

#SpeakUp: Burton Street Foundation

What is #SpeakUp?

#SpeakUp is Healthwatch Sheffield's micro grants programme, offering funding of between £500-£1000 to not-for-profit, voluntary, and community groups. The purpose is to run a project which will reach out to people across Sheffield, and hear what matters to them in relation to health and social care.



By working with groups which are already trusted partners in their communities, we can make sure we're hearing from even more people, including those whose voices aren't often heard by decision makers.

Burton Street Foundation

The Burton Street Foundation is a not-for-profit community organisation, based in Hillsborough. We provide a wide range of day services for people with learning disabilities.

All sessions are designed to help develop self-esteem, self-confidence and self-awareness. They explore new sensory activities, encourage discussion and expression of feelings and thoughts, and enable people to reach their own personal goals.



Healthwatch Sheffield

Healthwatch Sheffield Healthwatch Sheffield helps adults, children and young people influence and improve how NHS and Social Care services are designed and run. We're completely independent and not part of the NHS or Sheffield City Council. We want to understand your experiences, and help your views to influence decision-makers in the city.



Background

Why did we carry out this project?

People with a learning disability are likely to have poorer health outcomes compared to the general population. It is recommended that adults with a learning disability have [annual health checks](#) to help them stay well; their GP should offer this each year.

It is also advisable for people to have a hospital passport prepared, in case an individual has to go into hospital without a close carer. The hospital passport enables hospital staff to have a fuller understanding of the needs and preferences of that individual.

We wanted to understand people’s level of knowledge about annual health checks and hospital passports, find out people’s experiences of them, and if there are any barriers to accessing them. We also wanted to support people to access these resources where they have not previously done so. You can find a blank hospital passport on page 12.

Who did we speak to?

Staff at Burton Street Foundation have regular conversations with family carers and support workers, carrying out welfare checks and having a general chat. Between July and August 2021, staff surveyed the family members/support workers of 152 people to find out more about the experiences of adults with a learning disability.



56% of those with a learning disability were women, 44% were men



27% of people live with family
23% live in supported living
50% other/unknown



People ranged from 20 to 78 years old, with an average of 33

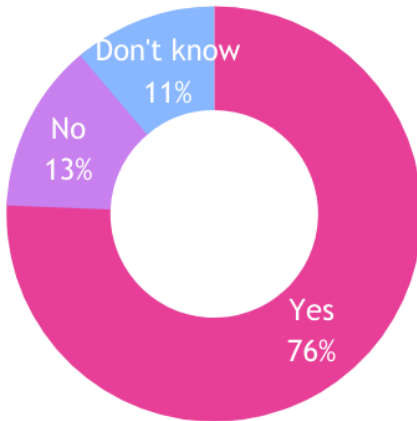


12% can read
32% cannot or have difficulty reading
56% unknown

Those surveyed had a wide range of needs. Each of them had a learning disability, and many had additional needs - physical disabilities, difficulties with mobility, mental health conditions, autism and more.

Findings

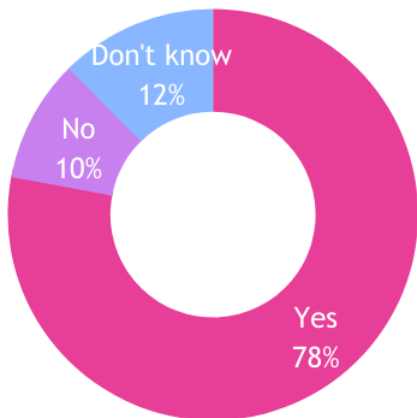
Annual health checks



Is your client/family member offered an annual health check from their GP?

The majority of people (76%) said that their family member does receive an offer of an annual health check from their GP.

26% of people said that they don't or that they didn't know.



If so, do you attend?

Most people (78%) do attend their annual health check when they are offered one.

However, when we consider those who don't take this up combined with those who are not offered an annual health check, a significant number of people could be missing out on this health intervention.

People's experiences of annual health checks

84 people told us more information about their annual health checks - whether they are invited for them, how their latest check went, and how suited they are to the individual needs of the person with a learning disability.

Good experiences



33 people said they were happy with the annual health checks their GP provides for their family member/client. Most of these said that *“all went well”* and *“everything was covered”*. Some gave more specific feedback, much of which focused on proactively identifying health issues as well as the importance of building a relationship with a regular GP and being accommodating of individual needs:

“We always attend as it gives me a chance to just think about any health issues [she] may be having that need to be addressed. I think it’s good for [her] to go to the surgery even if she is usually less than cooperative!”

