

Sheffield Physical Health Strategy for People Living with Severe Mental Illness, People with Learning Disabilities, and Autistic People

APPENDIX: Summary of engagement and feedback on the refresh of the Strategy for 2023-2028

To note –

When we refer to ‘people’ in this document this means people of all ages in Sheffield:

- with a learning disability*
- living with severe mental illness*
- who are autistic.*

Engagement plan summary

Aims of the engagement:

- The aim of the review of the *Sheffield Physical Health Strategy for People Living with Severe Mental Illness, People with Learning Disabilities, and Autistic People (2019-22)* is to refresh and update the strategy with a plan to extend it to run from 2023-2028.
- The overarching vision and aims of the 2019-2022 remain relevant to the city and to people living with severe mental illness, people with learning disabilities, and autistic people - and so the review is a “refresh” rather than a full “re-write” of the strategy.
- However partners involved in the Strategy still wanted to ensure that we took this opportunity to gain feedback from people with lived experience and their carers, and from organisations working to support them, to identify any ways in which we needed to refresh and update the strategy and influence the strategy’s high level delivery plans going forward. The engagement activity has enabled a range of individuals and organisations to contribute to the refresh.
- We are committed to continuing and increasing the ways that we engage and identify opportunities for co-production as part of the implementation of the 2023-2028 Delivery Plans for the Strategy.

Key themes from our engagement on the refresh of the Strategy:

- The work of the 2019-2022 Physical Health Strategy (and its associated workstreams and projects led by partners) has made a positive difference to people – but there is still lots more to do.
- Many people told us that they had good experiences of healthcare and that they had been treated well by services. However, quite a lot of people told us that they were not happy and that they are not having good experiences.
- The strategy should be extended to include the physical health of children and young people as well adults.
- Financial challenges and lack of practical support to access appointments and take part in physical activity make it harder for people to improve their physical health.
- Health and care staff need to be more consistent in making Reasonable Adjustments.
Supporting the physical health of people of people with learning disabilities, people with severe mental illness, and autistic people needs to be “everyone’s business” across health, social care, and key VCSE services.
More staff training, education and awareness (about supporting people with learning disabilities, people with severe mental illness, and autistic people) is needed
- (Informal/unpaid) carers, and parent carers, play a crucial role in helping their cared for ones maintain and improve their physical health
- The contribution made by the voluntary, community, social enterprise sector and faith and community groups in helping people to improve their physical health is significant.
- We need to better understand and meet the needs of all our different communities (across all Protected Characteristics) and identify ways to improve care and outcomes and address additional/cumulative health inequalities. The need to “get the basics right” was highlighted - in terms of culturally competent services, interpretation/translation, inclusive engagement and working with community organisations that support and advocate for diverse groups. Gaps in understanding support needs for people from LGBTQ+ communities was also highlighted in feedback – this is not an area that the strategy has focussed on specifically during 2019-2022.

The following pages include more details about what we heard from people with lived experiences and their family/carers

Listed below are the main ways that we engaged:

- Citywide Survey on the refresh of the strategy
 - Survey ran from 03/01/2023 - 10/03/2023
 - Online and paper based, incl. Easy Read and PHIG partners asked to share/support completion
 - 31 responses
- Physical Health Implementation Group - Focused Review Session (NHS organisations, Sheffield City Council, VCSE partner organisations)
- LEDER (Learning from the Lives and Deaths of people with Learning Disabilities and Autistic People) Steering Group - Focused Review Session
- Health experiences report (Disability Sheffield) (2022)
- MHLDDA Delivery Group Planning session workshop (Nov 2022)
- Related feedback from Sheffield Autism Strategy consultation (2022-23)
- Related feedback from the development of the Sheffield Learning Disability Strategy
- Feedback from commissioned physical health services for people with severe mental illness, learning disabilities, autism
- Feedback from Sheffield Parent Carer Forum
- Relevant feedback from the South Yorkshire ICB “What Matters to You” engagement
- Disability Sheffield *Healthy Living and Physical Activity for people living with severe mental illness, people with learning disabilities, and autistic people Project – Consultation 2022*

SURVEY: What do you think has helped to improve the physical health of people living with severe mental illness, people with learning disabilities, and autistic people in Sheffield over the *last* three years?

