

### **SEND Local Offer Review**

March 2023





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#### Acknowledgements:

We'd like to thank the Halton SEND Parent Carers Forum for its support of this project.

### **SEND Local Offer Review**

#### Introduction

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

Healthwatch Halton received feedback from parents, carers, and children and young people who have needed assessment and additional support in Halton, that demonstrated that there is a need for further development. They have also expressed concerns about the impact that this has had on their wellbeing – above and beyond the day-to-day challenges which they face.

We have completed a project to assess how young people with Special Educational Needs or Disabilities (SEND) their families or carers and SEND professionals of Halton feel about the SEND Local Offer, referrals and assessments, and any additional support received, and to gather their experiences, ideas and concerns so that they can be represented to key stakeholders.

#### What we did

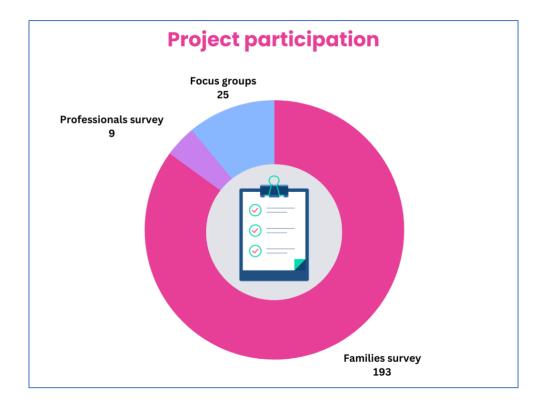
We utilised a mixed methods approach to this project using focus groups and surveys. The focus groups were aimed at young people, parent or carers, and we held two focus groups in total. There were two surveys created, one for professionals, and one for young people, their families or carers.

We worked closely with the existing network of Healthwatch Halton partner agencies to promote the project, provide us with opportunities to speak to young people and/or their families or carers, and complete a professional's survey. The survey for families was available online and in paper format from 20<sup>th</sup> September until 1<sup>st</sup> December 2022, the survey for professionals was extended due to a low initial response rate, so this was available online from 30<sup>th</sup> September 2022 to 6<sup>th</sup> February 2023.



#### Who took part?

A total of 227 people participated in our project, we engaged with 25 people at the focus group sessions, 193 young people, parents or carers, completed the families survey, and 9 professionals completed the survey created for them. The breakdown of participation can be seen in the chart below.



We asked only three relevant and necessary demographic questions for the surveys and focus groups to ensure we had reached all parts of the target community.

We asked for age, gender and ethnicity on all of the research materials, but participants were not required to complete these questions if they did not want to.

The data was collated and is represented on the table and infographic below.

Ethnicity	Number of people	Ethnicity	Number of people
Arab	4	Mixed / Multiple ethnic groups: Black African and White	2
Asian / Asian British: Bangladeshi	3	Mixed / Multiple ethnic groups: Black Caribbean and White	2
Asian / Asian British: Chinese	4	Any other Mixed / Multiple ethnic groups background	1
Asian / Asian British: Indian	2	White: British / English / Northern Irish / Scottish / Welsh	120
Asian / Asian British: Pakistani	4	White: Irish	5
Any other Asian / Asian British background	3	White: Gypsy, Traveller or Irish Traveller	5
Black / Black British: African	2	White: Roma	3
Black / Black British: Caribbean	1	Any other White background	20
Any other Black / Black British background	4	Prefer not to say	6
Mixed / Multiple ethnic groups: Asian and White	2		

### Who took part?



- 124 people were female
- 69 people were male
- 1 person preferred to self-identify
- 4 people were non-binary
- 1 person was intersex
- 8 people chose not to disclose their gender



- 5 people were 13 to 15 years of age
- 7 people were 16 to 17 years of age
- 21 people were 18 to 24 years of age
- 161 people were 25 to 49 years of age
- 23 people were 50 to 64 years of age
- 1 person was 65 to 79 years of age
- 6 people preferred not to give their age

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### **Report Findings**

#### **Focus Groups**

We completed two focus groups in total, we held one focus group at the Halton Parent/Carer meeting on 15th November 2022, this was attended by 13 parents/carers and 2 professionals, both of whom have personal experience of caring for young people with SEND. The second focus group was held at a SEND networking session on 21st November 2022 and was attended by 9 parents/carers and 1 professional.

