



healthwatch
Halton

14+ Annual Health Check review

March 2024



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14+ Checks Review Annual Health

Introduction

Halton SEND Parent Carer Forum (HSPCF) is a not-for-profit organisation. It is a representative local group of parents and carers of children and young people with special educational needs and or disabilities (SEND) aged 0 – 25 years. HSPCF work alongside the local authority, education, health, and other service providers to ensure the services they plan, commission, deliver and monitor meet the needs of children and families in Halton.

Healthwatch Halton is the independent voice of the public in health and social care services in Halton. They gather feedback from members of the public about their experiences of using health and social care services. They use that feedback to work with service providers and commissioners to find ways of improving services for the public. One of the ways that Healthwatch collects feedback is through carrying out a focused project around particular services, conditions, or groups within the community.

HSPCF and Healthwatch Halton worked together and completed a project to assess the eligibility for 14+ annual health checks in Halton and the impact for those with SEND who do not meet the criteria.

The project aim was to explore concerns around health inequalities and barriers in seeking support from medical services and to gather people's experiences, concerns, and ideas so they can be represented to key stakeholders.

The current criteria to qualify for an annual health check for those aged 14+ is to have a learning disability. The Halton Learning Disability (LD) nursing team currently use the Mencap definition:

<https://www.mencap.org.uk/learning-disability-explained/learning-difficulties>

What is a learning disability and learning difficulty? Upon looking at the Mencap definition, the following was established:

Learning disability is:

- Reduced intellect ability
- Difficulty with everyday activities such as;
- Household tasks
- Socialising
- Managing money

Learning difficulty is:

- Doesn't affect intellect,
- and includes conditions such as those below:
- Dyslexia
- ADHD
- Dyspaxia
- Dyscalculia

Using autism as an example which is a lifelong neurological condition. Close to 50% of autistic individuals have a learning disability too, so would be entitled to a 14+ annual health check. That means over 50% do not and are not entitled to an annual health check. Evidence tells us that many autistic individuals struggle with social communication and socialising, in addition to some struggling with managing money and organising household tasks, which are listed as a learning disability in the Mencap definition.

Previous data showed that the average life span of an autistic individual was 58 years old and 39.5 years with a learning disability too (Hirvikoski, T, et al. 2016). However, in contrast and demonstrating current awareness, new research has emerged (Lancet, 2024). Autistic men without a LD had an average estimated life expectancy of 74.6 years and autistic women without an LD around 76.8 years. Meanwhile the estimated life expectancy for people diagnosed with autism and a LD was around 71.7 years for men and 69.6 years for women. These figures compare to the usual life expectancy of 80 years for men and 83 years for women living in the UK. The article further stated autistic people experience health inequalities, meaning that they often don't get the support and help that they need, when they need it.

Furthermore, it is important to note that autistic individuals are 9x more at risk from suicide (Autistica, 2022) than their neurotypical peers. Many fear going to see their GP and other medical professionals. Again, this could be argued is more evidence to show that having an annual health check from a young age could help those individuals to get into a routine of seeing their GP and this could subsequently help to detect serious health conditions at an early stage and in essence save lives.

What we did

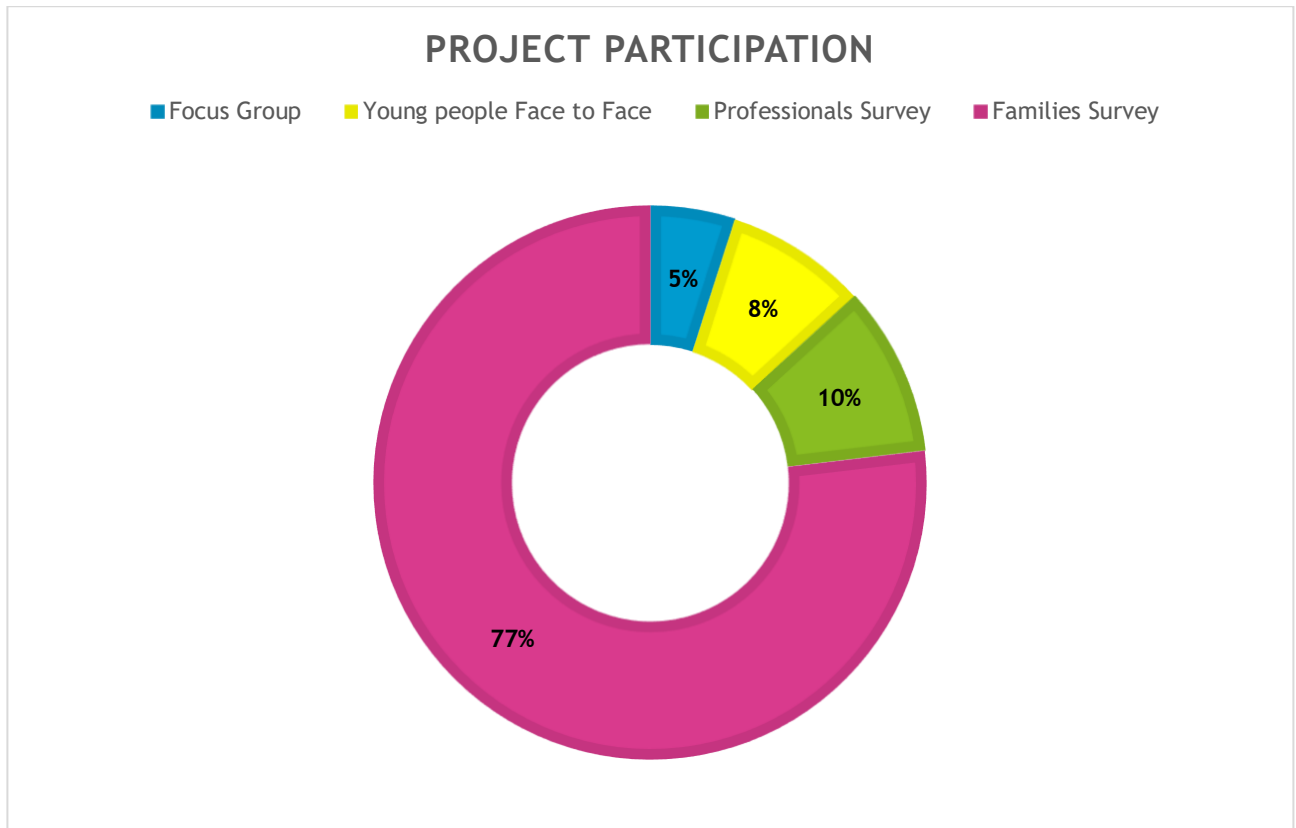
A mixed methods approach was utilised for this project by subsequently using surveys and focus groups. Two surveys were created, one for parents, carers, children and young people and the second for medical professionals at GP surgeries across Halton. Focus groups were aimed at both professionals and parents, carers, children and young people. One focus group was held for parents, carers, children and young people, as there was a limited uptake from medical professionals.

The surveys were promoted by using the existing network of HSPCF and Healthwatch Halton partner agencies. This provided the opportunity to speak with parents, carers, children and young people and complete the surveys. The survey for SEND families was available online from 08 December 23 to 08 January 24. Due to low initial response rate, the survey for professionals was available from the 08 December 23 and extended to 22 January 24.

Who took part

A total of 121 people from Halton participated in the project. Six people engaged in the focus group, ten children and young people in a face-to-face discussion, 93 individuals completed the families survey, and 12 medical staff completed the professionals survey. The breakdown of participation can be observed in the chart below.

Participation



Demographics

A total of three demographic questions for the surveys and focus group were asked to ensure all parts of the targeted community, had been reached.

Age, gender and ethnicity were on all research materials, however these questions were optional and participants did not have to answer them if they didn't want to.

The data gathered was subsequently collated and is represented on the tables below:

Who took part?

55 people were female
10 people were male
1 person was non-binary
55 people chose not to disclose their gender

9 people were 14 to 17 years of age
10 people were 18 to 24 years of age
10 people were 25 to 34 years of age
44 people were 35 to 54 years of age
4 people were 55 to 69 years of age
44 people preferred not to give their age

Ethnicity	Number of people
White	61
Mixed/Multiple Ethnic groups	3
Asian/Asian British	2
Black/African/Caribbean/Black British	2
Other Ethnic Group	0
Undisclosed	53

Report Findings

Focus Groups

A focus group took place at offices in the Runcorn Community Shop on the 01 February 2024. This was attended by six parents/carers, all of whom have personal experience of caring for children and young people with SEND, with two also having a medical background.

The feedback received was analysed thematically for themes and trends.

Question 1 asked attendees

Are you aware that the MENCAP definition is used to distinguish what a learning disability and learning difficulty is and this determines the eligibility criteria, for having a 14+ annual health check in Halton?

Two themes emerged, **eligibility** and **health inequalities**.

All attendees were not aware of the Mencap definition and criteria, all agreed that it is a grey area and that ALL individuals with SEND should be given the option to have a 14+ annual health check.

Eligibility was a commonly discussed theme that arose, with one person saying, *'all children with SEND should be given the opportunity to have an annual health check'*. Another said, *'SEND children are vulnerable and need more support than their peers'*, whilst another parent said, *'from looking at the criteria my son has a learning disability (LD) and I have never seen a learning disability nurse and don't know how to even get a LD diagnosis.'* One parent said, 'I have never heard of a 14+ annual health check.'

Health inequalities was another theme discussed with one saying, *'it can be hard to get support for children with hidden disabilities'* another commented, *'there are barriers to access healthcare services in*

Halton. Whilst someone said, *'It's hit and miss depending on what GP surgery you attend, with no continuity'* with another parent saying *'medical professionals often ignore parents and there is zero support post diagnosis.'* A further comment was *'health checks and blood tests are so important for SEND people, especially for those that are non-verbal or don't realise warning signs.'* Someone else said, *'it feels like no one takes ownership.'*

Question 2

What is your awareness or experience of 14+ annual health checks?

Two themes emerged, continuity and parents/carers feeling unheard.

Continuity

A lack of continuity of experiences from GP surgeries in Halton, this was discussed with one parent telling us *'I asked the nurse at my GP surgery about 14+ health checks for my child and was informed it is just to check that dental and optician checks are up to date'* whilst another advised that *'although my son is non-verbal and has significant delays, I have never heard of a learning disability nurse, or how to get a LD diagnosis or even a 14+ annual health check'.*

Another reported that *'although my son is not on the LD register as he doesn't have a LD, upon my request the GP surgery put him on the LD register and he gets called for an annual health check every year. I am happy with the service my son receives – blood tests, a full MOT check and medical things have been picked up as he sees a good nurse clinician.'*

Parents/carers feeling unheard

Parents/carers feeling unheard was discussed as they often have to advocate for their children who cannot do it themselves. One said, *'It is so frustrating when they ask my non-verbal child questions'*, someone else said *'I was able to view my sons medical records via patient access, but now he is 14 I cannot, he is non-verbal with lack of understanding so needs my assistance, better understanding of SEND children and their capacity is needed, rather than looking at their chronological age'*

Another person commented *'medical staff have a lack of SEND understanding and will believe what the young person is saying, SEND people can tell medical staff what they think they want to hear. My son will do this, so it is important to listen to the parents/carers who are their advocates/appointees too, who can guide and prompt their young ones to be able to elaborate.'*

Question 3 Are you happy with your children's health care support?

Two themes emerged, gaps in provision and post diagnosis.

Gaps in provision

Gaps in health services across Halton was another theme discussed, a parent informed *'when there are gaps in services and your child is left without support, GP's are not trained to help with conditions such as premenstrual dysphoric disorder (PMDD), then your child's mental health declines which has an impact on their daily life such as being able to go to college etc.'*

Another stated *'there is a lack of understanding with autistic burnout from medical professionals, I was asked to take my child into the surgery when she can't leave the house'*.

Someone else said, *'when your child is not diagnosed early with their conditions such as autism and ADHD and then doesn't receive the adequate support, they face trauma like my child who has been diagnosed with an eating disorder, anxiety and depression.'*

Post diagnosis

All six attendees highlighted the lack of support post diagnosis with one parent telling us, *'after battling for years to get the right diagnosis for my son which took going through the process 3 times at children's services, Woodview child development centre (CDC) my husband and I were shocked that, that was it - a piece of paper and then nothing.'*

Another person said, *'yes no support from medical professionals, just left to get on with it'*, with another saying, *'you learn more and get support from parent/carer groups and charities.'*

Another person agreed saying, *'you feel very alone and left to get on with it following your child's diagnosis, and definitely learn from and feel supported from other SEND families.'*

Question 4

Who do you think is best equipped to carry out annual health checks for those with SEND?

All participants shared the opinion that a LD nurse would be best suited.

Learning disability nurses

All attendees agreed that from their experiences with medical staff, learning disability nurses would be best suited to conduct 14+ health checks. One parent said *'GP's lack of understanding around SEND is*

very frustrating’ with another stating that *‘the nurse clinician was good and had a better understanding of SEND than our GP’*.