Support in the community was a key theme, including VCS services and work primary care networks...

Examples from people with lived experience and family carers

- “Community mental health intervention, helping people with there physical and mental health. Support from community services and voluntary organisations has helped so many people”.
- “I was diagnosed with autism 3 yrs ago after a lifetime of MH issues. Being diagnosed has been massively helpful, though the lack of support for dealing with the diagnosis isn’t... A short term art group funded by NAS was good, hoping they can continue funding something. A group for women with autism has met couple of times and that was good”
- “The groups and activities run by Flourish and the activity co-ordinators make a big difference to people's live and really help people with being isolated.”
- ““Many sport spaces not accessible and still not running disability aimed sessions. It's great people are welcome at any session, but to build confidence they need safe spaces”

Examples from people working with people with SMI/LD/Autism

- “Focus on local level support - primary care network teams - well supported and with enough capacity. also focus on tailored physical health support”
- “Projects like Safe Places are helpful in giving people a back up plan if they are out and feel unsafe for whatever reason. I think this can help people become part of their community, access health services and be mobile.”
- “Organisations working together eg Mencap working with GP practices... GP groups that have dedicated care co-ordinators who work with practices, share knowledge and monitor access to health checks”

SURVEY: What do you think has helped to improve the physical health of people living with severe mental illness, people with learning disabilities, and autistic people in Sheffield over the last three years? #2

Some people either gave no response to this question or responded negatively...

For example

- “Not much my support as been cut I am devastated”
- “In relation to my family member, nothing I can think of”
- “Nothing. I have no access to subsidised gyms, pools, supervised walks or anything else which is what is needed to improve my physical health, on top of my SMI and to keep my weight down. The same as for the last 15 years. Nor does my GP Practice have any access or even to know about Green Social Prescribing available in the south. In addition there is an inverted snobbery approach to delivery and strategy with everything focussed in the "deprived areas" showing a complete misunderstanding of how SMIs shorten people's lives REGARDLESS OF POSTCODE.”
- “I have seen nothing. I moved here from hospital in Oct 2020, to start life as a wheelchair user. I feel abandoned, hopeless, unfit and like I have no options. I haven't received mental or physical health support. I am broke.”
- “Nothing for us”
- “Nothing”

SURVEY: What have been the challenges in improving the physical health of people living with severe mental illness, people with learning disabilities, and autistic people in Sheffield over the last three years? #1

Key theme 1: Financial challenges and practical lack of support to access appointments and take part in physical activity make it harder for people to improve their physical health

- “A major problem is not getting to see a doctor, the lack of appointments...”
- “There is no access to NHS services for people who can't use a phone (e.g. autistic people with auditory processing disorder)”
- “Having to pay for a support worker to take me to appointments. Trying to get appointments when/if support worker available. Rarely getting to all essential appointments.”
- “Cost of Living increases have made things more challenging re heating, appropriate housing and having a healthy diet”
- “I need money for transport so I can access sports facilities that are otherwise inaccessible to me.”
- “I need mental health and practical support to get my life in order so I can go back to work and be more physically active”.
- “I have no access to subsidised gyms, pools, supervised walks or anything else which is what is needed to improve my physical health, on top of my SMI and to keep my weight down. The same as for the last 15 years. Nor does my GP Practice have any access or even to know about Green Social Prescribing available in the south. In addition there is an inverted snobbery approach to delivery and strategy with everything focussed in the "deprived areas" showing a complete misunderstanding of how SMIs shorten people's lives REGARDLESS OF POSTCODE.”
- “I moved here from hospital in Oct 2020, to start life as a wheelchair user. I feel abandoned, hopeless, unfit and like I have no options. I haven't received mental or physical health support. I am broke.”
- “More money could be spent on transport options, so we can get out and be active and socialise. There used to be lots of community stuff for the older generation, but not much now”.
- “Subsidised access to gyms, pools, walks, animal therapy, and more”