The feedback we received was analysed thematically and five themes emerged from the data.

Assessments were discussed frequently, one parent told us that 'mine was quite easy to be honest, I worked with the school and went to Wood View and he was diagnosed immediately and prescribed medication that helped him' whilst another advised that 'I am waiting for an autism assessment but it would be 2 years before my child can be seen' another stated 'It took forever to get an assessment and many referrals from our GP before they agreed to see our daughter', one person felt that 'children are being assessed too late and this has a negative impact on their transition to high school or alternative provision', and another reported that 'there is not enough communication between the agencies we are referred to and parents when you are waiting for assessments to be done'.

**School** was another theme that was discussed, one parent advised that 'school were of no help and she was finally diagnosed as an adult through adult services', someone else reported that 'many children with special needs are still in mainstream schools because we are waiting for the diagnosis but the diagnosis is underway and the school won't accept the paperwork as proof of additional needs, or when my child needs time off school because she is overwhelmed'. Another parent stated that 'school were not helpful at all, they often blamed my son and saw him as a naughty child, their input into the process was very unhelpful', and another reported that 'my child is still in mainstream school but is really suffering, the process is far too long, and our children suffer while we wait'.

**Medication** was discussed by some parents, one reported that 'we waited 2 years to get the medication needed after diagnosis' but that 'she isn't able to take it as the school don't have permission to give her the second dose during the day', another parent told us that 'my son was not on the correct level of medication and got so bad he became suicidal and he is 6 years old, nobody would respond to me when I called many times and I got no support', and another advised that 'I sent in medication to school and completed the forms, they agreed to give it to him and told me they were even though my son was saying it wasn't being given to him. I later found out, when they returned the full box back to me, that he had not been receiving his next dose and this coincided with him having a very difficult episode'.

**Waiting times** were also discussed by parents, one person told us that 'Wood View now has a 2 year waiting list + 6 month referral wait', another advised that 'between seeing doctor and it going to MDT to get the support in place it's between 14 months and 2 years', and another person reported that 'appointments are always 3 or 4 month delay, even if they cancel it you still have to wait three or four months for the next appointment'.

Parental blame was mentioned by three people, one told us that 'often the parents are blamed for the behaviour of the child for a long time and made to go on triple P programmes before the child gets even looked at, this is valuable time for education of my child', another stated 'school would not take me seriously and told me I wasn't using the correct techniques, fortunately my GP was really supportive', and the other advised 'before anyone will even start to look at my child I have had to do various parenting courses, I feel it is an insult to assume it is always the parents fault'.

Question 2 asked what parents know about the Halton SEND Local Offer, and three themes emerged from the thematic analysis of the feedback.

The Halton Local Offer Website was the most commonly discussed theme, one person told us that they find 'the website is very difficult to navigate', and another advised that 'I find the information isn't always relevant or up to date on the Local offer website', someone else reported that 'everyone directs you to the website', another stated that 'it needs to be more user friendly, I find it very difficult to know how to find the information I need' and another reported 'it needs reviewing, it is not fit for purpose and leaves parents and young people unsupported'.

**Meeting Criteria** was another theme discussed by some parents, one reported that 'often things on the local offer our children don't meet the criteria for', another felt that 'there are some really good things as part of the local offer, but only if your child meets the specific criteria so it excludes many', and another advised that 'our child with multiple diagnoses is not able to get support from the local offer because they don't yet have the EHCP'.

