

Bee Happy: Our Health and Wellbeing since COVID-19. Learning Disability Report

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Contents	Page
Summary	3 - 4
Introduction	5
Background and Methodology	6 - 7
Findings	8 - 10
Main Findings	11 - 12
Recommendations	13



Summary

<u>Healthwatch Stockton-on-Tees</u> collaborated with Stockton-on-Tees Borough Council Community Based Learning Disability Day Services (CBLDDS), with help from the key workers who provide support to those who attend this service. This enabled us to engage with people with a learning disability to find out their views and experiences of their health and wellbeing over the past year. One focus group was carried out at each of the four services across Stockton-on-Tees. In total we heard from 26 people who attend the day services.

The overall findings of this engagement, based on what people with a learning disability have told us, show that:

- The key workers at CBLDDS, the doctors, nurses and catering services at North Tees Hospital, the GPs, primary care nurses, dentists, and 'Creative Support', have given people with a learning disability, positive experiences of health and care.
- With support from family members and carers, a range of health care appointments have been easily accessible.
- There have been difficulties with communication and accessing information from some health care services. (Ref: Healthwatch Stockton, Accessible Information Standards Report: www.healthwatchstocktonontees.co.uk/report/2022-11-17/experiencesaccessible-information-standards-health-and-care-report-2022)
- People with a learning disability have experienced confusion around health messages and media stories.
- Outside of day service provision, there's a lack of opportunities for those with a learning disability to be able to participate in, and access enjoyable and meaningful activities which enhance learning and communication since the start of the COVID-19 pandemic.
- The lack of access to opportunities and participation in the local area has also had an impact on how people feel, their health and wellbeing, and their social contact, and continues to do so as the COVID-19 restrictions have lifted.
- Family members and carers of those with a learning disability have taken longer than expected to recover from the COVID-19 virus.
- A wide range of factors supporting health and wellbeing have also been identified.

Based on the findings, the following recommendations have been made:

- 1. Provide better access to local areas for people who use wheelchairs.
- 2. Provide more opportunities for people with a learning disability to participate in local activities that are enjoyable and meaningful, and that enhance learning.



- 3. Provide more opportunities for people with a learning disability to have social contact, and to communicate with others in a safe space, outside of day service provision.
- 4. Provide targeted health and wellbeing support for people with a learning disability, and their families and carers, to support their understanding of health messages.
- 5. Ascertain the effects of post-COVID infection on family members/carers of people with a disability.



Introduction

Local Healthwatch have been set up across England to create a strong, independent consumer champion with the aim to:

- Strengthen the collective voice of citizens and communities in influencing local health and social care services to better meet their needs.
- Support people to find the right health and social care services for them by providing appropriate information, advice and signposting.

Healthwatch Stockton-on-Tees works with local people, patients, service users, carers, community groups, organisations, service providers and commissioners to get the best out of local health and social care services. This doesn't just mean improving services today but influencing and shaping services to meet the needs of the local communities tomorrow.

Healthwatch Stockton-on-Tees is steered by a <u>Board of volunteers</u>, commissioned by the Local Authority and accountable to the public. Healthwatch Stockton-on-Tees are the only non-statutory body whose sole purpose is to understand the needs, experiences and concerns of people who use health and social care services and to speak-out on their behalf. The service is managed by <u>Pioneering Care Partnership</u>, a leading third-sector charitable organisation aiming to improve health, wellbeing and learning for all.

Healthwatch has:

The statutory right to be listened to:

- Providers and Commissioners must respond to Healthwatch within 20 days of submission of requests for information or reports.
- The statutory power to Enter & View publicly funded health and social care services.
- A statutory seat on the Health and Wellbeing Board.



Background and methodology:

Twenty-two researchers across the UK worked closely with local organisations to seek the views of adults with learning disabilities and their carers (Taggart, December 2021). The study found that the social lives of people with learning disabilities were severely restricted during COVID-19 and have yet to fully recover due to a lack of community activities, and less work and volunteering opportunities. The study also found that people with a learning disability have experienced a decline in physical health and emotional wellbeing with no improvements as restrictions have lifted (Taggart, December 2021).

As health and care service design and delivery develops, it's imperative that that people with a disability and their carers who experience inequalities, have their voices heard to help influence health and social care services to better meet their health and care needs. Helping local services to respond to the challenges of the pandemic and beyond, tackling health inequalities, helping communities thrive, and achieving the very best for everyone, are the main ambitions of the 42 new and developing Integrated Care Systems (ICSs) that were established across England in July 2022. ICSs are partnerships of organisations that come together to plan and deliver joined up health and care services, and to improve the lives of people who live and work in their area (NHS England 2022).

