



# A Conversation About 'Wellbeing' Adults with Learning Disabilities

March 2020

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# Healthwatch South Tees

## Introduction

There's a Healthwatch in every Local Authority area of England. We are the independent champion for people using local health and social care services. We listen to what people like about services and what could be improved and share these views with those with the power to make change happen. We also share views with Healthwatch England, the national body, to help improve the quality of services across the country. In addition, Healthwatch provides an Information and Signposting service to help people receive the right health and social care services locally.

In summary - local Healthwatch is here to:

- Listen to what people think of services.
- Use people's views to help shape better services.
- Provide information about health and social care services locally.

Healthwatch Middlesbrough and Healthwatch Redcar & Cleveland have been working together across Healthwatch South Tees, since 1 April 2017.

## Background

The NHS are working towards creating an Integrated Care System (ICS) that brings together all aspects of health and care. Healthy lifestyles and healthy living, in the communities where we live, is an essential part of this transformation. This approach forms the basis for improving the way in which health and care services are delivered. The Integrated Care Partnership (ICP) is the leading body driving this work forward.

A successful ICS is reliant on public engagement to shape services that work together to benefit the people it serves. We know that some groups of the population can be underrepresented in consultation and engagement opportunities. These groups may be more vulnerable and tend to be high level users of health and social care services. The ICP want to make sure it has provided opportunities for all sections of the

population to take part, and in doing so, ensuring the ICS meets the needs of a diverse range of people in our local communities.

Healthwatch South Tees (HWST) was approached by the ICP to host a focus group with adults with learning disabilities in Middlesbrough. The ICP wanted to find out the most important things that contribute to adults with learning disabilities overall wellbeing, the things they did to benefit themselves and how they supported others. The focus group theme followed the general ICS consultation framework, finding out how best to empower people and communities to take more control over their wellbeing.

The framework for focus groups was thus presented in the form of a questionnaire (*see appendix 1*). HWST simplified the questionnaire to inform creative activities and discussions more appropriate to a focus group setting and those taking part.

Myplace in Middlesbrough hosts a number of social groups for adults with learning disabilities and kindly agreed that we could attend two sessions. The team set up activities and discussion areas which could be accessed by attendees as and when they wished. Those caring for attendees supported them at times to engage.

Initial conversations highlighted barriers to people with learning disabilities taking part and we were required to alter language to ensure clarity of understanding for this group. For example, the word 'wellbeing' was changed into 'being happy and healthy' and an activity headed 'Our Community' was changed to 'Where we live'. Where questions about 'community assets' were asked, we used basic materials such as card, coloured pens and flip chart to make a visual creation called 'Where we live'! The conversations were then based on following a 'road' around the community to stop off and discuss how each element contributed to keeping adults with learning disabilities happy and healthy. Talking to individuals and small groups helped the team involve participants.

Detailed information was later transferred to the questionnaire. Despite participants never setting eyes on the complex questions, all sections were completed and provided structured feedback to ICP.

## Disclaimer Note

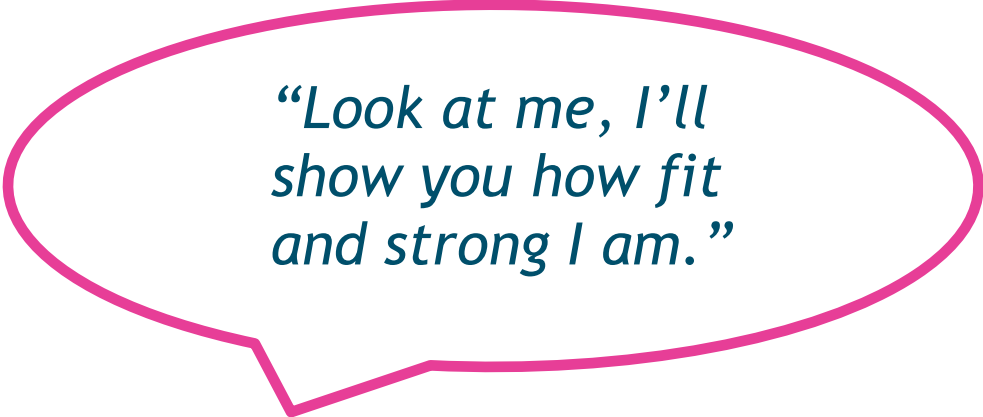
The opinions represented in this report are those of the participants we interviewed in the organised focus groups. Healthwatch is not claiming these represent the views of all young adults with learning disabilities. Nor do they represent the opinions of Healthwatch South Tees.