**Information** was mentioned by 2 people, one stated that the information they have about the Local Offer comes 'only from what the agencies I am involved with tell me', and the other advised that 'there should be more information about the local offer in GP surgeries, pharmacies, SEND agencies etc'.

Question 3 asked participants about their experiences of Education Health and Care Plans (EHCP) and we received 12 comments, all of which were very different and personal to the participant and their own experiences. For this reason, we were unable to draw out any themes for this question, one person told us that ' am not able to get an EHCP for my son, I have been told he needs one by four professionals in education but because he is meeting his targets at school he is unable to get one', in contrast another reported that 'my child is not meeting her targets at school but we are unable to get an EHCP because we are still awaiting diagnosis'. One person felt that 'parents aren't listened to enough', another stated that 'when you try to speak to someone about the progress of the EHCP you just get passed around and no real answers', another told us 'often the actions on the EHCP we have are unrealistic', another told us 'it takes too long, by the time my child got the education and support he needed he had suffered for far too long', and another advised that 'education do not help at all when we asked for an EHCP for our daughter even though she has a diagnosis, they seemed to do everything they could to stop it'.

**Question 4** asked participants how well services work together, feedback was analysed thematically, and 4 themes emerged.

**Information Sharing** was the most common theme discussed, one parent told us that 'services are not sharing information about our children between themselves, this means we have to start the process again', another advised that 'I don't think they do work well together, education and health don't communicate', someone else reported that 'none of the different agencies communicate with each other', whilst another added 'most agencies don't even communicate with us', another felt that it was due to the fact that 'all the different agencies use different systems and have different procedures for sharing information so it doesn't work', and another stated that 'we have to tell the whole story each time we see someone new, and often this is in front of my child who hates to be talked about'.

**Parental Expertise** was also discussed by some, one parent reported that they felt they are 'not recognised as the expert about my child', another advised they are 'often told to go on triple P courses even though I have already done them, they do not apply to my child, and it does nothing but cause further delays', and another stated 'professionals tell me we should be on the same page with regard to my daughter. I told them that they need to be on my page because their page is wrong'.

**Joint Working** was also discussed, one parent told us that 'it seems one service don't know what other services do', another stated that 'education do not work with health or other professionals about my child' and someone else told us 'services that should be working together to help us don't work together at all'.

Two people commented about **Advice and Information**, one told us that they are 'often told conflicting information by people from the same service', and the other reported 'the advice is often confusing, sometimes we are told one thing then someone else will tell us something else'.

Question 5 asked participants if they are satisfied with the support they have in place, feedback was analysed thematically, and three themes emerged.

**Support** was discussed by participants, one told us that 'the groups we have here are the best support we get', another felt that 'services don't support us or our kids, they see us as a problem', another stated that there is 'no consistency in support between children, some children get different offers of support in education and health', one stated they are 'not satisfied with the support we have at all', and another advised that 'my child is self-harming because he is not getting the right support'.

**School** was another common theme, one parent told us that 'the schools are unable to manage the needs of my child', another supported this by advising that 'my child suffers every day she is in the school she is at', another told us they let that the schools are 'failing to safeguard my child at school as she is in a mainstream', and someone else told us 'my child was told she will not get into another school because of her needs, this caused her a lot of distress and has affected her confidence'.

**Joint Working** was mentioned by two people, one said that 'services are not working together at all' and the other reported that 'education is not working with health'.

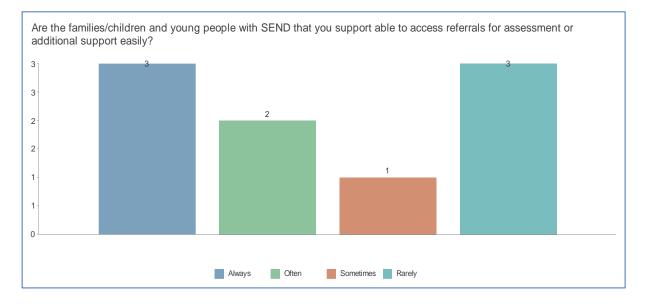
Question 6 asked participants if annual health checks are completed for their child by the GP, we received just six comments in response and no themes emerged, one person told us that 'we usually only go to see the doctor when he is unwell or we need another referral for support', another advised that 'we do get health checks but we have to book them, we don't get a reminder and often it is well over a year between checks', another stated 'my doctor is good with my son, we get a reminder to go for a health check but I don't think it is every year', and someone else told us that 'my GP is not very knowledgeable about my child's needs'.

