses for taking part in the work throughout this period and a contract was drawn up. A more detailed timeline, with the associated activities that took place that week is shown in Table 1 below.

Table 1: Project timeline and associated activities

Date	Activity
25th July	Introductions between Nikki Jones, QIT, and TAAA
8th August	Developing research questions around Health and Wellbeing
13th September	Reviewed research questions and discussed use of focus groups for research gathering
4th October	Focus groups with TAAA and immediate feedback
1st November	Presentation of focus group findings and reviewing photos

Co-production with TAAA

Research question development through TAAA engagement

To develop the research questions, the QIT shared with TAAA the core priorities for Wirral Council's Health and Wellbeing strategy. TAAA explained how it was important for the QIT to explain the HWB strategy to the group and to understand how this work feeds into its priorities.

TAAA suggested that for them it was important to start with questions about what health and wellbeing means to each person as it is different for everyone. TAAA provided the following suggestions for questions that could be asked:

- What does health mean to you?
- What does wellbeing mean to you?
- Do you have problems getting help?
- What challenges do you face in the following:
 - Contacting
 - Accessing
 - Experience
 - Impact
 - Anything else

Upon conclusion of these meetings, it was decided that we would pilot 2 questions with TAAA in which would be brainstormed in a focus group. These were:

1. What does health mean to you?
2. What does wellbeing mean to you?

Focus groups with TAAA

The QIT prepared an information sheet and consent form for TAAA to complete and the QIT went through both documents with the group step-by-step in the focus group session. TAAA were given an opportunity to ask any questions and have them answered by the QIT during these read throughs. The information sheet was read through at the start of the session and the consent form at the end.

To answer the two questions, the QIT split TAAA up into 2 focus groups: 1 with 3 participants, and another with 2 participants. Each group had 15 minutes to answer each question, and a total of 30 minutes to answer both questions. A researcher supported each focus group, with the analyst walking around both groups timekeeping, taking photographs and notes.

TAAA brainstormed their responses to each question using the pens and post-it notes provided and stuck them on flip chart paper. Researchers also wrote down and followed up any responses made by TAAA.

Written consent was provided by TAAA to use photographs that were taken in the focus groups for any future reporting on the work. TAAA had asked in previous sessions where and how photographs would be stored and used for the purposes of this work. The QIT explained that photographs would be stored within the QIT's OneDrive Teams folders (in the same way as the consent forms) and would only be viewed by the QIT. In the session on 1st November, the QIT shared the photographs that were taken with TAAA who decided on which ones they found suitable that could be used in any research outputs. Any photos they did not want used would be deleted from the Teams OneDrive folder.

Feedback session with TAAA and researchers

After the conclusion of the focus groups, the analyst led discussions whereby TAAA fed back their thoughts on how the focus group went and shared immediate findings from the discussions. TAAA's feedback on the running of the focus groups are as follows:

- Give more time to answer each question e.g., 30 minutes with breaks. This can depend on individual need and circumstances. E.g., some people have longer attention spans than others.
- Explain to participants at start of session they can leave the room whenever necessary.
- Make reasonable adjustments on focus group materials:
 - A3 size consent form.
 - Information sheet to be produced in Easy Read format. Using pictures from a 'picture bank' that are in the correct format. Some 'Clip Art' images are not suitable and some work better than others.
 - Share pictures of the researchers in the info sheet or in emails in advance of a session can help participants to build rapport with the researchers so that they feel safer and more confident to share information during the focus group.
- Official definitions of 'health' and 'wellbeing' to be explained as some people may not understand what they mean.
 - Also having pictures to visually describe these terms may be helpful for some people.
- Not everyone can read or write so make reasonable adjustments.
- Ensure participants are aware of how consent forms and photographs are stored and who has access to them.
- Health and Wellbeing priority wording to be presented in an Easy Read format and/or less wordy so it is easier to understand.