## Findings and Discussion

What does 'wellbeing' mean to you?

After discussion participants decided this was about being happy and healthy.

The association with being healthy revealed lots of knowledge and positive comments on healthy eating, plenty of sleep "to recharge batteries" and exercise like sports and dancing.



*"Look at me, I'll show you how fit and strong I am."*

Another member of the group explained how they had recently lost weight and how this now meant he could play football, ride his bike and enjoy doing more things he liked. The group also shared their knowledge of mindfulness and a member led a short demonstration about how we could benefit from some breathing exercises.

Discussions about being and keeping happy began with relationships with family and friends. It was important to have someone to talk to and someone to care for them when needed. Some significant time was spent on discussing how individuals cared

for friends, particularly supporting them when they were sad or had problems like depression. Two young adults talked frankly about one of them suffering from severe depression. They demonstrated a very caring and nurturing relationship, both benefiting from the genuine care they gave and received:

*“I help my friend when he is feeling very sad.”*

There were conversations about the importance of pets. One member explained:

*“My cat makes me happy, but he died. I loved him... I was sad when he died. I have 2 new cats now”.*

It was highlighted that these trusting and supporting roles and networks played a vital role in participants making healthy choices. This was demonstrated by members comments:

*“My carer helps me do things to keep healthy!”*

*“Mommy tells me about healthy food”*

*“My brother started making his own healthy pizzas”.*

People also expressed that they enjoyed learning new things. Trying new activities, meeting new people and making new friends and finding new interests.

Having a purpose and earning money was very important to some members. One member who had experienced abuse in her life told us:

*“Paid work at the club means so much to me. It helps with my confidence and self-worth and I enjoy helping other people”.*

The group then discussed how they would feel if they didn't have some of the above aspects in their life; they thought they would be homeless and poor, hungry, unfit and overweight, lonely, isolated and sad and bored. They discussed how being bored and doing little activity may lead to more damaging behaviours, like alcohol and drugs.

**We held a discussion around solving problems and making healthy choices, asking what needs to be in place for people to do this and what services can help.**

When asked how the group usually solve problems in their life, they related back to their support systems of friends and family, tutors, support workers and carers. The individual experiencing depression brought up again how he and his friend helped each other, but he also noted how doctors are needed to help.

These support systems have been important in enabling the individuals to make healthy lifestyle choices, which has had a positive impact in making them feel physically and emotionally happy, fit and strong. There was an element of understanding how this pleased and benefitted families, friends and carers as they worry less about health problems.

There were however some barriers to making healthy choices, particularly when cooking and eating; there was a perception that healthy eating was expensive:

*“I try to eat healthy, but I can’t all the time as its too expensive and we don’t always have money.”*

Also:

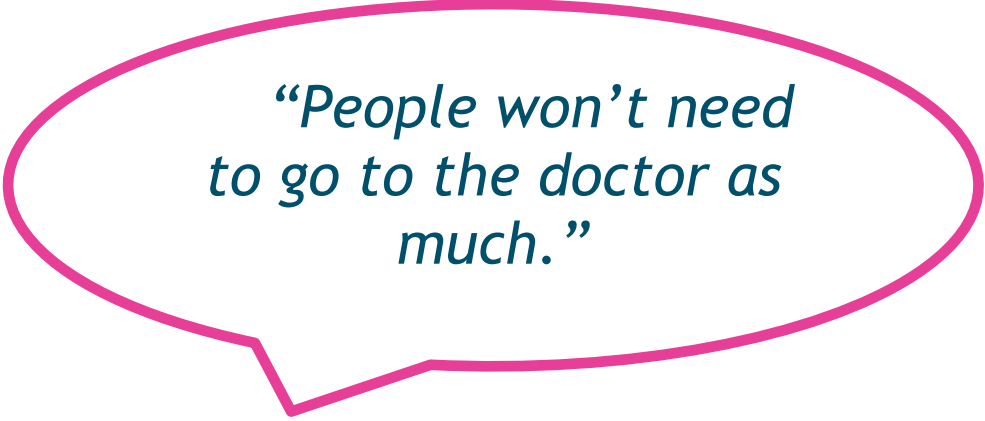
A member described cooking as hard work so sometimes he had easy or ready-made foods.