Question 7 asked participants if they felt there is a divide between young people with SEND and their peers. All comments received agreed that there is a divide, so no additional themes emerged from the feedback. Many simply stated 'without doubt', 'absolutely there is', and 'without doubt there is a divide' in response to the question. Others went on to give examples of the divide and how it affects their child, one person told us that 'there is no integration there is only segregation in schools', another reported that 'there are not enough opportunities for young people with SEND', someone else told us that 'at my sons school they have to earn a pen licence to be able to use a pen rather than a pencil during lessons, my son has academic issues and he is the only one in his class who doesn't have one, it affects his confidence massively', and another reported 'my son is in mainstream school, only he was not allowed to go on a trip'.

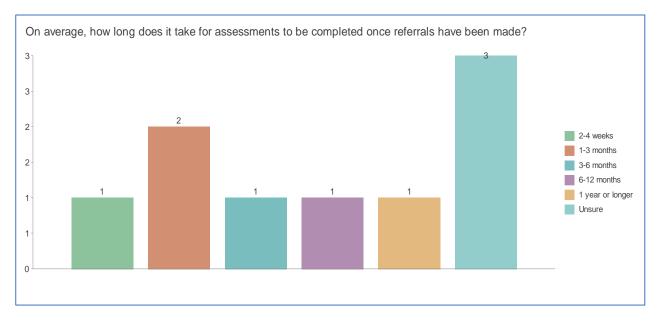
#### **Professionals Survey**

This survey was made available online and was emailed out through the Healthwatch Halton network, the SEND network, and was linked to on the SEND Local Offer website. We extended the deadline for this survey to try to gather more responses but received only nine responses.

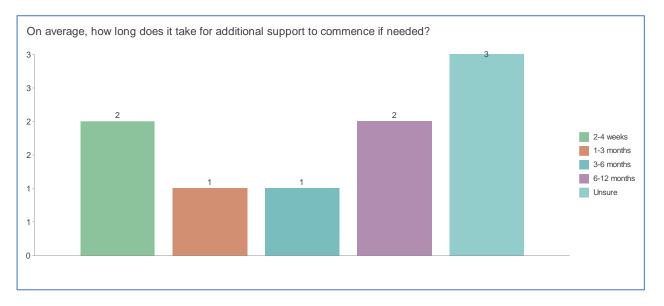
Question 1 was a multiple-choice question asking if the families that professionals support are able to access referrals for assessment an additional support easily, the chart below shows the responses, always and rarely are the most common responses which appears to contradict each other. However overall, findings appear to show that referrals for assessment or additional support are not hard to obtain.



**Question 2** was a multiple-choice question asking how long on average it takes for assessments to be completed once referral have been made, results are shown in the chart below. The largest group of professionals (n.3) were unsure, and the remaining responses show differences in how long the people they are working with have to wait for assessments.



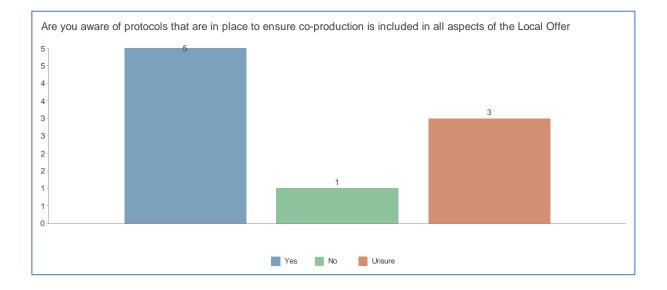
**Question 3** was also a multiple-choice question asking on average how long it takes for additional support to commence, results are shown in the chart below. The largest group of professionals (n.3) were unsure again, and the remaining responses again show there are differences in people's experiences of accessing additional support.