Another parent said *‘it is very frustrating when GP’s don’t have an understanding of SEND’* whilst another agreed with *‘ignorance from health care professionals not knowing about SEND when we take our children to see them is annoying’*.

One person asked *‘I would like to know what SEND training is given to healthcare professionals and staff who carry out the 14+ health care checks to be able to understand the young person and their needs?’*

Question 5

Is it Important for an advocate/appointee to attend medical appointments with individuals with SEND?

Two themes emerged unheard advocacy and health passports/one-page documents.

Unheard advocacy

One parent told us *‘whilst I appreciate it’s important to get the young person’s voice, my son is unable to do this and as his appointee/advocate I often feel ignored by medical staff’*, with another saying *‘it’s important I am there with my son as he would say everything is ok, but I help him with prompts and he is able to expand his answers with my assistance and important medical things have been picked up.’*

Someone else stated, *‘there is definitely a lack of understanding with hidden disabilities, just because a young person is verbal doesn’t mean they don’t have social communication difficulties and don’t need*

an advocate. Medical staff need to listen to advocates and appointees more, who are trying to support their loved ones to get the best medical support.'

Health passports and one-page documents

One person commented, *'my son has a health passport, but they are too long and medical staff don't have time to read them.'* Another told us, *'a short document is needed for those with SEND, so medical professionals know the important things straight away.'*

One person said, *'yes so medical staff would know straight away my child is non-verbal, so please don't expect a response from him.'* Someone else commented, *'having a short profile document would be a great benefit as it is not nice having to say negative things about your child to medical staff when they are sat right next to you, more awareness is needed about one-page profiles.'*

Question 6

For those eligible for a 14+ annual health check, is 14 the right age for them to start?

We received a unanimous **'no'** from all attendees. One parent said, *'this age is really difficult for many teenagers going through puberty and already being embarrassed and when you add SEND into the mix it brings a lot more struggles.'* Another stated *'I think the best age for annual health checks to start would be when they are in year 6 so about 10 years old before that transition to high school.'*

Another person commented *'starting them earlier about age 10 would help to get into the routine of having health checks and seeing a medical professional and would be less embarrassing than to suddenly start going when aged 14.'*

One more parent commented *'I am autistic myself and really do not like attending the doctors as it causes anxiety, I will bury my head in the sand and have nearly died in the past with a ruptured appendix as I didn't seek medical intervention earlier.'*

Question 7

Do you feel there is a link between medical and educational support for SEND children and young people?

Two themes emerged, education and wait times.

Education

One parent commented, *'absolutely they do, EHCP's need evidence and from my experience medical and education systems don't link up. It's a vicious circle really and very stressful.'*

Another parent said, *'masking/camouflaging your disabilities means there is a lack of evidence, my child does this and there was no evidence in school. Therefore, education staff could not provide detailed evidence to medical staff, which meant years of battling for a correct diagnosis and for an EHCP to be put in place.'*

Someone else said, *'they closely link but the two services don't talk to each other properly and children are left suffering without the right level of support'.*

Another parent stated, *'my son currently has an older teacher and she does not have a good understanding of ADHD, so I am having to educate her to be able to help and understand my son in school. More training is needed for education staff, this is important as health professionals ask teachers for evidence. This can result in children not receiving an EHCP or the right level of support.'*

One person said, *'teachers need a better understanding of health conditions such as PMDD and this should be taught in the curriculum alongside puberty and sex education. PMDD affects 1 in 5 girls and better education is needed so girls gain an understanding and are not left suffering without support.'*

Another commented, *'I feel it would be a good idea to give out handbooks to parents of what you may need to know when your child receives a diagnosis, it would also be a good idea for teaching staff to have something similar of how they can best support children with conditions such as autism and ADHD to have an understanding of these, so they can spot the signs.'*

Wait times

One parent stated, *'all SEND families I know have experienced delays in health assessments for autism and ADHD'* With another saying *'it has taken me years and 3 attempts to get my son correctly diagnosed, due to autistic masking.'* Someone else said *'the delays are so frustrating, with not only children's services at Woodview CDC, but the SENCo's at school being so busy, it's the constant chasing and lack of communication.'*

Finally, e-learning was discussed (by the parents with a health background) and how it was felt that face to face SEND training would be best delivered, by SEND experts by experience with the opportunity for medical professionals able to ask direct questions would be more effective.

Young person's voice

To help capture the young person's voice, a discussion also took place at an Inclusivitee CIC youth hub session. This was held at Cavendish High Academy, Runcorn on the 01 March 2024. This session caters for young people with SEND aged 16 to 25 years. Ten young people were asked for their opinions and experiences if any, about 14+ annual health checks. Again, the feedback received was analysed thematically for themes and trends and three themes emerged from the collected data.

Anxiety

Of the ten young people, seven confirmed they get anxious when attending medical appointments.

One young person said, *'I really don't like going, it is so stressful and horrible it causes my anxiety to rise.'*

Whilst another said, *'I have not had good experiences, I find the questions hard to understand so don't like going.'*

Another stated, *'I don't like on the spot questions as find communicating hard'*, whilst in contrast one reported, *'I am happy to see medical staff when needed and am ok talking to them, but still need a family member with me.'*

Another young person said, *'I will go to medical appointments as I know they are there to help me and am ok talking to the medical staff.'*

Advocates

Even though all who took part in the discussion are verbal, have varying levels of SEND and age range, all ten individuals stated they need an

advocate such as a parent to accompany them to medical appointments. One young person said, *'although I can talk to the medical professional, I still need my mum there just in case something goes wrong.'*

Another stated *'it's too stressful, but it's important so I know I have to go, but with my mum or dad.'*

Someone else said, *'I don't like going to the doctors, but it helps when my mum is with me as I know she will help if I struggle to speak or get mixed up as I am anxious.'*

Another individual said, *'my mum always comes with me to any doctor's appointment, as I sometimes don't understand what they are saying, and my mum helps me so I can answer. At some appointments I have felt they are rude to me when talking about my weight.'*

Eligibility

Six of the ten young people are not eligible for a 14+ annual health check.

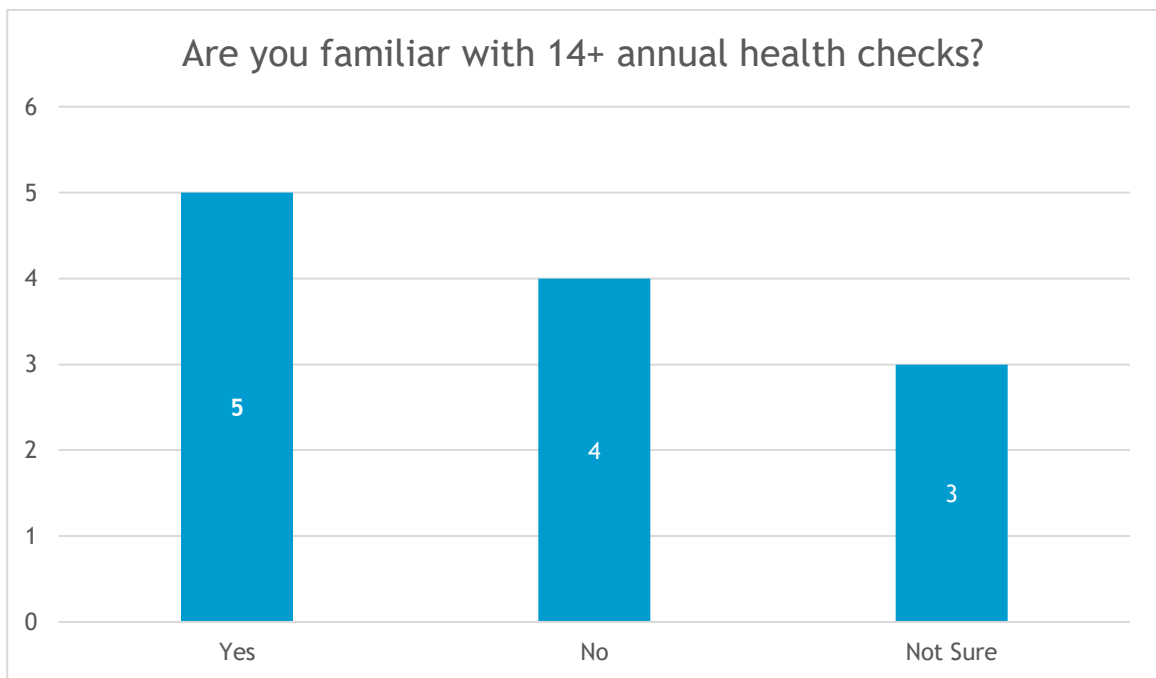
All ten individuals with SEND were not familiar with the term 14+ annual health checks. They rely on the help of their parents/carers to arrange medical appointments for them.

One stated, *'I don't know what a 14+ annual check is, my mum makes a medical appointment for me when I am not well.'*

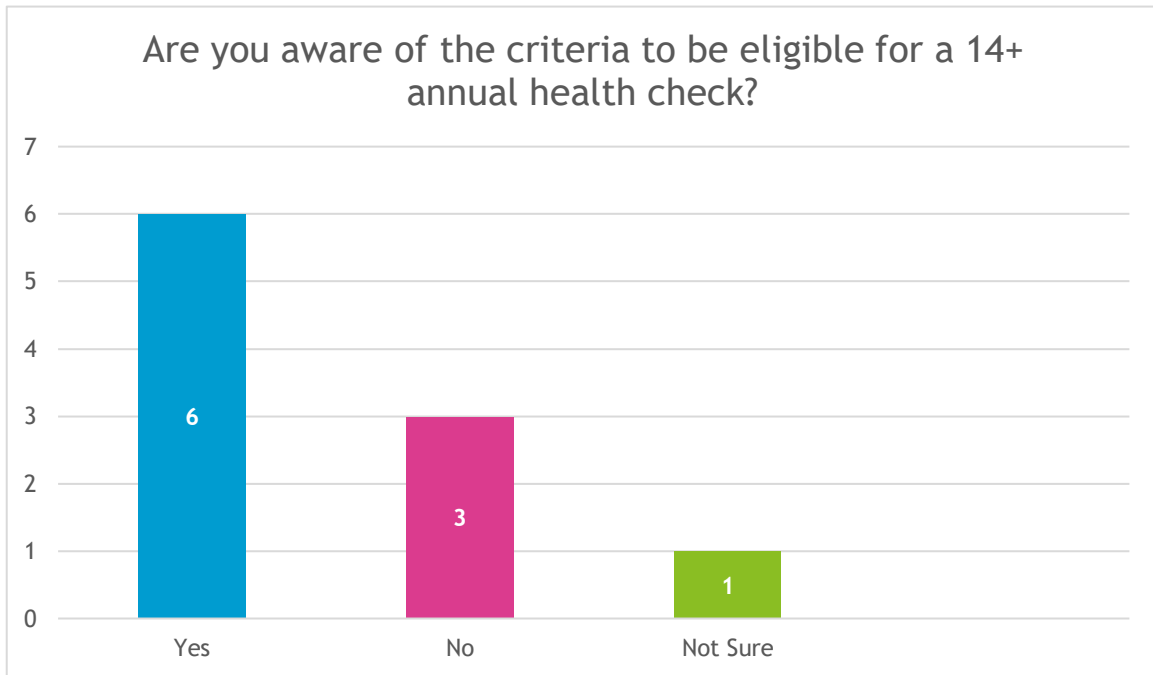
Another said, *'no I don't go to the doctors for an annual health check, I go to an EHCP annual review though.'* Someone else said, *'I have had health checks, my mum sorts it out for me as its very important to go.'*

Professionals Survey

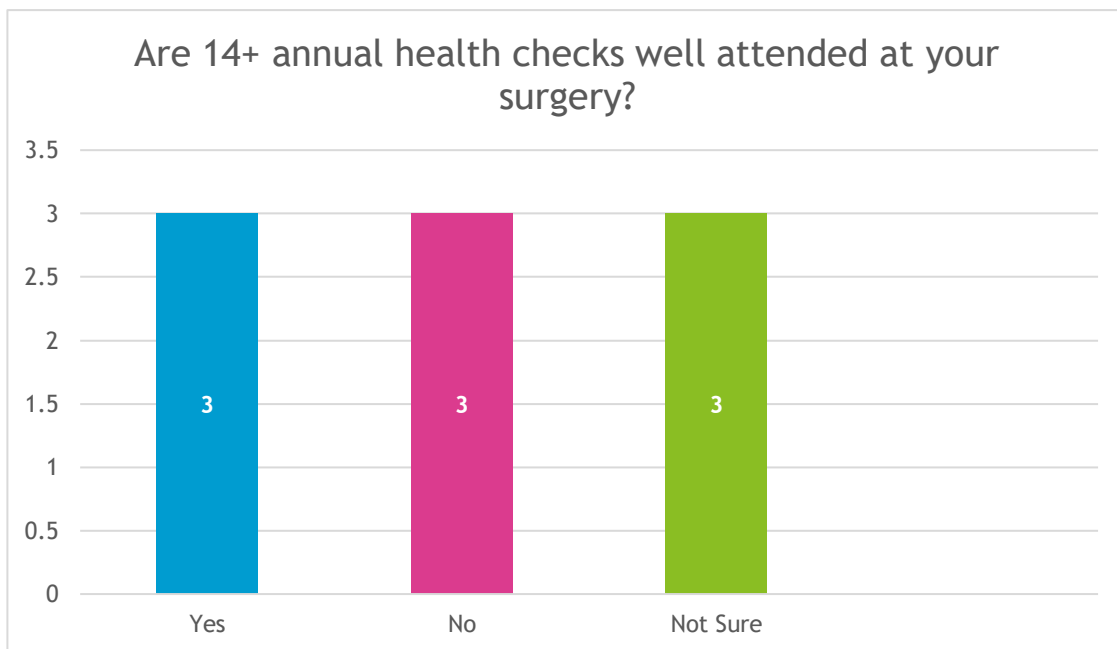
The survey was made available online and emailed out to all GP surgeries across Halton. The deadline was extended to try to gather more responses, twelve responses were received.