Members talked about how restaurants don’t make it easy as they have very few healthy options and should have more healthy choices.

When discussing what would help people stay healthy, participants said:

- More information about how to be healthy and why it is important.
- More affordable healthy options and activities to be available with the example of free fruit and veg boxes and using existing community groups to do healthy cooking workshops.

- Education where they live to learn new things like healthy cooking and how to look after themselves and what happens if you don't. They thought this would be a good idea because:



*“People won't need to go to the doctor as much.”*

When the conversation focussed specifically about mental health there was a shift in thought process. They agreed that feeling happy was very important.

Participants said:

- There should always be someone we know to talk to.
- Having support and places to go to do things they like, with friends and in groups.
- Having a sense of purpose helping others and having paid work.
- Getting the right help when its needed:

*“Doctors give tablets that sometimes don't work. They need to look after people instead of giving tablets”.*

**We looked into what people do to help others to keep well.**

Support networks were really important to the participants' own wellbeing and this was something they could relate to being important for others too. Discussions centred around offered support to their family and friends, with one member feeling very much responsible for his best friend and supporting him through poor mental health. Another participant had changed diet to eat healthier as their mum had developed diabetes:

*“Mum has diabetes and I want to help her stick to it”.*

During discussions, there was evidence of knowledge around healthy and unhealthy foods:

*“Don't eat too many chocolates or sweets, cakes or pastries.”*

Participants talked a lot about how they enjoyed helping and caring for other people through volunteering, their work and in their personal lives.

**We explored the concept of 'community wellbeing'**

This section took a little more thinking about. We had approached this section with an activity, using coloured card and pens and a large sheet of paper to create a visual image of a community from the perspective of participants.

A young man raised the first issue:



*“What is a  
community?”*

The first discussion was to re phrase the question and it was decided by the participants to call this activity “Where we live”. Labels, symbols and coloured shapes were drawn and stuck onto the sheet to create a community. As people dipped in and out of the activity, this was widened to include things that others never



thought of or had previously taken part in. Individuals and small groups took different routes around the creation to talk about how the different aspects of 'where they lived' contributed to keeping them happy and healthy.

Participants included a gym, a leisure centre and swimming baths, the Myplace centre and the doctors; these reflected the importance of exercise and of having people for support. Although one participant didn't like going to the doctors, they all recognised the importance of having health professionals within the community for when people are ill. The shopping centre was added by another participant as this enables her to do a lot of walking and gives her space away from her kids. Although her kids keep her well and happy, she noted the importance of having time for herself, for her emotional wellbeing due to a traumatic past and her previous struggle with post-natal depression.

Having indoor and outdoor leisure and sport spaces and community buildings that offered the space to meet and interact with others were seen as very important. Members of the group explained how they were part of certain activity groups, e.g. for dance and football, and how these were "good to keep healthy because it keeps [them] strong and fit and helps with all sorts of other things too... make friends and learn all about teamwork... laugh a lot and have a good time". This member also noted "another way to stay happy and healthy is to keep getting better at things". Their social worker was really important in helping them get into these activities.

Volunteering and employment opportunities were also vital parts of the community for the participants; this was important in terms of developing confidence and self-worth as well as learning, development and earning money. Another member noted how getting out into the community and "helping people" was important for them to feel happy, gain confidence and self-worth, noting how when they stay in they can "get bored and sometimes can feel sad".