During the focus group, researchers reflected on and made some reasonable adjustments in the focus group session. This included:

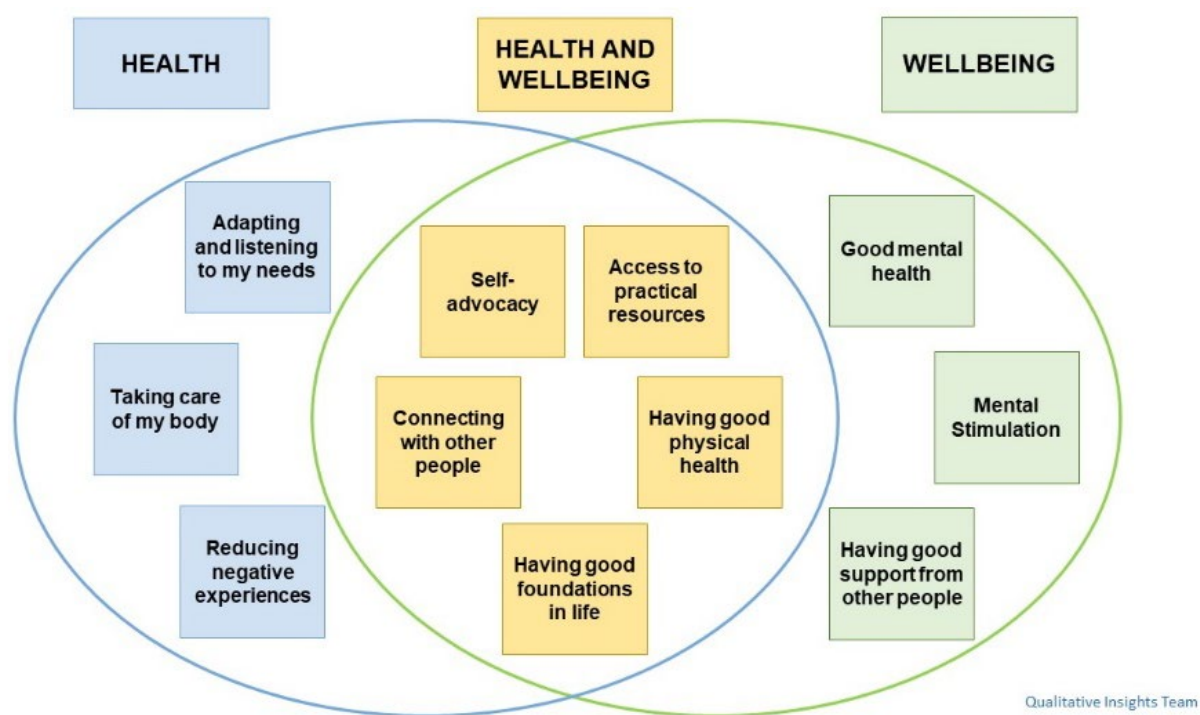
- Researchers appreciated TAAA's honesty in the focus groups as the feedback helped to inform the themes identified in the analysis.
- This was also helped by developing trust and rapport with TAAA over the last couple of weeks. This should also be factored into any future engagement with residents with disabilities moving forward.
- Being aware that some people TAAA know of would struggle with the same focus group set up and researchers would need to adapt research to fit their needs.
 - For example, during the focus group one participant required assistance from a researcher to write down responses and complete a consent form as they could not write.
- Researchers assisting the development of discussions and writing down responses (where appropriate) when participants didn't fill in post-it notes.
- Ensuring participants are comfortable in the room in which the session is taking place.

Research findings and themes

Thematic analysis

The data that was produced from the focus groups consisted of brainstorm maps that answered the two research questions. Data collected from this task consisted of responses written on post-it notes. From this, the analyst developed a thematic analysis by analysing responses on the post-it notes and developing a series of themes. Responses ranged from one-word to sentences and direct quotes were also included in this work from TAAA (see the appendices for details). The analyst then met with the researchers to confirm the thematic areas who then filled in any gaps from the discussions they had in the focus groups. One of the initial findings from the focus groups was that there were significant overlaps between responses related to health and wellbeing. The Venn diagram in Figure 2 illustrates these overlaps and the thematic areas identified in the focus group analysis of the responses by TAAA.