Question 1 Twelve people responded to this question, the chart above shows five individuals said 'yes', four said 'no' and three 'not sure'. Therefore, although 'yes' is the most common answer here, 'no' and 'not sure' combined confirm that medical professionals taking the survey do not know about or are not aware of 14+ annual health checks.



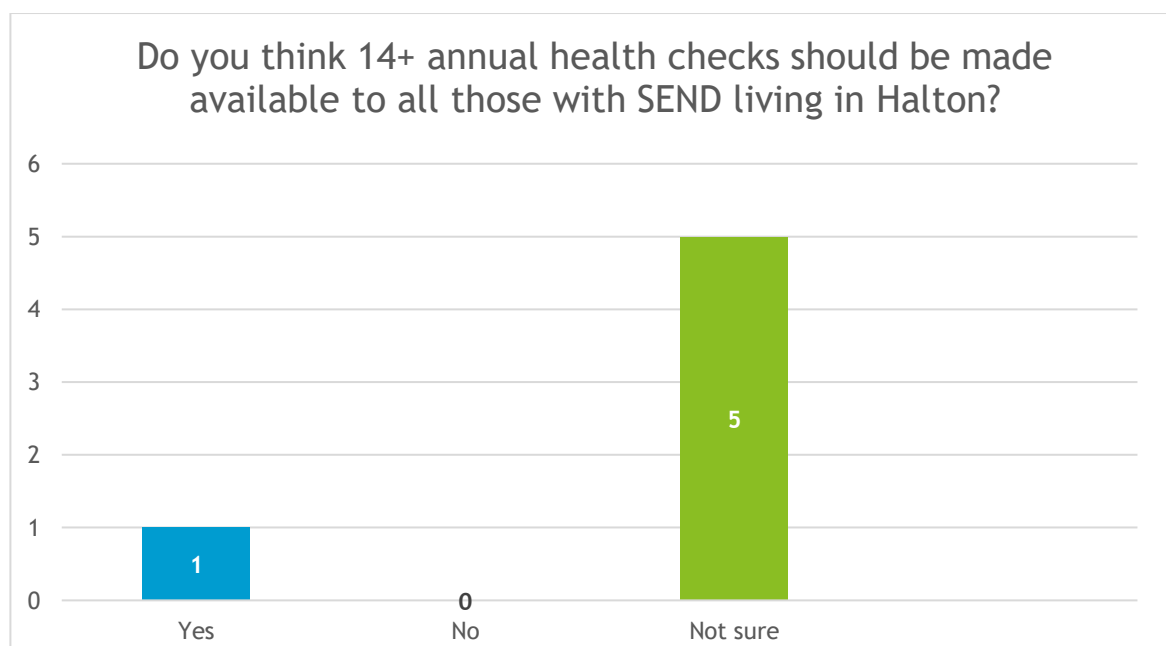
Question 2 Ten individuals answered this question, with results above showing six answered 'yes', three 'no' and one 'not sure'.



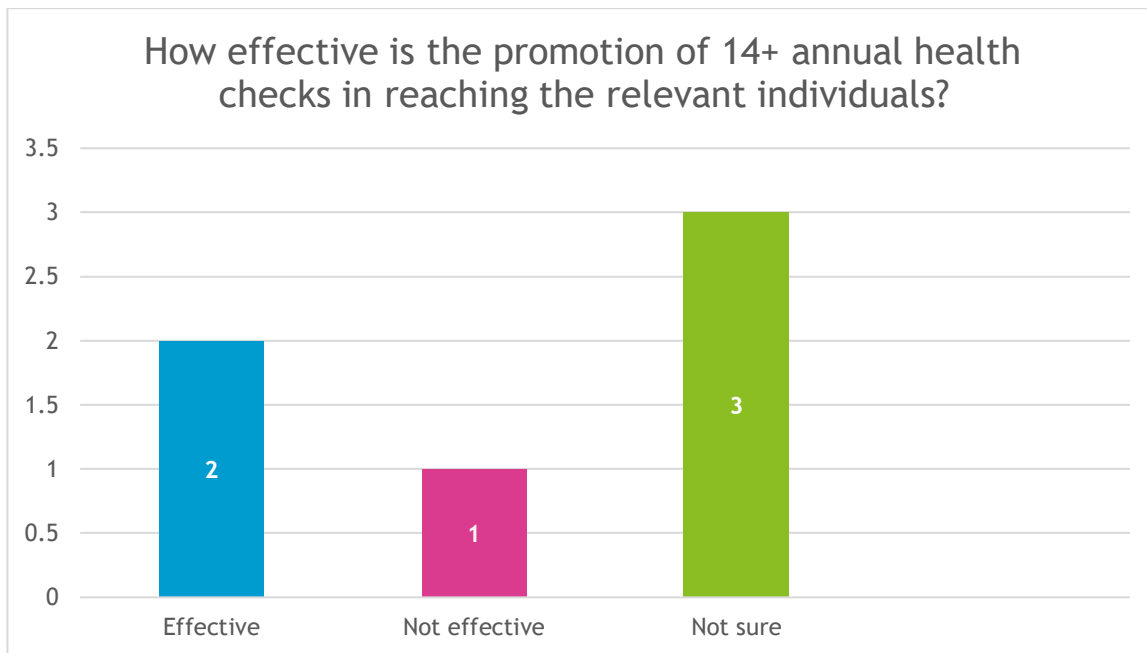
Question 3 Nine professionals answered this question. All three responses were equal. With only three out of nine saying 14+ annual health checks are well attended, there is an obvious need for improvement in this area.

Question 4 was an open text question asking professionals which GP surgery they work at. Six professionals answered this question with five GP surgeries in total, of which three are located in Widnes and two in Runcorn.

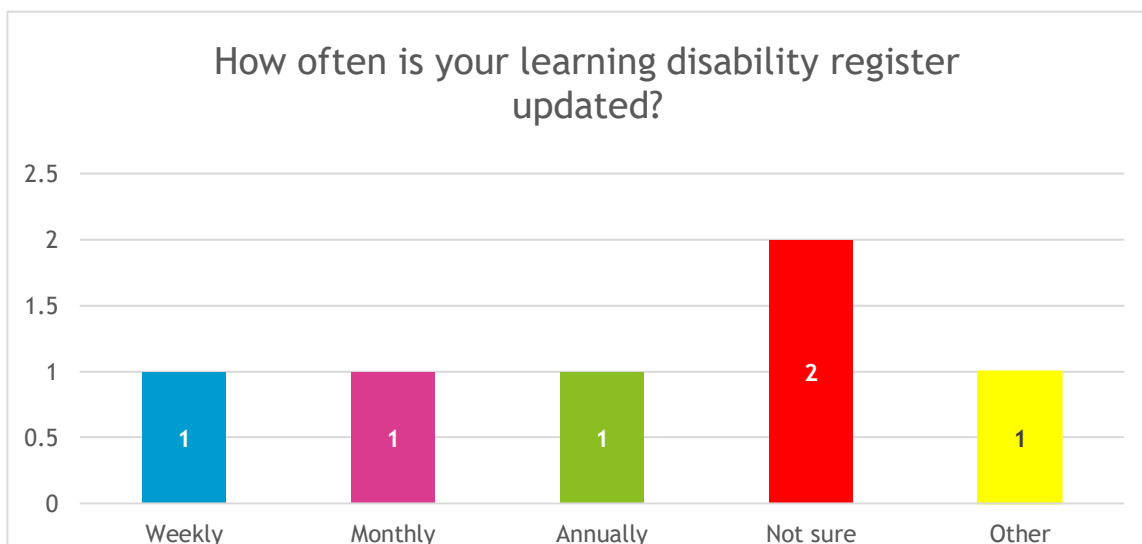
Question 5 was an open text question asking professionals what system they use to flag up when 14+ annual health checks are due for their patients. Six professionals responded, with one answering unsure. The remaining five was a mix of a recall system with the clinical system, learning disability (LD) coding, register that is diarised and regularly reviewed and two responded with EMIS. Across the six answers no theme emerged, and a lack of continuity appeared across the GP surgeries in Halton.



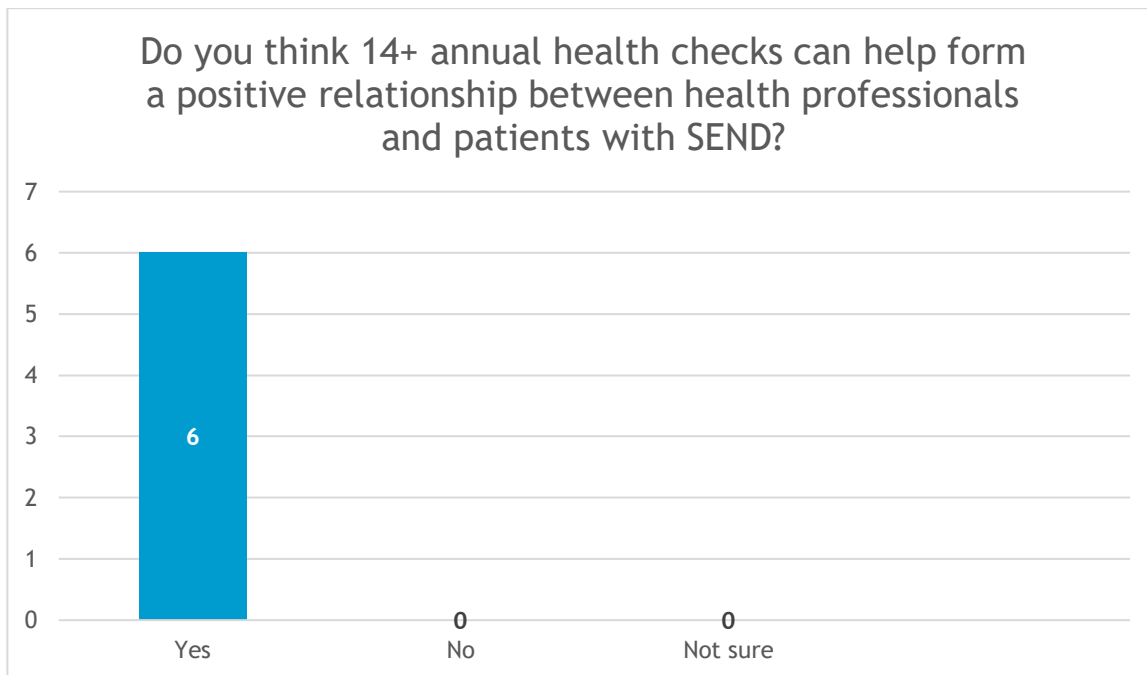
Question 6 The chart above shows six professionals responded, one answered 'yes' and five 'not sure'.



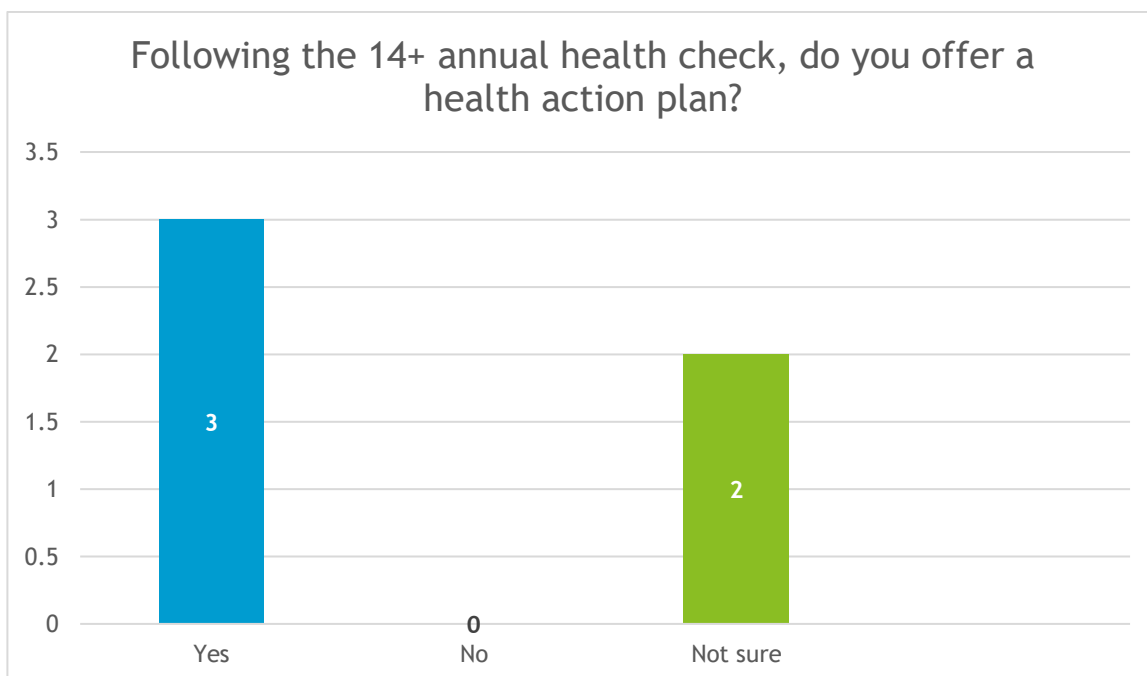
Question 7 was a multiple-choice question asking professionals how effective the promotion of 14+ annual health checks in reaching the relevant individuals. Six individuals responded, with two saying checks were 'effective', one felt they were 'not effective' and three responded 'not sure'.