“Could not have a better GP service, very accommodating to [her] needs. No complaints at all”

“Went very well last year, doctor showed interest and was chatty”

“GP is pretty good on annual health checks. It gets flagged up alongside his medication review so it isn’t missed”

“Very good, had blood tests, highlighted a vitamin D deficiency and an underactive thyroid”

“Really good doctors. Really good practice nurse. Always available. Known [her] since she was a baby”



Not being invited for a health check

19 people said their family member/client had not been offered an annual health check, or that they were not offered them consistently. Some people had had an annual health check previous but were no longer invited:

“Not been offered an annual health check”

“Never been offered one. Has an asthma review but that’s it”

“Would attend if one was offered”

“Only been invited to about 3-4”

“It’s been about 4 years since she had one”



Having check ups for other health conditions

5 people told us that their family member/client has regular health checks for other health conditions, so don’t always feel the need to take up their annual health check.

“[She] has very regular health checks due to her multiple health conditions”

“She does have a regular annual health check regarding [another health condition] and they have a medication review. She maybe doesn’t have an “annual Health Check” as it is covered by this”

“Sees so many health care professionals/consultants throughout the year, that a nurse taking some bloods once a year isn’t worth it”



Having a health check over the phone

16 people told us about their family member/client’s most recent annual health check taking place over the phone. People were generally understanding that Covid-19 meant they couldn’t attend in person, though many did feel that a telephone call wasn’t quite the same:

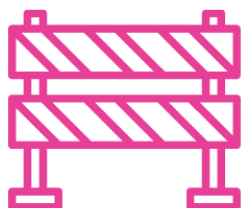
“Last health check was done by forms and over the phone. Mum is very pleased with the GP, could not be better”

“Telephone consultation - happy it still went ahead”

“Phone consultation last time due to Covid - not ideal, but generally fine”

“Normally very good, not so good over the phone as it had to be this year”

“This year it was done on the phone which was no-one near as good. Next time needs to be face to face. In this way they can judge the whole situation better. Even Zoom would be an improvement, but no substitute for face to face. You get a feel for the person advocating and their relationship with that person which is important to the way to support that individual.”



Barriers to getting a health check, and negative experiences

8 people shared more negative or mixed experiences with us, telling us about a barrier they’ve encountered or a way in which a GP practice hasn’t been suitable for an individual’s specific needs, which may have put them off:

“Could have been better. With the flu jab, an inexperienced nurse tried to give her the injection instead of the nasal spray. Mum was insistent she have the spray, mum was upset they hadn’t made reasonable adjustments. [She] needs experienced staff, taking their time”

“GP sent a questionnaire last year which was unsuitable. Questions not appropriate. [We] would like this process to be more tailored to [her] needs”

“Depends who you see. Practise nurse does the basics, GP asks more questions”

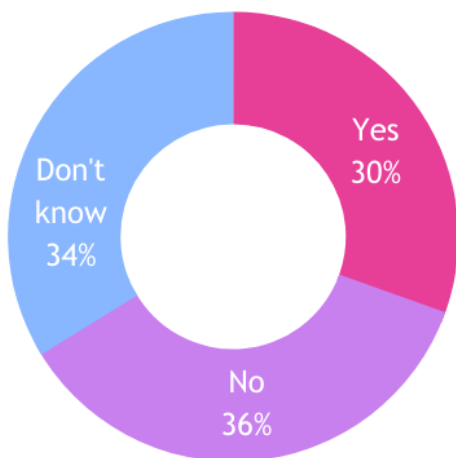
“Outcome depends who he sees. He needs access to the right GP, reception should be more responsive to his needs”

“It’s too far away”

“[She] doesn’t like the GP and refuses to go. She has a fear of GP’s. It took 4 people to get her to hospital in an emergency.”

“Can feel like a box ticking exercise sometimes”

“[He] is physically fine but mental health is up and down, needs more support in this area”



Has your annual health check been delayed this year due to Covid-19?

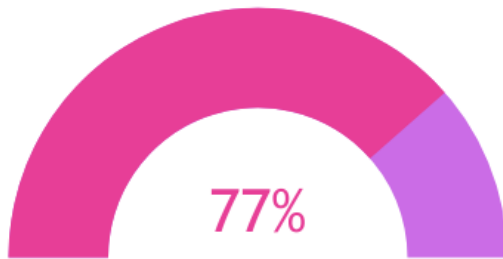
There was a fairly even split between ‘yes’, ‘no’ and ‘don’t know’ here. Based on what people told us above about their family member/client’s most recent health checks, it is likely that many of those which weren’t delayed took place over the phone.