**Question 4** was an open text question asking professionals to tell us anything else they wanted us to know about referrals, assessments and additional support, we received 12 comments in response to this question but as they are unique to individual roles and professional experience, no themes emerged.

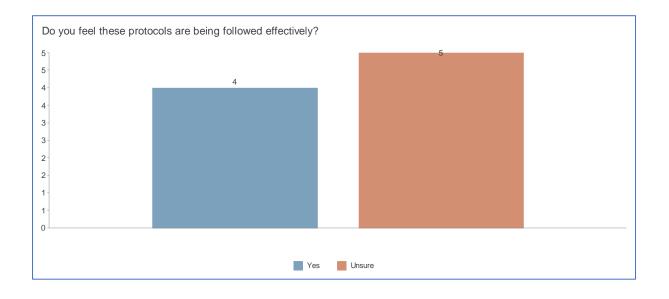
One person advised us that 'there is a huge piece of work being undertaken to develop an easier approach to referral and a more collaborative working approach' and went on to state that 'training is required to support parents during that wait between referral to assessment and all available referring agents to provide support to families needs to be identified', another told us that 'we can offer brief interventions but if specialist support is required we signpost/refer to other services', and another told us that there is an 'increased number of complex referrals following pandemic' and that 'we have limited resources to assess and meet needs if these children'.

**Question 5** was a multiple-choice question asking professionals if they are aware of the protocols in place to ensure co-production is included in all aspects of the Local Offer, five people felt that they were, one person reported that they were not aware and three people were unsure.

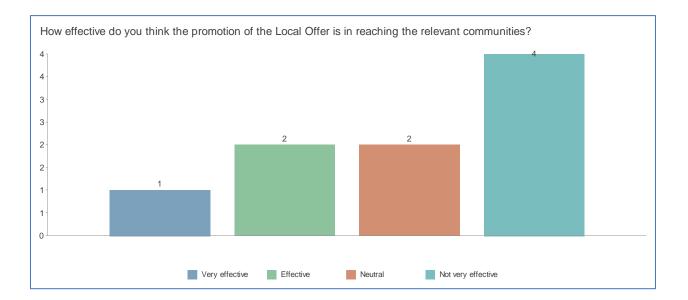




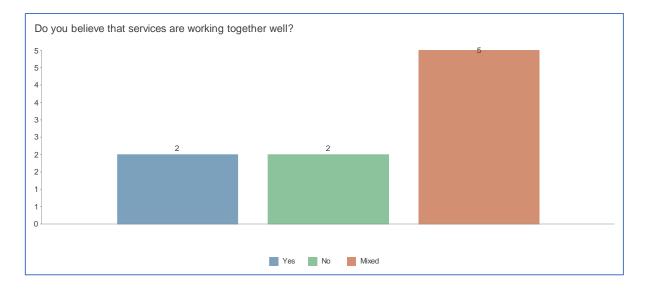
**Question 6** was again a multiple-choice question asking professionals if they felt these protocols were being followed effectively, four people felt that they were effective and five people were unsure.



**Question 7** was another multiple-choice question asking professionals how effective they felt the promotion of the Local Offer is in reaching the relevant communities, four people reported the promotion was *not very effective*, two people were *neutral*, two felt the promotion to be *effective*, and one person thought it was *very effective*.