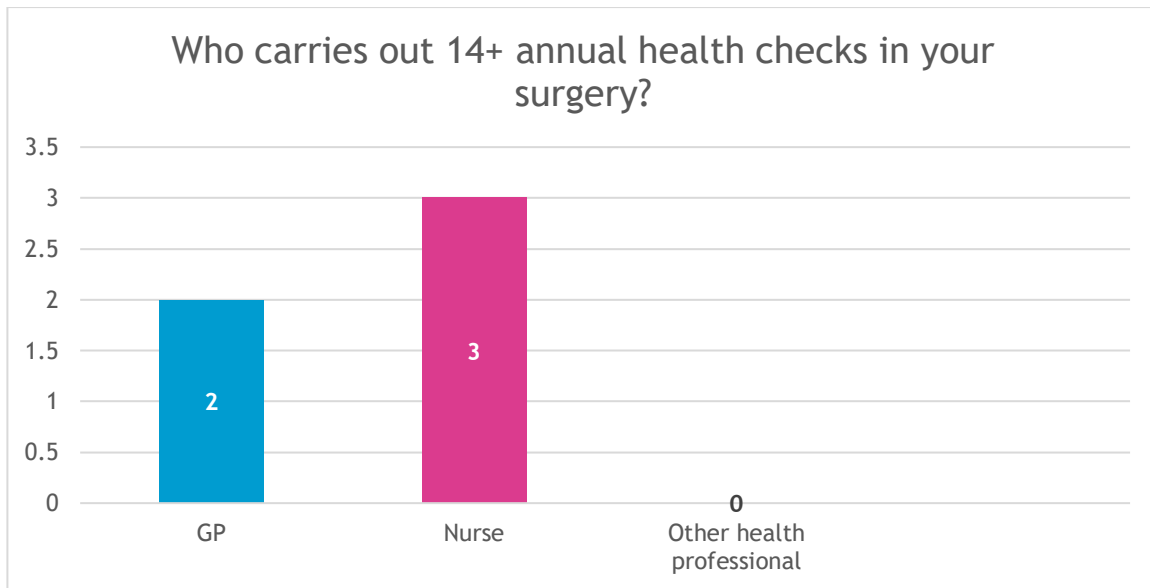
Question 8 The chart above shows six professionals responded, with one saying weekly, one monthly, one annually, two not sure and one answered with 'other'. These answers highlighted a lack of continuity across GP surgeries.



Question 9 Six people responded to the question above, with all six answering 'yes'.



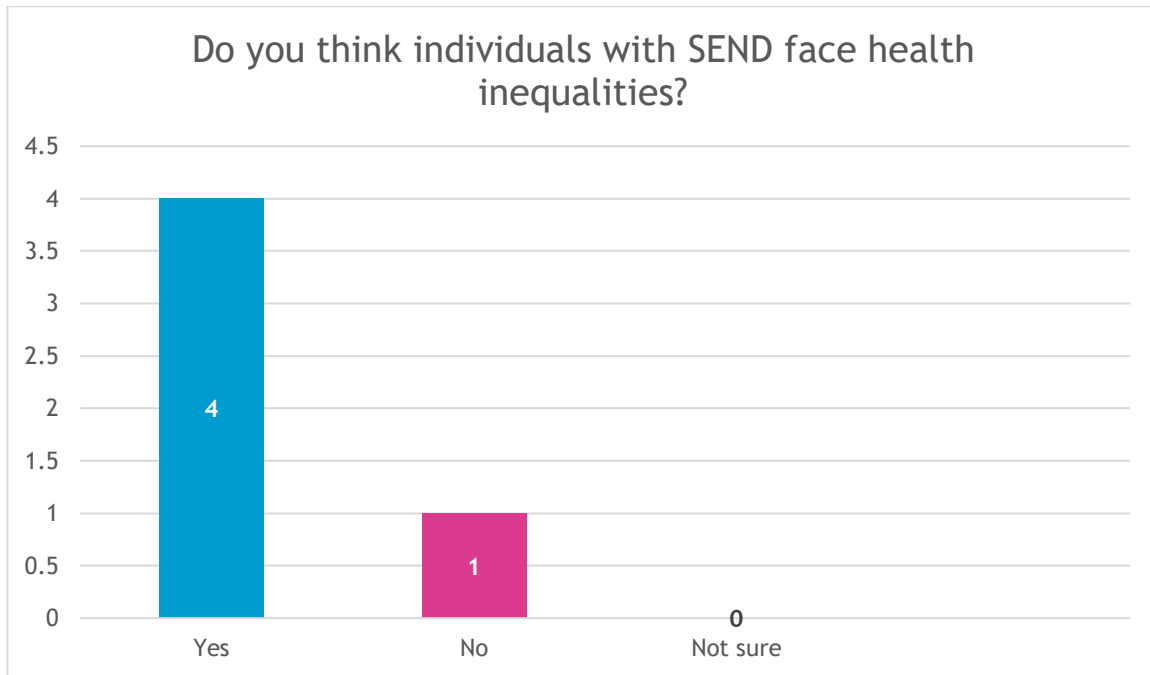
Question 10 Five responded to the question above, with three saying 'yes' and two 'not sure'.



Question 11 Five professionals responded with two stating a GP carried out the annual health checks and three stated the checks were carried out by a nurse.

Question 12 was an open text question asking professionals what the barriers were for SEND patients attending medical appointments.

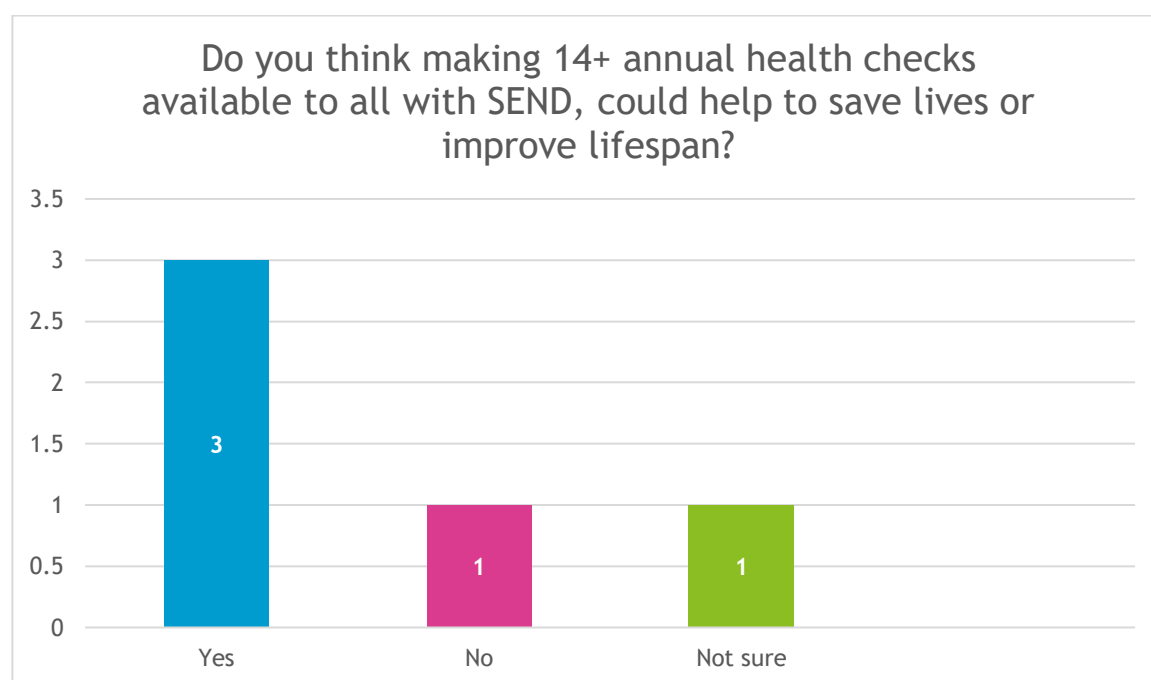
There were five respondents with one citing lack of engagement, another saying times of day. Someone said this question is best directed to SEND patients and parents. One person said they frequently have do not attends (DNA's), but now call patients to remind them and have made things more accessible. Furthermore, if more issues are identified, they will work around the barriers. Finally, one said some patients do not want to attend and their parents/carers are uncooperative.



Question 13 Five professionals responded to the question with four, (80%), believing that those with SEND do indeed face health inequalities.

Question 14 was an open text question asking professionals what reasonable adjustments/services are made for 14+ annual health checks.

Four professionals responded with, **offering appointments at quiet times, offering longer appointments, offering pre and simplified questionnaires prior to appointments and home visits.**

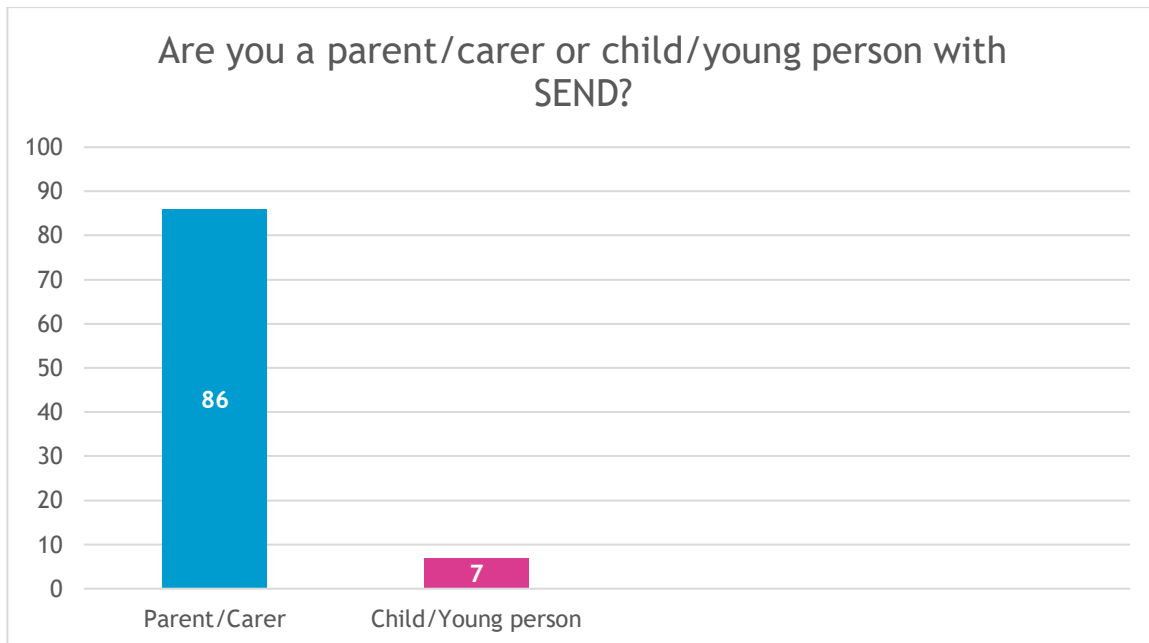


Question 15 Five professionals responded with three, (60%), saying 'yes'.