From this question we can see that people with a learning disability have not all been able to access care to the same extent during Covid-19. We do not know whether individual GPs took a blanket approach

to their patients who were on the learning disability register - ie decided to delay all annual health checks or do them all over the phone - or whether they were offered a choice between a telephone appointment or waiting for a face to face one.

A significant number of people also said they didn’t know whether their family member/client’s annual health check had been delayed. The reason for this is uncertain, but it does suggest that some people rely on the invitation from their GP to remind them that their check is due, rather than requesting one themselves. If this is the case, it is important that GPs are being proactive in reaching out and enabling people to attend their annual health check.

Hospital passports



Do you know what a hospital passport is?

The majority of the people we asked (77%) said they did know what a hospital passport was.

This question prompted a large number of additional comments, which we have summarised below.

People's experiences of using hospital passports

102 people had further conversations with us about hospital passports - many of these were so that staff could provide more information about them and send blank copies out for people to use. Some people also told us more about their previous experiences.



Many people already have a hospital passport

59 people told us that they already had a hospital passport.

Sometimes a health or social care professional was the one who suggested filling this out, while others said they had to find out about this themselves:

"The transition physio discussed it with me when she came to do transition report"

"Filled one out with a social worker once"

"Never been asked about a hospital passport before but did own research and has got one"

3 people told us that they had an alternative system in place - one parent had developed their own system for when they visit hospital, one used a form that their GP had given them, and one person's support provider had an online system which they could use, which was updated regularly.

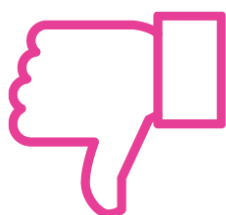


Some people think hospital passports are a good idea

We did not hear many experiences of people having successfully used a hospital passport during a trip to hospital, possibly because they haven't had to go into hospital since creating one. 1 person did say that it was a *“really good helpful document”* for them. Other people shared their support for the passports, even if they hadn't used one so far:

“Mum fully backs the hospital passport idea, as she had a difficult experience with the hospital when [daughter] broke her leg and it wasn't recorded on her notes that she had a learning disability”

“Understand potential importance in COVID times, if they can't be there in person. Has been their biggest concern”



Some people didn't think they would be useful

On the other hand, 8 people said they didn't think the hospital passports were useful. For a few, this was because they didn't feel they were suitable:

“Doesn't contain enough information”

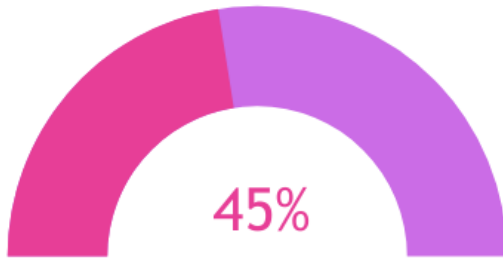
“Constantly updating the information. By the time you've finished, something has changed”

For most people, it was because they didn't believe that hospital staff would actually read and use the passports. There was a lack of faith that people's needs and preferences would be taken seriously:

“Have only ever seen one nurse reading it late on a night shift. Overwhelmingly people never read them”

“Doesn't serve purpose. Recent trip to hospital no hoist/generally unprepared”

“Mum happy to fill it in and knows it is a good idea but from her experience working in hospital settings, she fears that they won't look at the passport”



Would you like a blank hospital passport to be sent out to you?

Nearly half of the people we surveyed wanted a hospital passport to be sent to them, so they could fill it in with their own individual needs.

Despite most people initially saying they knew what a hospital passport was, a lot of people didn't currently have one. The number of people who wanted help to create one after we were able to have a more detailed discussion about them does show enthusiasm for the idea, but also suggests there had been barriers to creating one in the past.

Some people (23% as seen on page 7) didn't know what they were, but for others the things stopping them had been more varied. Some had heard of them before but didn't fully understand their purpose. Others needed support to fill one in, while for some people the other pressures of their caring role may have meant they had struggled to find the time:

“Wanted to get one more tailored but has got bogged down in the paper work”

“Would like help to make one”

Project impact: Increasing uptake of hospital passports



The discussions we had about hospital passports resulted in a number of people wanting to create one. As a result, we sent out **66** blank passports to people who requested them, and offered guidance on how to fill them in.

We hope to see wider uptake of this resource as well as more consistent use of them by hospital staff.