To find out about the local views and experiences of people with a learning disability, in relation to their health and wellbeing over the past year, Healthwatch Stockton-on Tees (HWS) collaborated with Stockton-on-Tees Borough Council (SBC) Community Based Learning Disability Day Services (CBLDDS), between February 2022- June 2022.

The CBLDDS provides a range of opportunities for people with learning disabilities, which are designed to maintain and where possible to develop skills which can be used in everyday life. Those who attend the day services are supported by a team of key workers.

The key workers provide support to help increase independence by enabling choice and opportunities which enhance people's quality of life. The key workers build working relationships with the people they support, understanding what is important to them and how they want to be supported within the agreed care/support procedures. The key workers communicate with the people they support in a way that is appropriate to their needs, enabling people to make informed choices and decisions about what is important to them. They also enable the people they support to be part of their community with the social and educational activities of their choice.

The engagement with CBLDDS, was not to provide a review of the service provision, alternatively, the key workers have enabled the day service to be a platform for



those who attend, to share their views and experiences of their health and wellbeing over the past year, in safe space, if they wish to.

HWS were able to visit all four CBLDDS in the Stockton-on-Tees area. One focus group was carried out at each of the four services. In total we heard from 26 people who attend the day services. Within each focus group there were 1-3 key workers present, with the aim of supporting those who attend the service and focus group to have their say.

HWS facilitated open ended, unstructured questions within the focus groups. A guideline was used for questions; however, these questions were adapted to suit the needs of each individual focus group, whilst considering the fluidity of the communication. The guideline of questions include:

- What makes you feel well/good/happy?
- Is there anything that doesn't make you feel so good?
- Who gives you help and support when you need it?
- What does a good day look like for you?
- What does a bad day look like for you? Is there anything that would work better for you?
- Can you always get the help when you need it? How does this make you feel?
- Do you have any hobbies or activities that you enjoy?
- Are there any activities that you would like to be able to do/try?
- To help keep you well, are there any groups or activities outside of daytime/ during the week that you would like to be part of?

This has enabled us to find out what has been working well, and areas for improvement in relation to, supporting health and wellbeing, experiences of health and care services, communication in health care, understanding health messages, accessing equal opportunities within the local area, social contact, and the effects of COVID-19 on support networks. The information provided has supported HWS to make recommendations based on these findings, with the aim to better support the health and wellbeing of people with a learning disability within Stockton-on-Tees.



Findings:

People have told us about what makes them feel well, good, and happy:

- Family and friends
- Being able to work 'I work at Little Sprouts Café'
- Being able to meet with friends
- Developing skills 'Learning at College and being able to show people what I can do'
- Having a choice of things to do
- Having support to get out and about
- Keeping fit and going to the gym
- Exercises such as chair exercises, football, walking, dancing, horse riding, swimming, gardening, pool, and snooker
- Going out to buy books
- Independence 'having my own place'
- Going to church
- Activities such as arts and crafts, bingo, sewing, jigsaws, reading, puzzles, cooking

People have also told us that the support they receive from key workers at the community-based day services, makes them well, good, and happy:

'Support from Elaine to help me talk about things'

'Staff helping to keep me safe'

'Now I know about fire safety and how to keep myself safe'

'Baking with George'

'Being able to use Makaton'

People have told us about the things that they have found hard, difficult, upsetting, and the things that don't make them feel good:

- Losing family members
- Family members taking a long time to get over the COVID-19 virus.
- Having regular COVID-19 tests and vaccinations
- Hearing/watching news stories and health messages that keep changing.

'The news and health and what's good for you are all confusing'

• Losing the contact with the friends that they had before the start of the COVID-19 pandemic:

'I miss seeing my friends'



'I miss my friends, I don't see them anymore, it makes me feel sad'

• Difficulties in accessing leisure, recreational and learning activities outside of day service provision.

'I have difficulties in using leisure centres, with me being in a wheelchair - it's hard to get about most things. I get very panicky when trying to get around in my wheelchair. I start to panic and get upset- it makes it difficult to go out and go out with friends.'

'Not being able to do the things that I like to do after day service- not all places have opened since covid.'

'Some discos and clubs have closed'

'I miss playing pool'

'I can't do the activities that I use to be able to do'

People have told us about their experiences of helpful and supportive health and care services:

• The Key Workers at Stockton-on-Tees Borough Council Community Based Learning Disability Day Services:

'I worry about COVID, but staff help me with this'

'I always feel that I can get the help when I need it'

'My key worker and community nurse support me with feelings about relationships'

'I get support from here, to talk about feelings and when I find these hard, it helps'.

North Tees Hospital:

'I got my appendix out. They're good nurses and doctors. I really liked the hospital food. They looked after me well and helped me with visitors. I was happy with it all.'

'Nice people at North Tees Hospital. The Drs and nurses looked after me.'

'I really like the hospital food. I'm diabetic'

'I went into hospital. It was a good hospital. It was North Tees where I stayed.'