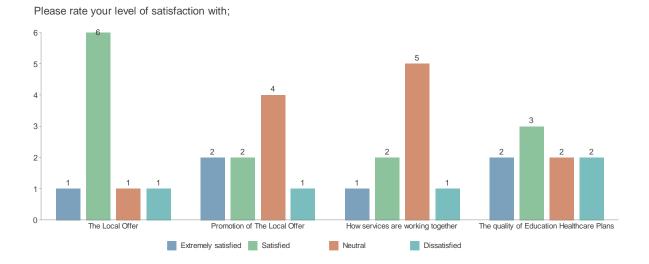


Question 8 asked if professionals believed that services are working together well, two people selected *yes*, two people selected *no*, and five people selected *mixed* as their responses.



**Question 9** was an open text question asking professionals to describe the protocols that are in place to share information across agencies and adopt a 'tell it once' approach. We received nine comments and no clear themes emerged from the feedback, one person told us that 'it is often only shared if the child/young person is known to the service and consent has been obtained', another told us that 'not all services are on the same electronic records', another told us that it 'requires further development', and another advised that 'information sharing across health and HBC can be disjointed most of the time' and that they are 'not aware of any protocols in place'.

**Question 10** was a multiple-choice rating question asking professionals to rate their level of satisfaction with the Local Offer, promotion of the Local Offer, how services are working together, and the quality of EHCP's. Whilst there are only four selection options shown on the chart below, there was another option of *extremely dissatisfied*, but this was not selected for any of the rating questions.



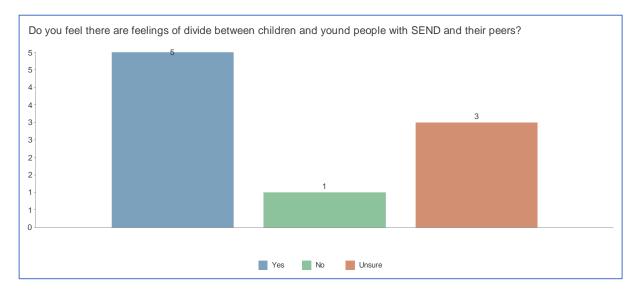
With regard to the Local Offer one person reported they were *extremely satisfied*, six people reported they were *satisfied*, one person selected *neutral*, and one person reported they were *dissatisfied*.

When rating the promotion of the Local Offer two people selected *extremely satisfied*, two people selected *satisfied*, four people selected *neutral*, and one person selected *dissatisfied*.

When asked to rate how services are working together one person selected *extremely satisfied*, two people selected *satisfied*, five people selected *neutral*, and one person selected *dissatisfied*.

When asked to rate the quality of EHCP's two people reported they were *extremely satisfied*, three people reported they were *satisfied*, two people reported they were *neutral* and two people reported they were *dissatisfied*.

**Question 11** asked professionals if they feel there are feelings of divide between children and young people with SEND and their peers, five people selected *yes*, one person selected *no*, and three people selected *unsure*.



Question 12 asked professionals to tell us anything else they wanted us to know about the Halton SEND Local Offer, or how it affects the families/children and young people they support. Only four responses were received so thematic analysis was not possible, one person advised that 'SENDAISS would be great if more advisors so no waiting times. A leaflet or bar code to be able to sign post to it', another questioned 'how do you advertise the SEND local offer for parents/YP who do not have access or understand digital technology?' going further to advise that 'the literacy skills for parents is quite poor in Halton and parents struggle to access information', another told us that 'information sharing has improved', and the final person advised that the 'Local Offer is great', and that they 'would like to see more choice for users'.