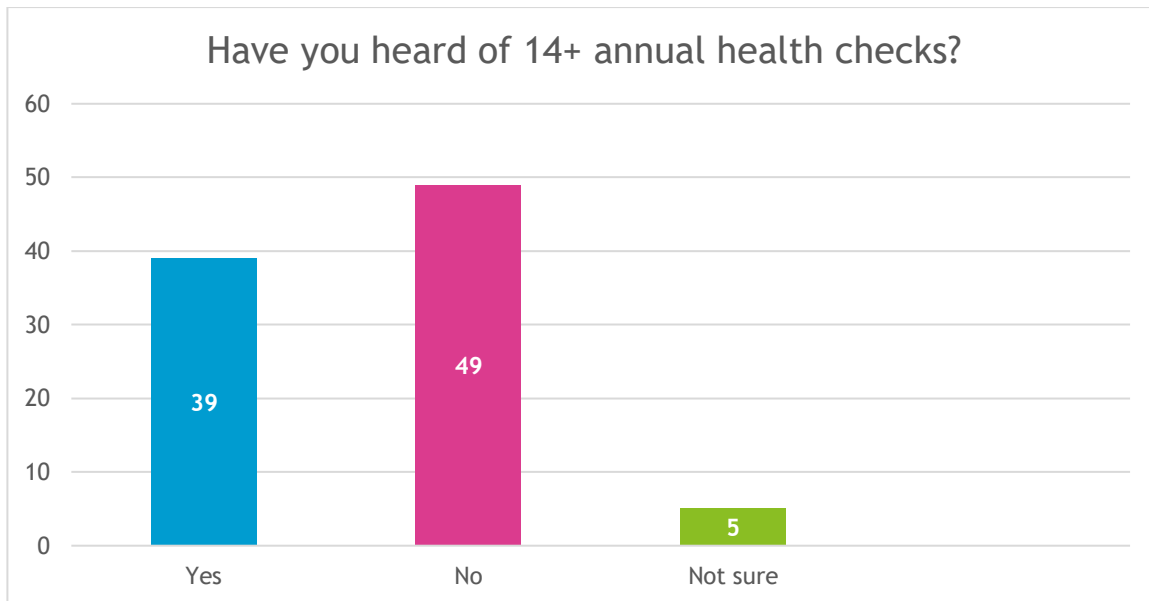
Question 16 was another open text question asking professionals if they had any other comments they would like to add.

Two professionals responded, with one saying 'no', and the second said, **'any health check on any person should have a positive outcome in terms of reinforcing healthy choices and options.'**

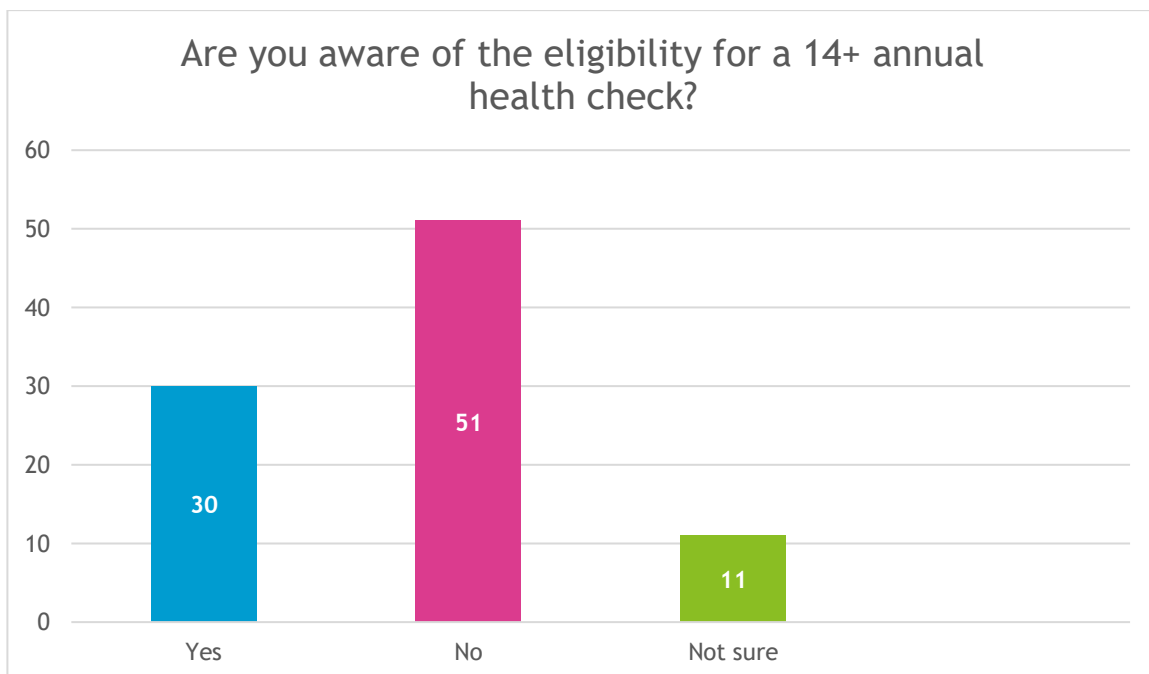
Parents/Carers, Children and Young People's Survey



The parents/carers, children and young people's survey was made available online, a link was circulated through both Halton SEND parents carers forum and Healthwatch Halton network. It was also promoted to specialist SEND schools in Halton. This subsequently amounted to 93 responses of which there were 86 parents/carers and 7 children and young people. See bar chart above.



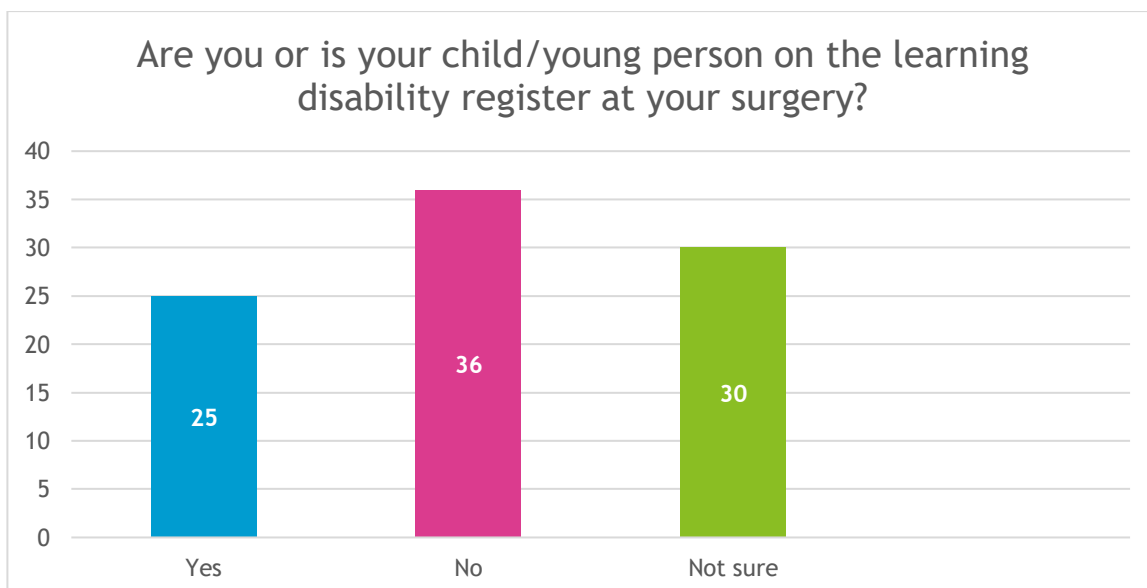
Question 1 The chart above shows thirty-nine (42%) said yes, forty-nine (53%) had not and five (5%) were not sure.



Question 2 There were ninety-two responses, with thirty (33%) citing 'yes', fifty-one, (55%), saying 'no' and eleven, (12%), not sure.



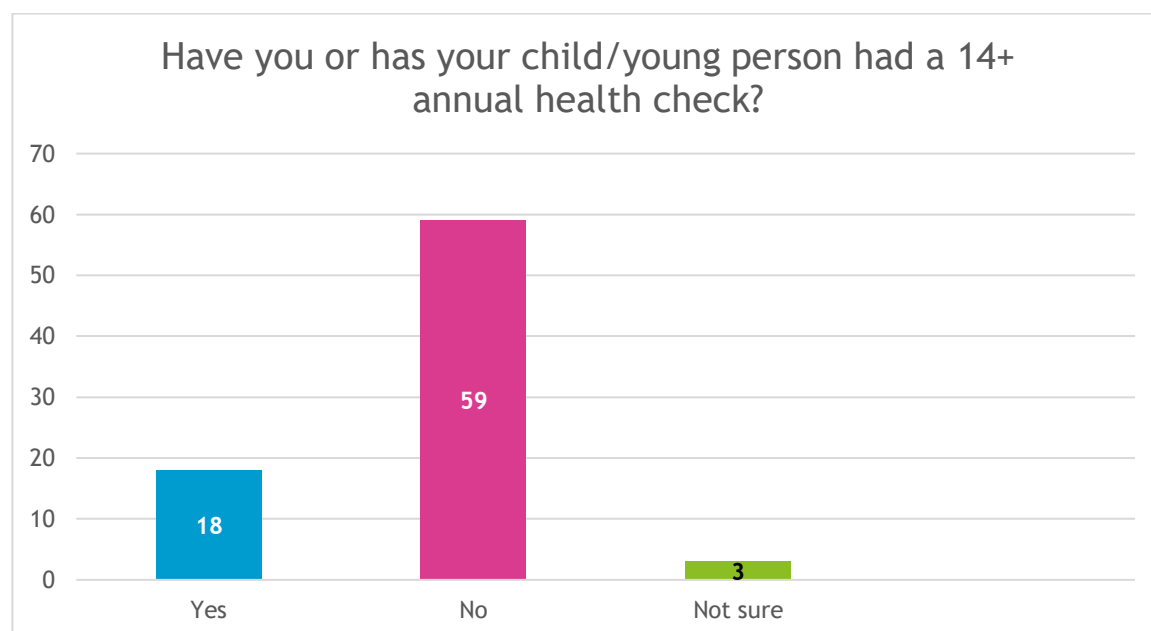
Question 3 A total of ninety-one responded to the question. Twenty-five, (27%), said 'yes', sixty-one (67%), 'no' and five 'not sure'. Following the responses to the first three questions, a theme emerged with more individuals not knowing about 14+ annual health checks, or the eligibility to receive one and also not being aware of the learning disability register.



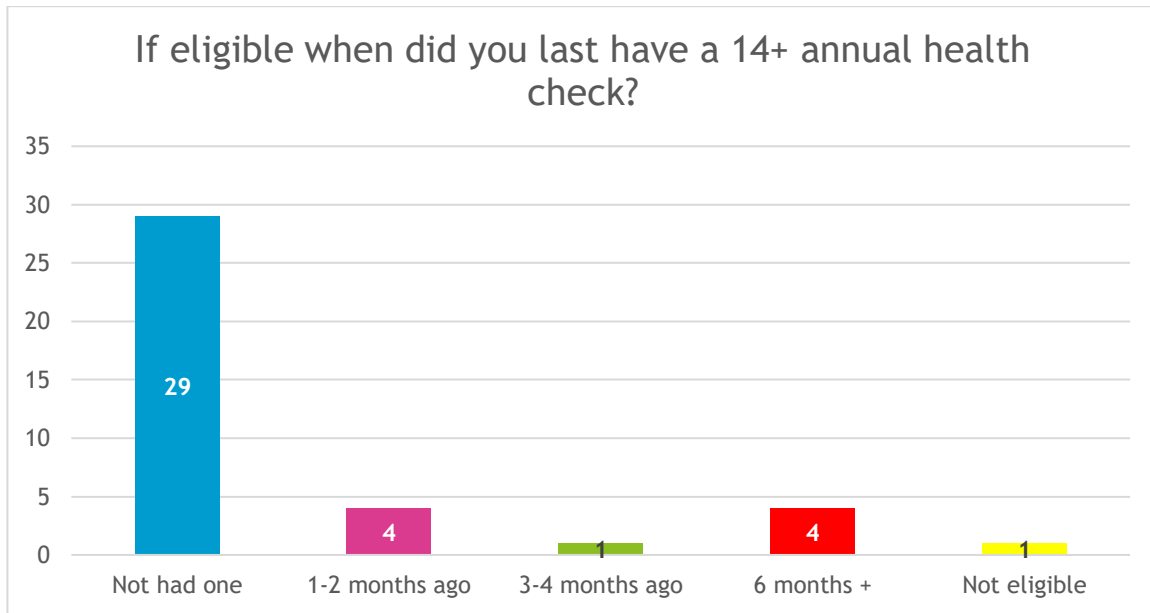
Question 4 The evidence above shows ninety-one responded, with twenty-five, (27%), saying 'yes', thirty-six, (40%), citing 'no' and thirty were 'not sure'.

Question 5 was an open text question asking for the name of their GP practice.