Figure 1: Thematic areas identified in the focus group analysis



From identifying these thematic areas, Tables 2, 3 and 4 define and break down the themes in further detail. Table 2 outlines the overlapping themes associated with health and wellbeing, before focussing on health (Table 3) and wellbeing (Table 4) separately.

Table 2: Health and wellbeing theme definitions

Theme	Definition
Connecting with other people	<ul style="list-style-type: none"> • Maintaining in-person and online connections with others. <ul style="list-style-type: none"> • Includes connecting with people around the world using Zoom, playing games for socialisation, and having fun. • Meeting in a hybrid way as some people still feel uncomfortable meeting in-person. • Meeting people to offload troubles.
Having good physical health	<ul style="list-style-type: none"> • Having good physical health for overall wellbeing: <ul style="list-style-type: none"> • Going to the park, taking part in in-person and online exercise classes, indoors and outdoors.
Self-advocacy	<ul style="list-style-type: none"> • Have self-advocacy to raise concerns, to tell stories and to speak up for myself and other people. • Raising awareness of issues related to learning difficulties to inform decision making.
Access to practical resources	<ul style="list-style-type: none"> • Having access to IT equipment and accessible technology. • Having access to travel passes. • Having the right housing environment. <ul style="list-style-type: none"> • Having a nice home environment makes it more appealing for visitors to come round.
Having good foundations	<ul style="list-style-type: none"> • Having access to suitable housing, transport, the internet, and stable finances are foundations for health and wellbeing.

Table 3: Health theme definitions

Theme	Definition
Taking care of my body	<ul style="list-style-type: none"> • Attend health appointments and to be proactive in managing your health. <ul style="list-style-type: none"> • Sleeping, eating well, managing weight help you to have peace of mind. • Being active: undertaking exercise, walking, and getting out and about. • Using a smartwatch to monitor your exercise and health.
Adapting and listening to my needs	<ul style="list-style-type: none"> • Understand how someone communicates so that you can adapt your care to their individual needs. • Be able to access services that can make reasonable adjustments. • In some settings, like Day Care, it is important to have access to wellbeing activities that relate to individual needs.
Reducing negative experiences	<ul style="list-style-type: none"> • Reduce negative experiences of health care. • Tackle discrimination.

Table 4: Wellbeing theme definitions

Theme	Definition
Good mental health	<ul style="list-style-type: none"> • Have positive self-image and positive self-esteem. • Having headspace and living in the moment. • Connecting and socialising with other people. <ul style="list-style-type: none"> • But, having the balance between socialising with other people and taking time for yourself. • Music is helpful for rest, relaxation, recuperating, emptying your mind and helping you think.
Mental stimulation	<ul style="list-style-type: none"> • Taking part in activities that you enjoy, such as shopping, fun and games, going to the pub. • Having time to reflect, rest and sleep. • Have fun, have a laugh, and learn new things.
Having good support from other people	<ul style="list-style-type: none"> • Having good support from other people such as family, friends, work colleagues, support workers and services that adapt to my needs is important for wellbeing. • One participant shared that support workers were essential to assist them with travelling around Wirral.

Knowledge exchange and impact

Future considerations in conducting research with Wirral residents with disabilities

In the meetings, TAAA identified how research documents and focus groups could be better tailored towards Wirral residents who have diverse disabilities and needs. This provides us with many opportunities to conduct research to address wider council aims and objectives and policy-making decisions.

Research documents and outputs

- Accessibility needs differ depending on the person.
- Large font size.
- Black text on yellow paper for people with visual impairments.
- Black text on yellow paper can 'feel loud' for people with Autism.
- Easy Read Words and Pictures:
 - Ensure that the pictures reflect what the words say.
 - "If you have to use it, you have to explain it" "And if you don't explain it, you look silly".
 - Suggestion to use Inspired Services: <https://www.inspiredservices.org.uk/>
- Terminology:
 - Don't use jargon or complex words.
 - Use words that are easy to explain.
- Opportunity to work with internal colleagues to review report drafts, such as the neuro-diverse staff network.