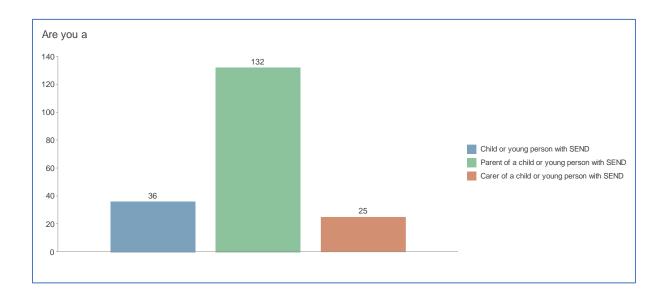


#### Children and Young People, Parents and Carers Survey

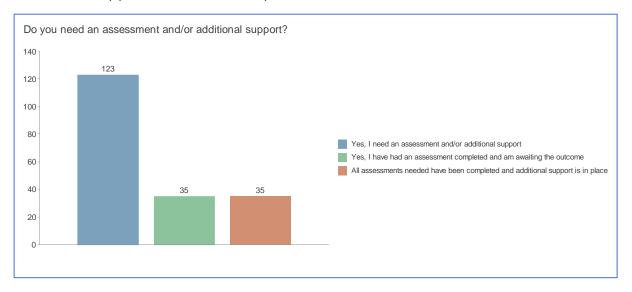
The Children and Young People, Parents and Carers Survey was made available online and a link to this was also circulated through the Healthwatch Halton network, the SEND network, and was promoted on the SEND Local Offer website.

We received 193 responses in total to the survey.

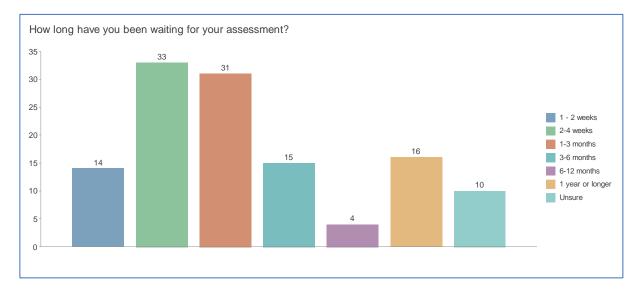
Question 1 was a multiple-choice question which asked respondents to report whether they were a child or young person with SEND, a parent, or a carer. 36 of respondents were *a child or young person*, 132 respondents were a *parent*, and 25 were a *carer* of a child or young person with SEND, please see the chart below.



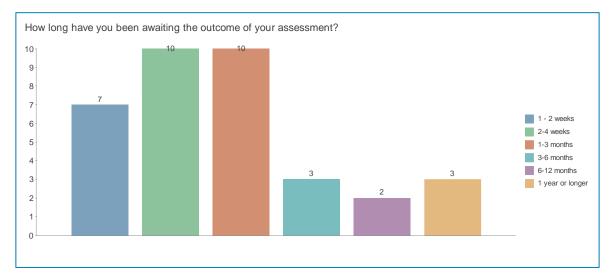
Question 2 was a multiple-choice question which asked participants if they or the person they cared for needed an assessment and/or additional support. 64% of respondents reported they were in need of an assessment and/or additional support, 18% reported they have had an assessment and are awaiting the outcome and 18% reported that assessment had been completed and any additional support needed was in place.



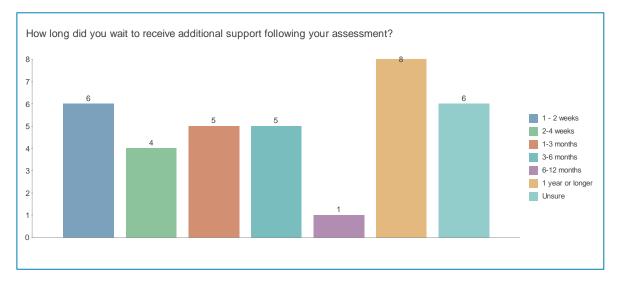
People who said that they were in need of an assessment were asked **Question 3**, which was a multiple-choice question, asking how long they have been waiting for their assessment. 14 people reported they had waited *1 to 2 weeks*, 33 people reported they had been waiting for *2 to4 weeks*, 31 people told us they had been waiting for *1 to 3 months*, 15 people reported they had waited *3 to 6 months* so far, 4 people reported they had been waiting for *6 to 12* months, 16 people reported they had been waiting one year or longer and 10 people were unsure how long they had been waiting.