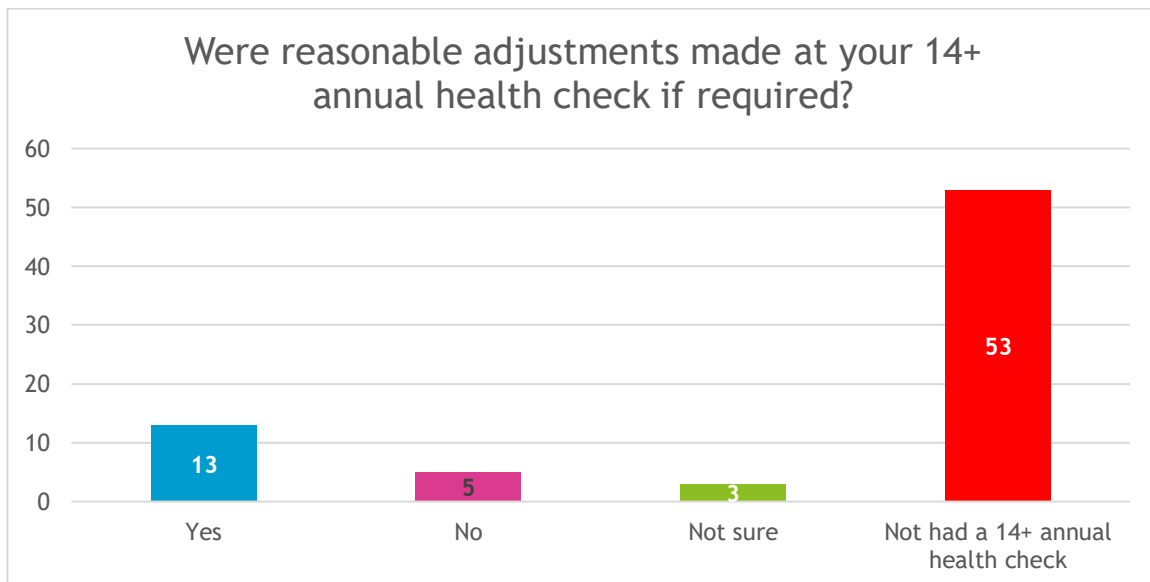
There were sixty-four answers to this question. Forty-one people were registered at GP practices in Runcorn and twenty-three in Widnes.



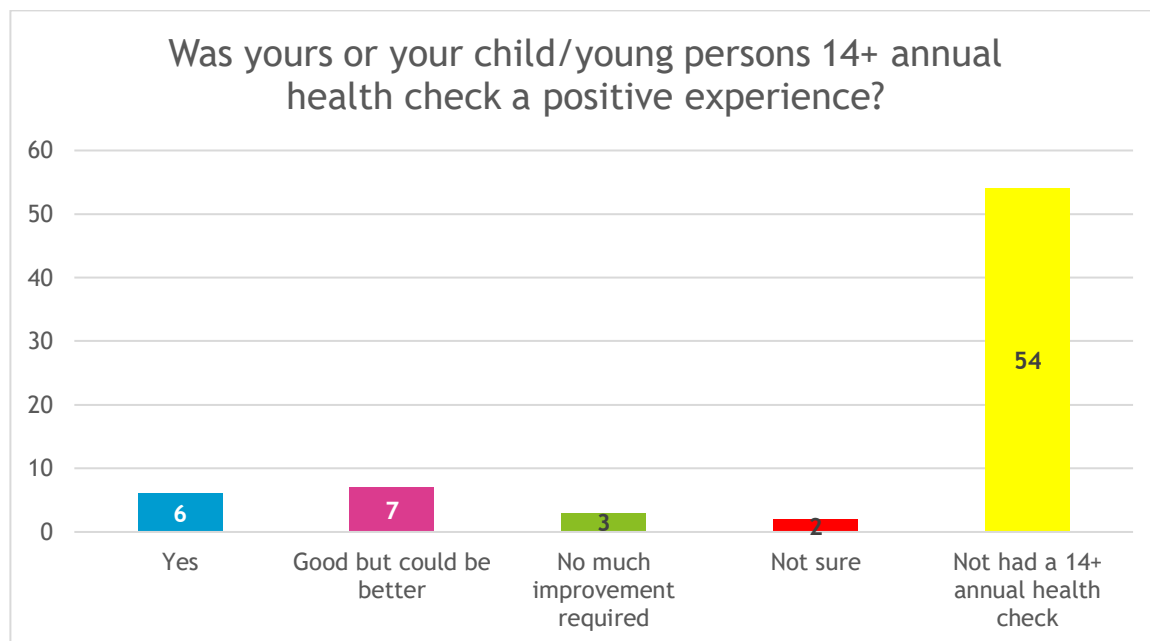
Question 6 Was a multiple-choice question. Eighty responded to this question with eighteen, (22%) opting for 'yes', fifty-nine, (74%), said 'no' and three were 'not sure'.



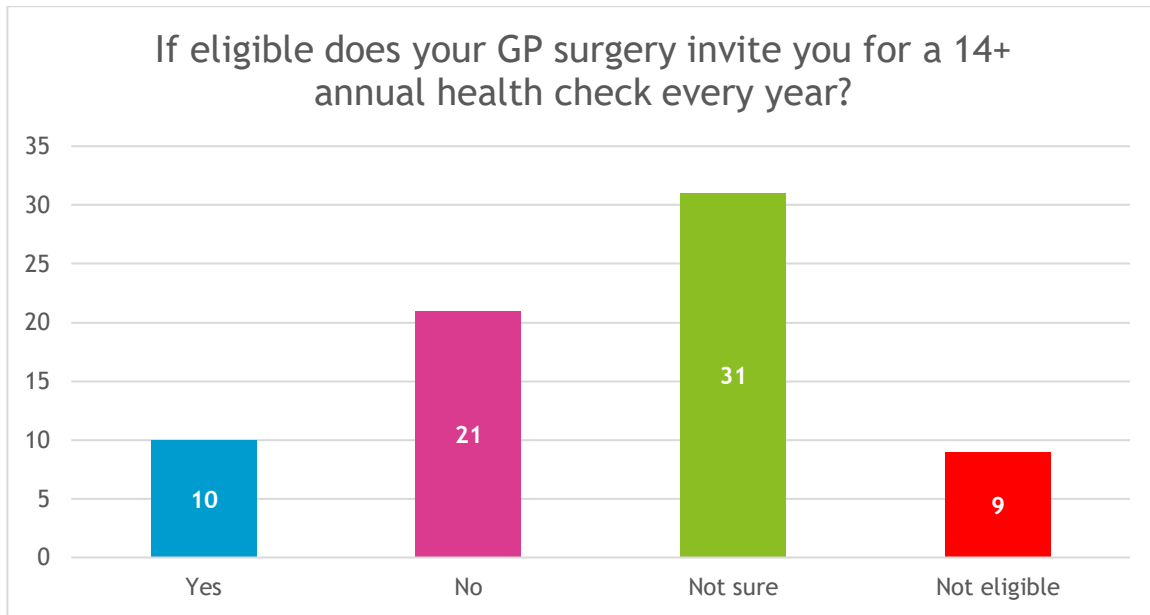
Question 7 Was an open text question with answers being placed into the bar chart above. Thirty-nine responded to the question, twenty-nine reporting they had not had one, four individuals having one in the last one to two months, one person having one in the last three to four months, four people over six months ago and one was not eligible.



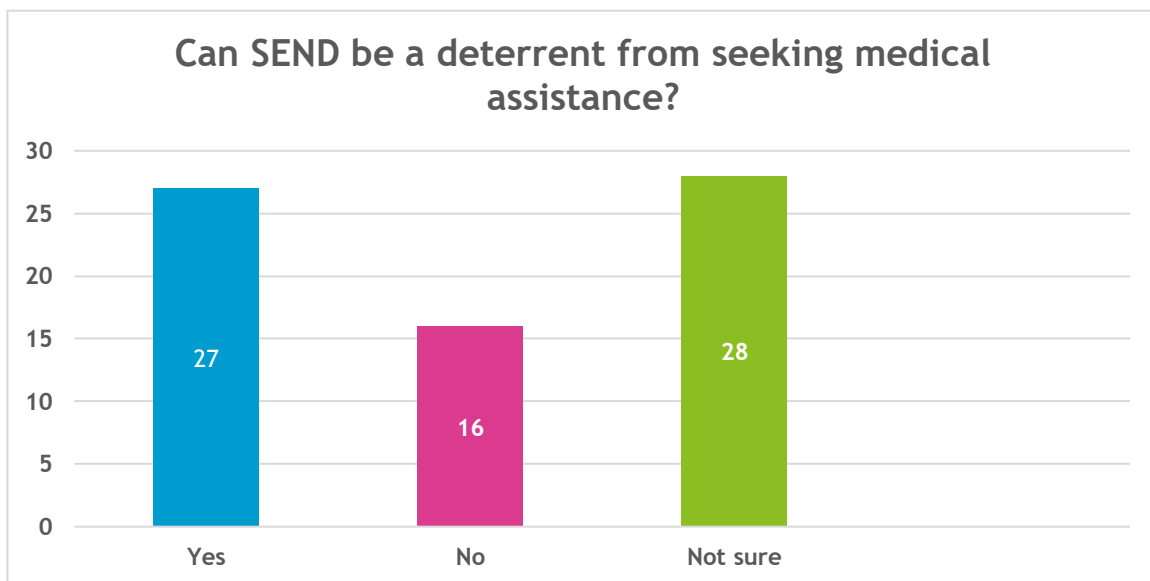
Question 8. Seventy-four responses received for this question with thirteen saying yes, five no, three not sure, fifty-three not had a 14+ plus annual health check. **See the results in the above bar chart.**



Question 9 A total of seventy-two responses were received. Six said 'yes', seven said, 'good but could be better', three 'no with much improvement required', two were 'not sure' and fifty-four individuals not had a 14+ annual health check.



Question 10 Seventy-one people responded with ten saying 'yes', twenty-one saying 'no', thirty-one 'not sure', and nine not being eligible.



Question 11 Seventy-one responses, with twenty-seven saying 'yes', sixteen citing 'no' and twenty-eight 'not sure'.

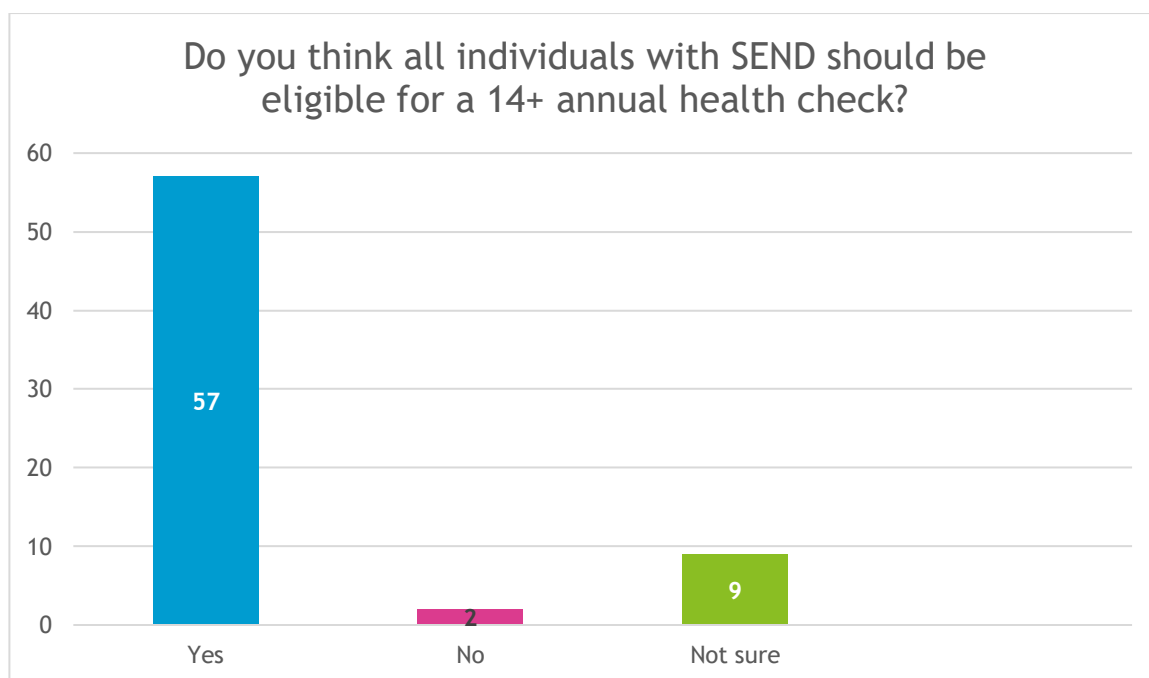
Question 12 was an open text question asking if they answered yes to the previous question to explain why. A theme of lack of SEND awareness emerged with staff not understanding autistic individuals.