Overall, the members' social care was very important as this enabled them to access the things they now enjoy and to be active members of their communities; without this help and support, and the social work input behind this, they may not have the opportunities to take part in activities that are so important to them and their overall wellbeing.

## Case Studies

### Participant 1:

The park, community centre, leisure centre, dentist, doctors, hospital, police, my house and where I live. These are all the places that I go to.

At the dentist they do needles and fillings. This is how the dentist helps to keep me healthy. I think there should be more men working at the dentist so they could tell me everything is ok. More men should do training at the dentist so they can do the same as the ladies there. I'd like to work at the dentist cos I know all the tools and what they do and I could tell other people what to do to keep healthy.

Doctors make me better if I get sick. I get medicine and the doctor told me to stay in bed and don't get up until I feel better.

People stay healthy at home because the house keeps you warm. I will be moving soon to live with my girlfriend. I was once attacked outside and I feel safe at home. The police help people feel safe, they came to see me and spoke to the person and said don't do that again.

I like doing dancing and performing plays at the leisure centre and activity club. This is where I feel happiest. Dance is good to keep healthy because it keeps me strong and fit. It helps me with all sorts of other things too. I make friends and learn all about teamwork. I even see some people I went to school with. We laugh a lot and have a good time. When I'm happy, I feel healthy.

I also do activities outside. I have joined the football team and I am getting better at it. Another way to stay happy and healthy is to keep getting better at things.

I have a social worker who I really like. She helps get me into places I can do activities I enjoy. She got me into Back Street so I can dance and do performances.

When asked, 'If you had to choose something that was most important to being healthy and happy, what would it be?' He replied *"Dancing... It makes me feel strong and happy."*

**Participant 2:**

I go to most things on the paper (Where we live). Some things I don't like doing - like when I need to go to the doctor or the dentist.

The thing I like most is volunteering at the "youth club" (adults with learning disabilities) and at the hospital. I like helping people. It makes me happy and I meet friends. I do things I like to do instead of staying in all the time. If I stay in, I get bored and sometimes I can feel sad.

**Participant 3:**

Added the shopping centre to 'Where we live'. She said she really likes shopping.

Making healthy choices can be hard to do if you buy the wrong things to eat. I do lots of walking at the shopping centre and I feel happy so that must count. When I think hard about it, it also gives me space away from my kids.

The community centre was a real help to me when I was at my worst - I had a lot going on in my life and had a traumatic past. I had post-natal depression. I was given therapy which made me worse. I was unable to go back to what happened to me. The community centre helped me move forward. I did mindfulness there and it was very helpful. It made me feel things again but good things.

Because of everything that happened to me, I took my dad's brain tablets when I was 11. I kept taking them.... lots of them.... sometimes 30. This went on for over a year. They (the doctors) thought I had something wrong with my brain, but they never asked me so never found out what I was doing. They didn't protect me, and I got sent to Pakistan for a year. I couldn't marry until I started my period but that didn't come so my marriage was arranged later back in UK. I was 16 then and my husband was abusive. I became very ill with anorexia. I'm better but now I have learning disability and anxiety.

Coming to work for a short time is helpful. My kids (3) keep me well and happy. Looking back, what would have helped me would be having someone, who I could trust, to talk to. Someone who would listen and find out what was really happening. I believed I was dumb and deserved to be beaten and badly treated.

## **Important Messages**

From these discussions, HWST has summarised the conversations held with adults with learning disabilities:

Overall, the most valued contributory factor to good physical and emotional health was engaging in activities of choice, making friends, meeting with them and having someone to talk to. Participants valued the right care and support, as well as community meeting places to enable this to happen. Activities mentioned were wide ranging and included things like drama/dance and sport as well as opportunities to develop life skills such as healthy eating/cookery and affordable meals.

Participants demonstrated significant knowledge about how to keep happy and healthy. They drew on the relationship between physical and mental health, advocating how engaging in things like dance helped with strength and fitness as well as feeling good and making friends. They felt that more could be done to educate other people to look after themselves better.