Conclusion and recommendations

Conclusion

Annual health checks:

- Most people are offered an annual health check and do take them up, but there are still improvements to be made to ensure everyone can benefit from these checks
- People were understanding when annual health checks had to take place over the phone during Covid-19, but most would like to see them return to face to face appointments as standard
- Where people are happy with the service they get from their GP, key factors are a familiar GP who they can build a relationship with, and a GP practice which recognises their individual needs
- Where people are unhappy with the service, their experience largely lacks those key factors - they see a different professional each time which means their experience varies or they cannot build a relationship, or the check is not carried out in a way that is suitable for their particular needs
- People do not always know when their next annual health check is due, so it is important that they receive reminders from their GP

Hospital passports:

- Most people know what a hospital passport is, but this does not mean everyone has been able to create one. For some this is because they needed to be given more information about it to make a decision, or needed support to understand and fill one in
- Another barrier to using hospital passports is a belief that hospital staff will not read and use them - for some this is based on previous experiences of health and care professionals not taking the time to learn the specific needs of the individual, either through a hospital passport or other means
- Many people are interested in having a hospital passport, but people's reservations about them would need to be addressed in order to make them more useful and more widely used

The barriers that some people face accessing these resources may be further amplified due to factors such as ethnicity or socio-economic background; service providers should be especially mindful of those who may find it even harder to access support and be pro-active in reaching out.

Recommendations

The recommendations below are based on the findings in this report. These recommendations are aimed at commissioners and providers of health and social care services working with adults with a learning disability and their families.

GP practices should endeavour to increase uptake of annual health checks by:

- Ensuring that all their patients with a learning disability are on the learning disability register so their needs are identified
- Proactively inviting all people eligible for an annual health check each year; not everyone will reach out to book one themselves
- Enabling people to attend their annual health check wherever possible; this may mean making reasonable adjustments such as time of appointment, seeing their regular GP, who they can bring with them, what information you should send out to them to prepare for the appointment (eg an Easy Read pamphlet explaining the procedure)

Hospitals should increase awareness and use of hospital passports by:

- Increasing awareness and knowledge of the importance of hospital passports amongst hospital staff through training. Training sessions could also explore existing barriers to staff using the passports (eg due to their length) and changes that could be made to the passports or the hospital systems to increase their ongoing use
- Developing a monitoring mechanism to check whether hospital staff are looking at hospital passports during an inpatient stay
- Ensuring that hospital systems flag that a patient is on the Learning Disability register when they are admitted; if so, staff should ask the individual/their family if they have brought a hospital passport that staff should be made aware of

Community based health professionals and social workers should support use of these resources by:

- Providing information to individuals with a learning disability and their families/carers to help them understand the benefit of a hospital passport
- Supporting people to fill in their hospital passport, or signposting them to voluntary sector organisations who can support them with this
- Encouraging all patients with a learning disability to attend their annual health check appointment

Appendix - blank hospital passport




This is my hospital passport

For people with a learning disability coming into hospital

My name is:


If I have to go to hospital this book needs to go with me, it gives hospital staff important information about me.




It needs to hang on the end of my bed and a copy should be put in my notes.


This passport belongs to me. Please return it when I am discharged.

Nursing and medical staff please look at my passport before you do any interventions with me.






Things you must know about me





Things that are important to me





My likes and dislikes


Things you must know about me


 Name:


 Likes to be known as:


 NHS number:

 Date of birth:

 Address:

 Tel no:


 How I communicate/what language I speak:


 Family contact person, carer or other support:

Relationship eg Mum, Dad, home manager, support worker:

Address:

Tel no:


 My support needs and who gives me the most support:

 My carer speaks:

Date completed by 1

12


Things you must know about me



Religion:

Religious/spiritual needs:

Ethnicity:




GP:


Address:

Tel no:


Other services/professionals involved with me:




Allergies:



Medical interventions – how to take my blood, give injections, BP etc.



Heart
Breathing problems:



Risk of choking, dysphagia (eating, drinking and swallowing):

Date completed by 2

Things you must know about me



Current medication:



My medical history and treatment plan:



What to do if I am anxious:

Date completed by 3

Things that are important to me



How to communicate with me:



How I take medication: (whole tablets, crushed tablets, injections, syrup)



How you know I am in pain:



Moving around (posture in bed, walking aids):



Personal care (dressing, washing, etc):

Date completed _____

by _____

4

Things that are important to me



Seeing/hearing (problems with sight or hearing):



How I eat (food cut up, pureed, risk of choking, help with eating):



How I drink (drink small amounts, thickened fluids):



How I keep safe (bed rails, support with challenging behaviour):



How I use the toilet (continence aids, help to get to toilet):



Sleeping (sleep pattern/routine):

Date completed _____

by _____

5

My likes and dislikes

Likes: for example - what makes me happy, things I like to do
ie watching TV, reading, music, routines.

Dislikes: for example - don't shout, food I don't like, physical touch.

Things I like

Please do this:



Things I don't like

Don't do this:



Date completed

by

6

Notes

7