One person said, *'Surgery is not SEND friendly and no reasonable adjustments were made.'*

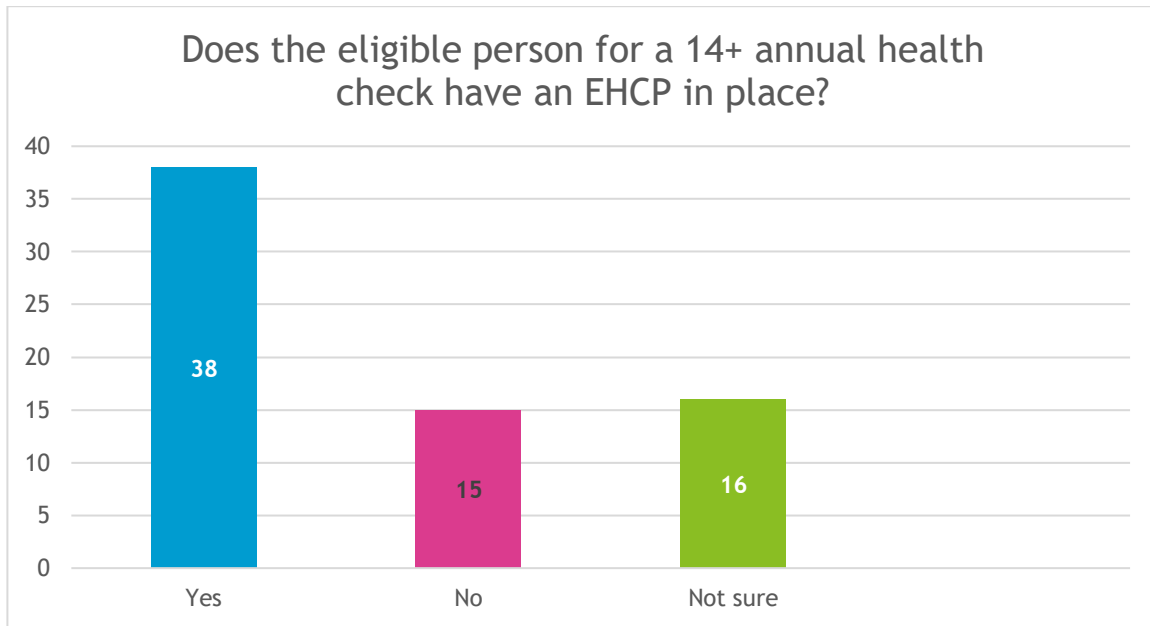
Another stated, *'doctors don't understand my needs'.*

Someone else said, *'I need an advocate, but doctors don't like that',* with another person replying, *'Anxiety and the demand on social communication stops me from attending the doctor surgery, I also feel that my lack of motivation can stop me'.*

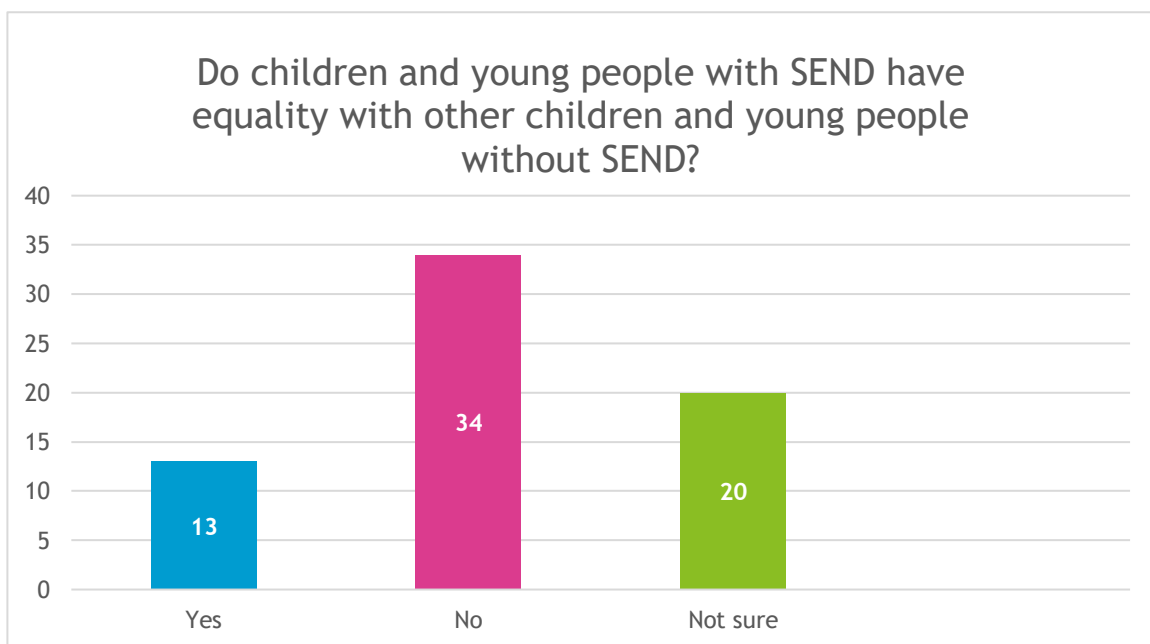
Another stated, *'Due to my autism if it does not interest me then I can't be bothered going even if it is my health.'*



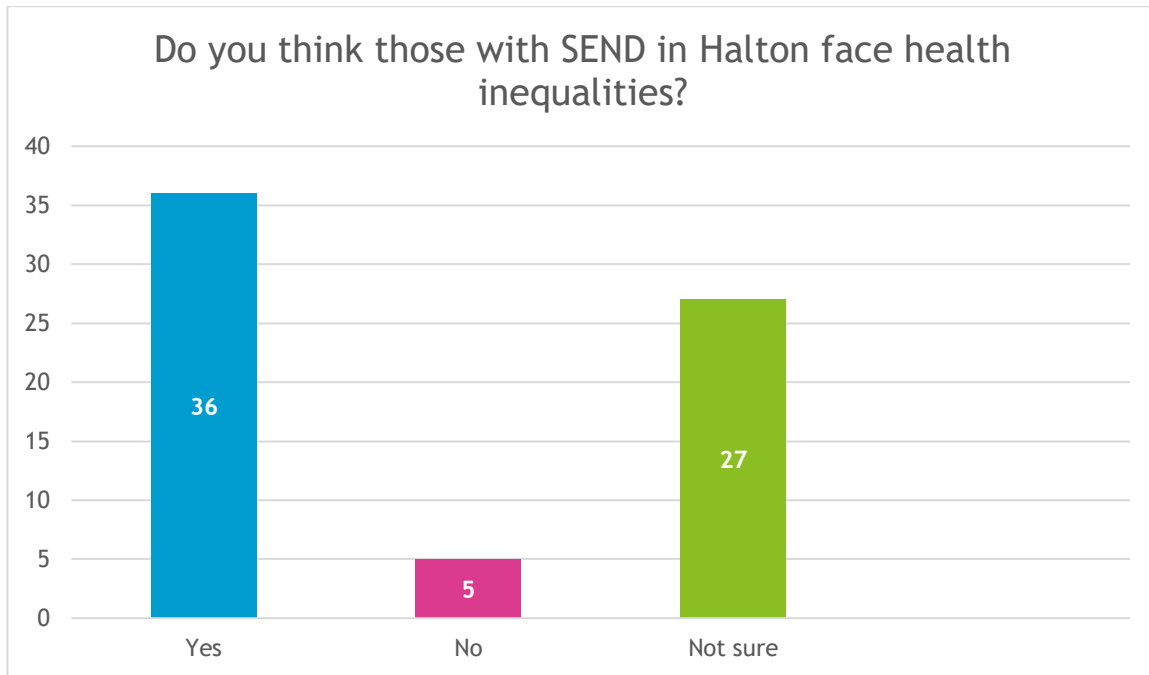
Question 13 Sixty-eight people responded, with fifty-seven saying 'yes', two 'no' and nine 'not sure'.



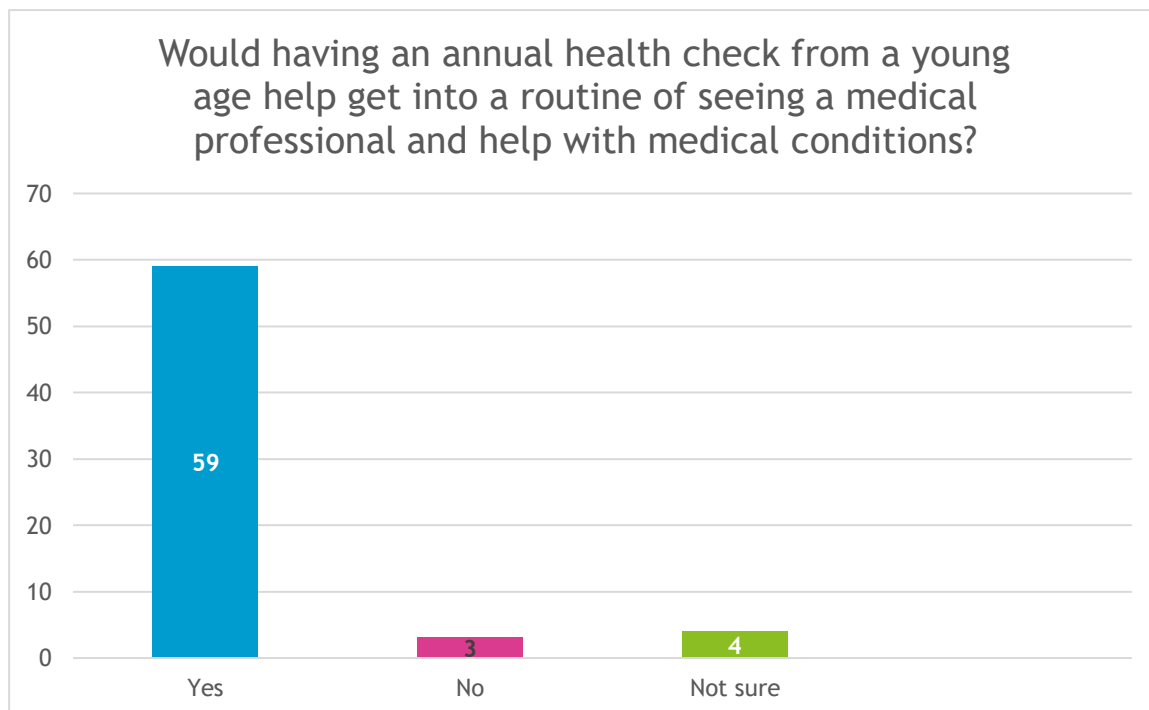
Question 14 Sixty-nine responded with thirty-eight citing 'yes', fifteen 'no' and sixteen 'not sure'.



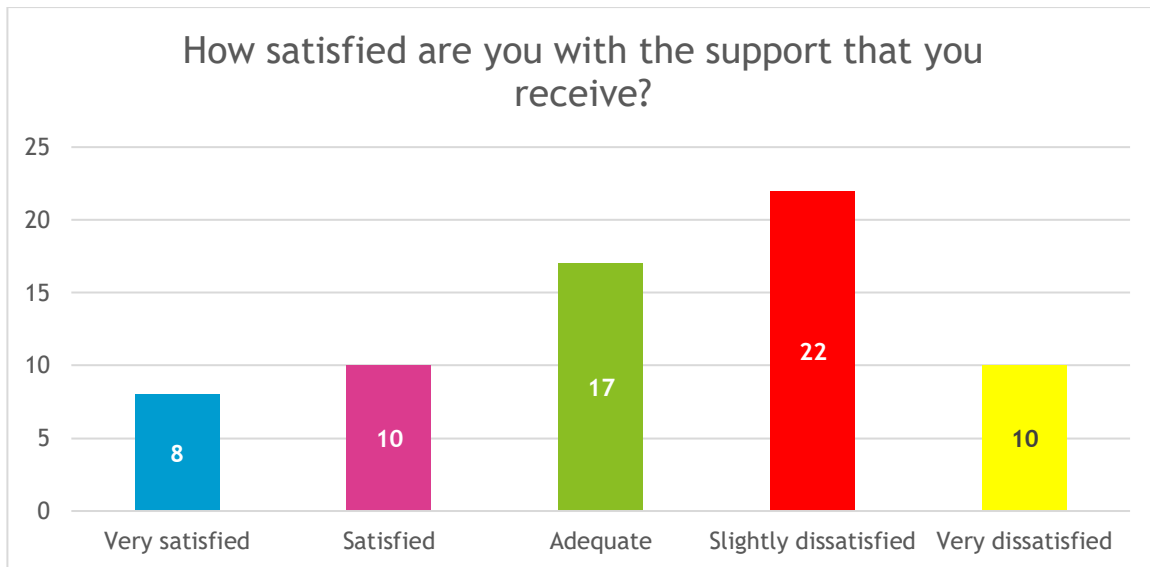
Question 15 A total of sixty-seven individuals responded with thirteen saying 'yes', thirty-four citing 'no' and twenty 'not sure'. The results have been recorded in the bar chart above.



Question 16 Sixty-eight responded with thirty-six saying 'yes', five 'no' and twenty-seven 'not sure'.



Question 17 Sixty-six individuals responded with fifty-nine saying 'yes', three said 'no' and four were 'not sure'.



Question 18 Sixty-seven responded to the question, with eight very satisfied, ten satisfied, seventeen adequate, twenty-two slightly dissatisfied and ten very dissatisfied. In total 48% of respondents were dissatisfied with the support received.

Question 19 was an open text question asking individuals if they would like to say anything else about their experiences or level of satisfaction.