Developing research questions and gathering responses

- If questions are to be closed, they require a 'Yes' or 'No' answer.
- If asking too many questions, then people with certain disabilities may switch off.
- Open-ended questions are fine, but don't pose too many questions in interviews or focus groups.
- Creative and accessible ways of responding to questions could involve:
 - Drawing pictures.
 - Using feedback cards, such as happy, sad, and neutral face, that participants could point to.
- Be aware that some participants may not be able to write or use verbal communication.
- Participants may communicate through blinking, smiling, and communication technology.

Preparing focus groups with people with disabilities

- Send information sheet to participants in advance of the focus group so that they can think about what they would like to say.
- Focus groups to last no longer than 2 hours.

- Organise small focus groups (4 participants maximum).
- Having 2 researchers is a comfortable number for a focus group.
- Possibility of arranging 2 focus groups in parallel with a researcher facilitating each group.
- Be aware that no two people are the same when it comes to disability so accessibility should be based on individual circumstances and requirements.
- People's levels of comfort are different. Some people may not be able to concentrate for longer than 15 minutes so regular breaks and comfort breaks should be factored in.

Conducting focus groups with people with disabilities

- Some participants may not feel confident to speak up in a group setting. Some ways of creating equal access for participants to contribute include:
 - Provide each participant with a yellow card which can be raised if they want to contribute to the discussion. It also helps to see who is next.
 - The chair of the focus group can have a red card to indicate when it is time to stop.
- Provide the core questions to the group at the beginning of the focus group so that people can go back to them. For example, put them up on the wall.
- Provide opportunities for people to give additional information after the focus group if they have more to add.
- For example, researchers could provide their contact details to follow up with participants.

Safeguarding

- Identify in recruitment a safe space in which research gathering can take place.
- Participants may find answering a question directly too difficult but may find it easier to provide an example or experience to explain their point of view.
- There is concern that participants may share sensitive information about themselves that could imply that they are at risk. Thus, research teams to consider informed consent and safeguarding procedures in relation to potential disclosures of participants.
- In some instances, have a professional or advocate available during the session if a participant requires support with an issue.
- Work with internal colleagues around safeguarding processes for research purposes.
- Provide opportunities for participants to talk to a researcher about the subject matter in a more private setting if they do not wish to disclose information in the focus group.

Conclusion and future co-production opportunities

This work has used co-production as a methodology to work with Wirral residents with disabilities. It has demonstrated how this method can be used to develop a grounded approach to research to help shape council policy and decision making. It has also informed the health and wellbeing strategy, in particular priority 5, and we have worked with and listened to TAAA to ensure their voices and concerns about health and wellbeing are heard.

Future work with residents with disabilities could also take a co-production approach. This could include involving local community organisations who work with residents who have disabilities in the research design process. These organisations can help the QIT to:

- Scope out venues for insight gathering
- Recruit disabled residents who are hard-to-reach and to map the wider disability landscape on Wirral, and
- Discuss future research design and adapt it, where necessary, to people with different communication needs.

Contact details

Contact

For further details, or to give us feedback please contact:

qualitativeinsightteam@wirral.gov.uk.

About us

Qualitative Insight is a type of research that speaks to people to gather their thoughts, experiences, and ideas on particular subjects. The Qualitative Insight Team at Wirral Council work with residents to ensure that their voices are heard when informing council policy and decision making. The team supports the delivery of the Health and Wellbeing strategy, in which residents' voices are a key strand.

Appendices

Appendix 1: Focus Group Photos

Image 1: Photos of research participants and researchers in the focus group



Appendix 2: Responses to health and wellbeing theme

Figure 2: Responses to health and wellbeing theme made by TAAA in the focus groups



Appendix 3: Responses to health theme

Figure 3: Responses to health theme made by TAAA in the focus groups



Appendix 4: Responses to wellbeing theme

Figure 4: Responses to wellbeing theme made by TAAA in the focus groups