There was much compassion and willingness to help others in need. This was evident in discussions about everyday life and in the sessions attended. Participants could be seen to emotionally benefit from the kindness, consideration and support for each other in the groups.

Discussions about ambitions, continuous learning opportunities, developing confidence and self-worth centred around opportunities to volunteer and get paid work. Participants 2 and 3 both talked about the benefits of volunteering and paid work to their self-worth and mental health.

Within the community, participants recognised the importance of home contributing to emotional wellbeing. Home was somewhere warm and cosy to feel physically relaxed, as well as a safe place, where they had someone to look after them and to talk to.

Other areas of discussions recognised times or circumstances in people's lives when out of the ordinary help was needed: If someone was ill, they would need a doctor; the police can help to make someone feel safe in the community.

## **Conclusion**

Although this engagement work was carried out on behalf of the ICP for a specific purpose, it's important to recognise the value of this information locally. This report provides some strong messages for social care, community level specialist and mainstream providers. We hope therefore the voices of adults with learning disabilities can have an impact on what we do locally.

We are also keen to demonstrate how it works inclusively with people who may otherwise find it difficult to have their voice heard. We recognise that we need to consistently think about how we involve people in our work and make those appropriate adjustments to make sure everyone has a voice to influence and shape local services.

## **Acknowledgements**

We would like to thank staff and attendees at Myplace, Middlesbrough for supporting the consultation and for sharing insightful knowledge, views and experiences with Healthwatch South Tees.

# Appendix 1: Healthwatch Focus Group Guide

## A CONVERSATION ABOUT WELLBEING

### INTRODUCTION

We are Healthwatch [add some information about your own organisation].

We are working with TONIC, a research organisation, that has been asked by the Integrated Care System (a regional partnership between health and care services) to talk with people across the North East and North Cumbria about health and wellbeing.

We want to hear your views about what matters most to you. Your responses will help to shape the way health and care services are delivered across the region.

**DATA PROTECTION:** This is anonymous and confidential - we won't ask for any identifiable information. No personal data about you will be stored. All quotes used will be anonymised. All data will be destroyed at the end of the research.

### DISCUSSION 1: WHAT DOES “WELLBEING” MEAN TO YOU?

i) What does “wellbeing” mean to you?

Notes:

ii) How easy is it for you to make changes or keep healthy?

Notes:

iii) What benefits or rewards are there for you to make these healthy changes? For you, others, and health and care services?

Notes:

**Key themes from overall discussion:**

**Quotes:**

## DISCUSSION 2: SOLVING PROBLEMS & MAKING HEALTHY CHOICES

i) How do you usually solve problems in your life? What do you use to help you with this?

Notes:

ii) What would you need to have in place to help you make healthy changes to your lifestyle?

Notes:

iii) What could services do to help you achieve this? Prompt: How can health and care services empower people to look after themselves better? (e.g. health or care services, friends, non-medical people, pharmacist etc.)

Notes:

**Key themes from overall discussion:**

**Quotes:**

## DISCUSSION 3: HELPING OTHERS TO KEEP WELL

### Prompts

i) Have you ever asked anyone you know to do something to improve their wellbeing? (For example, asking a parent or partner to give up smoking, take some exercise, or see a doctor?) If yes, How did it go? Would you do it again?

Notes:

ii) What could you do in future to help people who are important to you to keep well?

Notes:

iii) Do you think the health and care system needs people to be better at looking after themselves? Why is this?

Notes:

**Key themes from overall discussion:**

**Quotes:**



## DISCUSSION 4: COMMUNITY WELLBEING

### Prompts

i) What groups / communities do you feel part of? (e.g. The North, a local area, interest group, ethnic/religious group etc.) Why do you feel this?

Notes:

ii) What role could “communities” have in keeping people healthy or promoting “wellbeing”?

Notes:

iii) What community assets (buildings, people, services) could be used to promote good health to the wider population? How could these be used to do this?

Notes:

**Key themes from overall discussion:**

**Quotes:**



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