One person said, *'better training and understanding is needed for health professionals to deal with SEND individuals.'*

Another commented *'surgery does not meet need.'* Someone else said *'GP's need to be more advanced on hidden disabilities.'*

A further comment was, *'my GP practice is not SEND equipped'*, another parent commented *'everything is a battle when requesting a referral'* and finally another commented, *'there is no support or understanding for conditions such as avoidant restrictive food intake disorder (ARFID), autistic burnout, school anxiety and psychological trauma.'*



Conclusions

The feedback received from all participants was very mixed from personal experiences of 14+ annual health checks, the awareness of them and the eligibility criteria. In addition to the sentiments of medical support received and the subsequent standard of medical professionals' experience and their understanding of SEND.

Feedback received from the survey and focus groups did provide evidence of some positive experiences of 14+ annual health checks, such as reasonable adjustments made.

However, the data also showed there is significant room for improvement in this area, with almost two thirds of individuals entitled to an annual health check did not have a positive experience.

Feedback highlighted from the SEND community, the lack of awareness and knowledge of the 14+ annual health checks and the criteria for them. Furthermore, there was also a lack of understanding of what a learning disability (LD) is, where you can gain access to an LD nurse for support, how to receive a LD diagnosis and knowing there is a LD register at GP surgeries.

The data raised the lack of continuity across GP surgeries in Halton. This was regarding knowledge of the 14+ annual health checks, what they should entail and the criteria for getting onto the LD register. In addition to how practices update their LD records. Evidence showed that those not eligible to be on the register (having SEND but not a LD) have been placed onto it and those subsequently meeting the criteria for a LD diagnosis, have not been diagnosed with a LD. Furthermore, SEND families have been given incorrect information, of what 14+ annual health checks entail. Many are unaware of or how to gain access to a LD nurse, with families in Halton never having heard of the 14+ annual health checks or LD register until they took the survey.

Evidence confirmed that SEND can be a deterrent from seeking medical assistance. It was further highlighted from the SEND community that there is a lack of SEND awareness from medical professionals, with surgeries not being SEND friendly such as being busy and not understanding the needs of non-verbal individuals, along with advocates/appointees of SEND patients feeling unheard.

The feedback highlighted that almost 100% of participants believe that those with SEND, would benefit from having access to an annual health check. With many agreeing that those with SEND do face health inequalities and do not have equality in line with their neurotypical peers. It was also raised that lowering the age from 14 to 10 years for annual health checks, before the transition to high school would be of benefit too.

The feedback further highlighted inconsistencies across practices in Halton with many patients not being called annually, to receive their 14+ annual health checks.

Further evidence from medical professionals themselves highlighted a lack of awareness around 14+ annual health checks and understanding the criteria for one. Also, a lack of knowledge with the promotion of the annual health checks and how well they are attended, in addition to the update of the surgeries learning disability registers.

The feedback also raised issues of education and health professionals and their systems being disjointed. It highlighted how they should be better aligned to meet the needs of those with SEND.

The current mode of e-learning for health professionals was also raised and how it was felt that face to face SEND training would be best delivered, by SEND experts by experience.

Recommendations

- 1.** Annual health checks should be offered to all those with SEND, not just those eligible with a LD.
- 2.** Improve 14+ annual health checks:
 - a. Review the quality of annual health checks.
 - b. Ensure they are SEND friendly and a positive experience.
 - c. Ensure consistency across Halton in the delivery of health checks.
 - d. Ensure reasonable adjustments are put in place when required.
 - e. Ensure a robust annual recall system is in place in all surgeries across Halton, to ensure eligible patients are contacted within the relevant timescale.
- 3.** Commissioners to liaise and work with HSPCF and Healthwatch to improve health services in Halton.
- 4.** Improve learning disability (LD) awareness:
 - a. Review how those with SEND are diagnosed with a LD.
 - b. Review LD nurse support to individuals with a LD and their families.
- 5.** Improve communication between medical professionals and SEND families.
- 6.** Deliver current SEND awareness training to medical professionals and to ensure there is continuity at GP surgeries across Halton. This could be delivered by SEND experts by experience.
- 7.** Explore the implementation of one-page documents for SEND individuals, this will assist medical professionals being up to speed of the patients' needs prior to the medical assessment taking place.
- 8.** Improve training and communication between health and education professionals. Working together more effectively will assist in SEND individuals receiving better support.

9. Improve medical professionals understanding of advocacy. A verbal individual with hidden disabilities can often require an advocate.
10. Improve health inequalities for those individuals with SEND. The Lancet 24 article¹ stated autistic people experience health inequalities, meaning that they often don't get the support and help that they need, when they need it.

¹ [https://www.thelancet.com/pdfs/journals/lanepi/PIIS2666-7762\(23\)00195-3.pdf](https://www.thelancet.com/pdfs/journals/lanepi/PIIS2666-7762(23)00195-3.pdf)

Report response

Response received from Philip Thomas, Associate Director Transformation and Partnerships – NHS C&M ICB Halton Place

Thank you for the time and efforts Halton Healthwatch and Halton Special Educational Needs and Disability (SEND) Parent Carer Forum (HSPCF) have spent in reviewing individual's experience of the 14-years+ annual health checks (AHCs) in Halton and consideration of whether the eligibility for an AHC should be broadened to include individuals with SEND.

The findings in the report support NHS Cheshire and Merseyside Integrated Care Board's (NHS C&M ICB) aim to improve the quality and uptake of AHCs for those 14years+ with a learning disability in Halton.

Please see below the responses to the recommendations you have set out in your report to NHS C&M ICB Halton Place.

1. Annual health checks should be offered to all those with SEND, not just those eligible with a LD.

General practices are contracted to provide AHCs to individuals with a learning disability through a national Designated Enhanced Service (DES) scheme with associated uptake targets for ICBs.

There is no local or national plan for Learning Disability AHCs to be offered to all individuals with SEND who do not have a learning disability.

To ensure that all individuals who are eligible within the national scheme are invited for a Learning Disability AHC, Halton undertook a project in 2023 to ensure the learning disability registers held in primary care are accurate and up to date.

Each Halton general practice's learning disability register review process and timeliness of review will be reviewed by the Halton

Learning Disability AHC Quality Group. A fair and consistent approach will be adopted across all Halton practices to ensure equality.

2. Improve 14+ annual health checks:

a) Review the quality of the annual health checks.

The Halton Learning Disability AHC Quality Group membership includes Halton Healthwatch and HSPCF. In 2024/25 Halton will put an evaluation process in place to monitor service user and family member experiences of the Halton Learning Disability AHCs. The evaluation process will be initiated via the Halton Learning Disability AHC Quality Group. It will be co-produced with Halton general practices and children and young people (CYP) and family members/carers.

b) Ensure they are SEND friendly and a positive experience

Qualitative outcomes put in place (as suggested in response 2a) will help to ensure CYP and family/carers views and experiences are monitored and learnt from to adopt a culture for continuous learning and improvement.

c) Ensure consistency across Halton in the delivery of health checks

During 2024/25 the Halton Learning Disability AHC Quality Group will identify, measure, and monitor existing baselines against national guidance standards. Where unwarranted variation does exist, measures will be put in place to ensure corrective action is taken so that national standards are complied with.

d) Ensure reasonable adjustments are put in place when required

During 2024/25 the Halton Learning Disability AHC Quality Group will work with Halton general practices to ensure there is a digital flag on an individual's record who has a learning disability and/or autism. The digital flag will be used to alert general practices to identify and review reasonable adjustments in advance of an individual's learning disability AHC and other health appointments that individuals with a

learning disability and/or autism attend. Halton will work with general practices to understand what process they currently use and explore options to adopt a consistent approach across all the Halton practices.

e) Ensure a robust annual recall system is in place in all surgeries across Halton, to ensure eligible patients are contacted within the relevant timescale.

The Halton Learning Disability AHC Quality Group will review the existing recall system each Halton practice uses. The Halton Learning Disability AHC Quality Group will work with the practices to ensure a consistent and co-produced recall system is put in place.

3. Commissioners to liaise and work with HSPCF and Healthwatch to improve health services in Halton.

NHS C&M ICB Halton Place will continue to work in partnership with HSPCF and Halton Healthwatch to co-produce the improvement of health services. Monthly co-production meetings will remain in place with the HSPCF and other health partners.

HSPCF are member of the Strategic SEND Improvement Board and in specific workstreams as part of the SEND Improvement Plan

4. Improve learning disability (LD) awareness.

a) Review how those with SEND are diagnosed with a LD.

If a Halton child has a suspected learning disability, they can be referred by health, education, or social care professionals to the CYP neurodiversity pathway for this to be explored and a diagnosis given if appropriate. In some cases, a Global Development Delay (GDD) diagnosis will be given where it is not possible to confirm a learning disability diagnosis. A process will be explored and initiated by the Halton Learning Disability AHC Quality Group that ensures a GDD diagnosis is reviewed before the child's 13th birthday to ensure a

learning disability diagnosis is not missed prior to their first learning disability AHC.

During 2024/25 NHS C&M ICB Halton Place will work with partners to review the neurodiversity pathway. Co-production will be a central feature of this transformation programme.

b) Review LD nurse support to individuals with a LD and their families.

Halton's CYP Neurodiversity Nursing Team Service is a service for CYP and their families who have one or multiple neurodiversity conditions. The service works to promote the rights of the child to have the same opportunities as everyone else. The service provides a person-centred, personalised, and outcome driven service which promotes family life and offers preventative support in the community to avoid crisis.

The service works closely and in a collaborative way with paediatricians, education, social care, specialist, and universal health services and providers including primary care and acute health care. The service will optimise functionality in daily life, to promote family self-management skills and maximise the child's and family quality of life.

NHS C&M ICB Halton Place will work with the CYP Neurodiversity Nursing Team and transition teams to ensure all neurodiversity individuals receive the highest standards of care they need and require supporting the child to live their life to the fullest.

5. Improve communication between medical professionals and SEND families.

The Halton SEND Improvement Plan includes 'improving communication between practitioners across health, social care and education and with SEND families'. NHS C&M ICB Halton Place will work

with HSPCF to understand where and how communication between medical professionals and SEND families can be improved.

6. Deliver current SEND awareness training to medical professionals and to ensure there is continuity at GP surgeries across Halton. This could be delivered by SEND experts by experience.

The SEND awareness training in the Halton SEND Improvement Plan includes developing a practitioner learning and development programme (including core and role specific mandatory training) to improve:

- Awareness, understanding and identification of CYP with SEND.
- Awareness and understanding of specialist health services, their referral / acceptance criteria.
- The quality and appropriateness of referrals to services.
- Awareness and understanding of universal and targeted services.
- Support to CYP, parents/carers, including onward referral / referral to the right service.

Halton will continue to work with the NHS C&M ICB SEND Team to ensure training of all health and medical professionals is regularly monitored and facilitated in accordance with the requirements set out in the Halton SEND Improvement Plan.

7. Explore the implementation of one-page documents for SEND individuals, this will assist medical professionals being up to speed of the patients' needs prior to the medical assessment taking place.

There are Learning Disability Health Passports, and Education Health and Care Plans (EHCPs) in place. NHS C&M ICB Halton Place will work with partners to explore the development of a one-page document that will support this initiative.

8. Improve training and communication between health and education professionals. Working together more effectively will assist in SEND individuals receiving better support.

Within the 2024 Send Improvement Plan Halton has a priority action to improve the efficiency and quality of information gathering and sharing processes across health, education, and social care to ensure that CYP needs are understood accurately and met more swiftly and effectively through co-ordinated approaches.

9. Improve medical professionals understanding of advocacy. A verbal individual with hidden disabilities can often require an advocate.

NHS C&M ICB Halton Place will ensure the understanding of advocacy is linked into the SEND training that medical and health professionals receive as part of the training and development activities within the SEND Improvement Plan.

10. Improve health inequalities for those individuals with SEND. The Lancet 24 article stated autistic people experience health inequalities, meaning that they often don't get the support and help that they need, when they need it.

One of the priority actions within the 2024/25 Halton SEND Improvement Plan is to improve the early identification of needs and access to specialist health pathways. During 2024/25 NHS C&M ICB Halton Place is working with Halton partners to review the neurodiversity pathway, identify opportunities for improvement, and ensure care is provided by the right person, in the right place, at the right time, and is needs rather than diagnosis led.

As mentioned previously, in addition to the quality improvement work being undertaken with Learning Disability AHCs, work will be undertaken to ensure there are digital flags on records of all patients who have learning disability or autism to ensure reasonable adjustments can be put in place for these individuals.

Health Impact Assessments will continue to be utilised when changes to existing services are considered or when new services are being planned to ensure health inequalities are reviewed, monitored, identified, and changed where they exist.

NHS C&M ICB Halton Place participates in the national LeDeR programme (Learning from Lives and Deaths Review of people with a learning disability and autistic people). This programme enables care systems to identify good practice, where improvements can be made, and to reduce health inequalities. Local actions are taken to address any local actions identified in reviews. Recurrent themes and significant issues are addressed at a regional and national level.

NHS C&M ICB Halton Place would like to thank you once again for the dedicated efforts and tireless support you provide to championing Halton SEND CYP voices.

We look forward to working together with you and all our Halton SEND partners in achieving the best possible outcomes for individuals with SEND and their families both now and in the future.

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