Primary Health Care:



'I see the doctors and they've helped me with my feet and to get iron tablets'

'I get bloods done every month and I'm happy with how they look after me'

'I can get in at Lawson Street Drs well'

'I get on with my diabetic nurse, Sue. She explains things to me'

'My diabetes nurse helps me'

'Dentist has been good, had teeth out, I feel better now'

'I went to the dentist for a filling. I got looked after well and it was quick.'

• Community Support Services:

'I get support at home. It's called 'Creative Support'- its good.'

Difficulties with communication and accessible information:

One person told us that they attended hospital with a parent (The hospital name was not provided) and found that waiting for their appointment was 'stressful' and that they 'don't understand what's been talked about' when they are at the appointment.

People told us about what they need to improve their health and wellbeing:

'a friendly and safe place for us to meet new friends and friends that we don't see anymore'

'Being able to try new activities on weekends or on an evening'

'Jogging, walking groups, outdoor things, more social clubs'

'Better access to places for people like me who are in wheelchairs'

'More ramps needed everywhere'



Summary of Findings:

Positive experiences of health and care services.

People have told us that they've experienced accessible and supportive health and care services to meet their needs. This includes being able to access health care appointments, the support that they receive from their key workers, the doctors, nurses and catering services at North Tees Hospital, GPs, primary care nurses, dentists, and 'Creative Support' https://www.creativesupport.co.uk/

Communication difficulties and accessing information in health care services.

One person told us that they've experienced stress and confusion when attending a health care appointment at a hospital (not specified), due to a long waiting time and not being able to understand what was being talked about. This finding concurs with the survey feedback on the Accessible Information Standard (AIS) in health and care. Further reference to this finding and recommendation can be found in the Healthwatch Stockton-on-Tees, AIS in Health Care (May 2022-July 2022) (name and link to be inserted).

Confusing health messages and media stories.

People have told us about receiving confusing news stories and health messages. These messages aren't only related to COVID-19, but a wide range of other current affair stories and health subject matters conveyed by the media.

Supporting health and wellbeing

People have told us about a wide range of factors that support their health and wellbeing. These include being able to access local places, leisure facilities and being able to participate in enjoyable and meaningful activities that enhance their learning and ability to communicate. A good support system of key workers and carers to help to promote safety, choice and independence helps to support people's mental health and wellbeing.

However, people have told us that opportunities outside of the CBLDDS, are either limited, not accessible, or no longer available, since the start of COVID-19 pandemic, and since the restrictions have been lifted. People have told us that this has influenced how they feel, their health, and the opportunities they have, to participate in local activities. The lack of opportunities available has also had an impact on social contact. People have not been able to see the friends that they once had contact with, prior to the COVID-19 pandemic.



People have also told us that the friends they once had contact with, don't go out in the same way that they would have done. The exact reasons for this, and the impact that this could have on the experiences of social isolation, for those who don't attend day services are unknown.

People have told us that family members have taken a long time to recover from the COVID-19 infection. This may also have an impact on those people who require support from family members/carers to access day opportunities/opportunities out of day service hours.

Equal opportunities

People have told us that they need better access to local areas and leisure activities for people in wheelchairs.

People have told us that they would like the opportunity to meet with others in a safe space, after day service (and for those people with a learning disability who don't receive community-based day support), to meet old and new friends, and be given the opportunity to try out and participate in new activities and exercises.



Recommendations:

For full responses from service providers and commissioners, please see links below.

Stockton-on-Tees Borough Council -

https://www.healthwatchstocktonontees.co.uk/response-stockton-tees-borough-council-bee-happy-our-health-and-wellbeing-covid-19-learning

NHS North East & North Cumbria Integrated Care Board -

https://www.healthwatchstocktonontees.co.uk/response-nhs-nenc-icb-bee-happy-our-health-and-wellbeing-covid-19-learning-disability-report-2022

Tees, Esk and Wear Valleys NHS Trust - no response

Recommendation number:	Recommendation	Responsible body	Comments
1	Provide better access to local areas for people who use wheelchairs.	Stockton-on Tees Borough Council	
2	Provide more opportunities for people with a learning disability to participate in local activities that are enjoyable and meaningful, and that enhance learning.	Stockton-on Tees Borough Council	
3	Provide more opportunities for people with a learning disability to have social contact, and to communicate with others in a safe space, outside of day service provision.	Stockton-on Tees Borough Council	
4	Provide targeted health and wellbeing support for people with a learning disability, and their families and carers, to support their	Stockton-on Tees Borough Council Tees Esk and Wear Valleys NHS Trust	



	understanding of health messages.		
5	Ascertain the effects of post-covid infection on family members/carers of people with a disability.	Stockton-on Tees Borough Council NHS North East and North Cumbria	
		Integrated Care Board	