SURVEY: What have been the challenges in improving the physical health of people living with severe mental illness, people with learning disabilities, and autistic people in Sheffield over the last three years? #2

Key Theme 2: There need to be more Reasonable Adjustments and more staff training, education and awareness to help people improve their physical health

- “More awareness of the connection between mental and physical health.”
- “You are only allowed to discuss one problem at each appointment, it is unacceptable.”
- “Lack of specially trained staff, lack of general training”
- “A major problem is ... the way people are treated by the reception staff.”
- “Receptionists need education regarding annual health checks for people with SMI”
- “People with serious mental health problems are also more likely to miss appointments and be late for appointments and be registered as a DNA. Flexibility in this regard would be appreciated”
- “Still particularly in the primary care sector there is poor understanding of the impact of mental illness on physical health - often things get missed because of this. A personal example is being in A&E with low heart rate/blood pressure, it says on my records that I have an eating disorder yet doctors dismissed it as me being physically very fit...until I collapsed and needed the crash team as I was going into cardiac arrest, then they made the connection between my eating disorder and my low heart rate”
- “Inability or unwillingness of NHS services to make reasonable adjustments for accessing medical care - e.g. no alternatives to phone calls for making appointments, long hold times before phone is answered, or cutting off without even answering, long waits in intolerable environments when attending appointments, important information provided verbally only and rushed, phone calls without warning from withheld numbers leaving no voicemail message”.
- “Stop putting everything online; e.g., physio seems to be all done online. It assumes that those with SMI are well enough and motivated enough to carry it out - and that they have access to and can use IT.”
- “Many sport spaces not accessible and still not running disability aimed sessions. It's great people are welcome at any session, but to build confidence they need safe spaces. There are still most disabled changing paired with baby/family changing for swimming sessions which is not acceptable.”

Other areas of feedback from the survey:

We specifically asked for feedback on ways to make our delivering plans for equitable and effective in supporting our diverse communities across Sheffield to be healthier – feedback included how we could use the refreshed strategy to help provide opportunities to:

- **Embed more culturally competent care:** “Availability of interpreters, information in other community languages, training for staff re cultural perspectives (professionals still making unnecessary appointments on Eid for Muslim families).” “Sources of material/different platforms in different languages”
- **Ensure engagement is inclusive:** “Co production of services, including these people's voices in decision making. Utilising less formal approaches to engagement and creative ideas to collect information.” “Make sure that EbyE are included in the work”
- **Work more closely with organisations that represent diverse groups:** “Working with established organisations who have record of delivering” “Using existing groups like Sheffield Voices, LGBTQ cafe, Say it, Disability Sheffield” “Work with community leaders, organisations within communities and those with lived experience.”
- **Become all age -** the strategy plans should include the physical health of children and young people as well adults. There should be more in the delivery plan about helping older people with their physical health
- **Address gaps in supporting and engaging LGBTQ+ communities:** “I don't think we really know the experience of some groups because we don't collect the data (e.g. sexual orientation data is very poorly collected in general). I therefore think it is especially important to ask people how we can include them more in the plan”. “LGBTQIA+ is rarely asked about or taken into account from either physical health services or mental health services” “Use the names and pronouns we ask you to use, consistently across services, and if you aren't sure don't just guess”
- **Recognise with higher levels of need and cumulative impact:** “Certain communities have far more people struggling to manage their mental health i.e Lowedges, Southey, Pitsmoor. Focus funding on areas with higher deprivation and hold clinics, wellbeing sessions in these areas”

Feedback relating to physical health that was received as part of the development of the Learning Disabilities Strategy

This feedback supported the key themes coming out of the Physical Health Strategy Survey, in particular relating to reasonable adjustments, staff training, and accessibility in the community:

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- Most people said that their GP knew they had a learning disability but not that many workers in hospitals had taken time to find out
- People said there are a lack of reasonable adjustments in hospitals and doctor's surgeries such as easy read, extra time for appointments, quiet spaces, etc.
- Many people and staff find it difficult to go out in the community due to a lack of accessible toilets and changing rooms, as well as not knowing where they are.
- Some people stop going to services altogether when their buses are removed or the times are changed, and they don't have money for a taxi or their service doesn't have a minibus.
- People feel there is a lack of disability awareness in the public and spaces they visit while using services. They don't always feel safe because of this.

Disability Sheffield *Health Experiences report for people with learning disability and autism (2022)* highlighted similar issues around reasonable adjustments and the need for more staff training and awareness. Headlines from the engagement were:

- Many people told us that they had good experiences of healthcare and that they had been treated well by services.
- However, quite a lot of people told us that they were not happy and that they are not having good experiences.
- People told us that there is a lack of reasonable adjustments such as easy read, extra time for appointments, quiet spaces
- Most people we spoke to said people working in the hospitals don't know they have autism or a learning disability
- People told us that information about them is often not passed on
- Autistic people appear to be having a more difficult time in accessing healthcare than other groups
- There is a lack of understanding about learning disabilities and autism and a lack of understanding about what reasonable adjustments need to be put in place
- The booking of appointments on the telephone was very difficult for a lot of people but it was especially difficult for autistic people

Examples of feedback from the Disability Sheffield Health Experiences report for people with learning disability and autism (2022):

- “I have to remind people a lot that I have Autism, especially at hospital”
- ‘What I don't like is when the receptionist doesn't know that I have autism even after I've communicated this to them on many occasions’
- ‘I've been in hospital and being Autistic it's not a fun time. The only time it was acknowledge when I was asked whether I have other health issues’
- “I have had so many bad experiences I don't know where to start. It's hard to separate what is because of Autism and what is because of my gender history or other things”.
- “More training around autism and learning disabilities needed”
- ‘What would help me is for doctors and nurses to be trained how to cope with people with learning disabilities and autism it would be good for doctors and nurses to know what it's like in our shoes’
- ‘Just very disappointed that there seems to be a lack of support for children with Autism’
- ‘My daughter has not experienced any good examples of health care. She is 16 years old, has autism and it feels like the services are waiting for her to turn 18’
- ‘My daughter has autism and the Psychiatrist will not engage with her until she has attended CAHMS on six occasions. Social Care have now discharged her. She is currently managing her heightened anxiety by going to a dealer and purchasing weed . Nothing has really changed for my daughter apart from the injuries caused by her self harm has intensified when she does do this behaviour’
- ‘People don't read my hospital passport’
- ‘I don't get letters to tell me about changes. Letters I do get are not in easy read. Pictures would be good’
- ‘No reasonable adjustments in place’
- “I tried to ask for a quiet room often I am promised this but when I get there I might not have a quiet room and that upsets me”

Feedback relating to physical health that was received as part of the development of the Autism Strategy

This feedback supported the key themes coming out of the Physical Health Strategy Survey, in particular relating to reasonable adjustments, staff training, and accessibility in the community – for example:

Making health and care services equal for autistic people

What people have told us

Having to fight for a diagnosis of your child so they can get the appropriate support and care should not be that difficult

A lot of GPs still have old fashioned views on Autism

Turn the music off in waiting rooms and bright lights should be dimmable

As family members, we're very skilled people - care providers should ask us, we're the experts

Disability Sheffield Healthy Living and Physical Activity for people living with severe mental illness, people with learning disabilities, and autistic people Project – Consultation:

Parents/Carers:

- 90% carers said that they would only take their son / daughter to a disability specific activity.
- 88% felt that there were not enough suitable physical activities for their son / daughter to access.
- 63% said that they didn't know where to search for information about activities and relied on word of mouth from other parent / carers.

Lived Experience – Autism:

- 87% said they didn't feel confident joining an activity.
- 40% said the professionals who worked with them didn't encourage them to take part in physical activity.
- 89% said they would only access a disability specific activity.
- 67% said they didn't access groups or activities due to travelling a far distance.
- 100% said they are more likely to attend a group or activity knowing the staff have had disability training

Lived Experience – Learning Disability:

- 72% said they were aware of the benefits of physical activity.
- 48% said they had never taken part in a formal physical activity.
- 75% said they didn't know where to search for information about physical activities.
- 79% said they struggled to access public transport without support.

Lived Experience – severe mental illness:

- 66% felt there wasn't any suitable activities for them to participate in.
- 80% felt they were unable to commit to an activity due to their health.
- 69% said that costs of activities were a contributing factor for not participating in physical activities.
- 88% said they didn't feel confident joining a group /activity.

Common Themes:

- Transport
- Money
- Lack of confidence
- Physical environment
- Suitability of activities / groups
- Lack of disability awareness
- Unaware of where to look for activities

We have also drawn upon what people have said as part of wider engagement exercises... for example

“What matters to you” conversations – **key themes coming out of the NHS South Yorkshire wider engagement that are relevant to this strategy...**

- **Accessibility**

Being able to access care services in a timely and convenient way was the most commonly mentioned concern because it affects the quality of a patient’s experience. This was felt particularly strongly in terms of demand for accessing GP services. Removing barriers to accessing information, support and services were mentioned by all.

- **Affordability**

The costs of transport, parking, medication, treatments, as well as being able to live more healthily, were also mentioned universally. The cost of living challenge provides the context to these responses.

- **Agency**

Many people want to be in control of their own care and want better access to the information, tools and capacity to manage this.

“Don’t think that ‘Oh no, they have mental health conditions so we can’t use shock tactics!’ Of course you can! The dangers of smoking don’t stop just because you have a mental illness. All patients should be taught about the risks.” *Rethink expert by experience, Hannah Moore (Quoted in 7 Tips for helping smokers with MH problems quit, MH & Smoking Partnership)*

“Since starting on antipsychotics I’ve put on about four stone. It’s not the medication’s fault per se, but taking them means that I care less about things, while this is good for schizophrenia symptoms, it is not good for losing weight. I find that I am lethargic often, and the weight I’ve put on doesn’t matter to me the way that it would’ve done before I started taking meds.” – Service user (Quoted in [More than a Number](#), Centre for Mental Health).

Examples of feedback on services that have been commissioned by NHS SY ICB (Sheffield) to improve the physical health of people with SMI and LD and autistic people...

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- “I usually don’t come for my bloods as I don’t like having my blood taken, you reassured me on the phone and made me feel comfortable so I trusted you that if I came and I didn’t want them then that was also ok.” *Patient who had the full SMI check completed by the PCS SMI Annual Health Check team.*
- “The support to both patients and practice has fantastic. You have been able to provide focused care to a cohort of patients that we are not always able to reach.” *Feedback from a Surgery on the impact of the PCS Annual Health Check team*
- “Sheffield Mind helped me to book my [cancer screening] appointment, helped me get a taxi there and back and even called me to talk me through leaving the house and sitting in the waiting room. If it hadn't been for those phone calls I might have got up and left I was so nervous ... It was an easy process, simple and quick. Now I am enjoying a sense of security that I haven't felt in a while, like I just took charge of my life again. It's my body, I am going to look after it!” *Sheffield Mind SMI Physical Health Outreach Project*
- “Our Women’s mental health football league has a 30% increase in participation due to increased confidence due to networking” *Example of ‘what’s changed’ through the Disability Sheffield SMI, LD, autism Healthy Living and Physical Activity*
- “[Sheffield Mencap staff] made going to the doctors easier for me and I really appreciated her support, understanding and kindness” *Sheffield Mencap Physical Health Outreach Project*

Example of LeDeR Steering Group “Jam board”:

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