People who said that they had had an assessment but were waiting for support were asked **Question 4**, a multiple-choice question, that asked how long they had been waiting for the outcome of their assessment. Seven people reported they had waited for *1 to 2 weeks*, ten people advised they had waited *2 to 4 weeks*, ten people reported having waited for *1 to 3 months*, three people reported waiting for *3 to 6 months*, two people advised they had waited *6 to 12* months, and three people reported having waited for *one year or longer*.

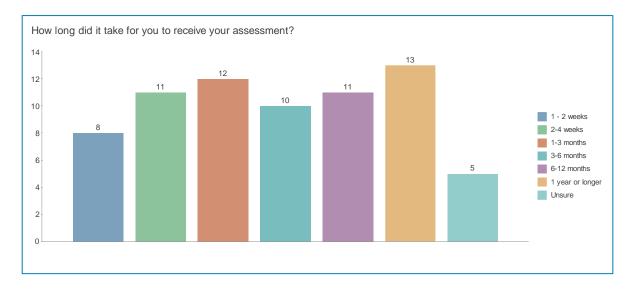


People who said that they had had an assessment and support was in place were asked **Question 5.** This asked how long people had waited to receive additional support following their assessment. Six people reported they waited *1 to 2 weeks*, four people reported they waited *2 to 4 weeks*, five people reported they waited *1 to 3 months*, five people stated that they waited for *3 to 6 months*, 1 person reported waiting for *6 to 12* months, eight people advised they had waited for *one year or longer*, and six people were *unsure* how long they had waited for additional support to be in place.



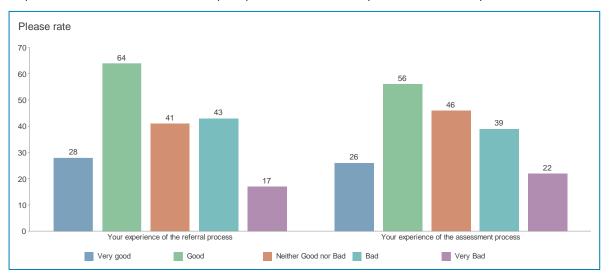


Question 6 asked how long it took for respondents to receive their assessment. eight people reported that it took *1 to 2 weeks*, 11 people stated it had taken *2 to 4 weeks*, 12 people reported that it took *1 to 3 months*, ten people advised it took *3 to 6 months*, 11 people reported it took *6 to 12* months, 13 people reported that it took *1 year or longer*, and five people were *unsure* how long it took to receive their assessment.



Question 7 asked participants to rate their experience of the referral process, and their experience of the assessment process.

When asked to rate the referral process 28 people felt that it was very good, 64 people felt that it was good, 41 people felt it to be *neither good nor bad*, 43 people rated it as *bad*, and 17 people found it to be very bad. When asked about their experience of the assessment process, 26 people felt it was very good, 56 people rated it as *good*, 46 people rated it as *neither good nor bad*, 39 people felt their experience was *bad*, and 22 people rated their experience as *very bad*.



**Question 8** asked participants to tell us the impact that the referral, assessment or additional support process has had on them and their family. The feedback that we received was analysed thematically and **six themes emerged from the data**.

1. Impact on families was the most commonly discussed theme, one participant told us that they found the whole process to be 'stressful, repetitive and not customer focused', and that this 'impacted our family greatly causing additional unnecessary distress', another person told us that they had been made to feel like 'a failure as a parent', someone else reported that it had caused a 'very bad effect on all of the family's mental health', and another advised that 'it has seriously affected my mental health' and that 'this is due to the amount of stress and the fight I've had to put up, just to get his referral accepted and for someone to actually listen to me', they went further to add that 'it made me feel like I was going insane and it was all in my head'.

Others told us that the process had caused 'stress on family mental health', that it had 'financial implications', caused 'family breakdown' and 'isolation of children', another reported that the process caused 'extra stress' and 'more time taken away from work to chase phone calls and emails for updates', and someone else stated that 'it's draining and exhausting' and that 'it impacts our jobs and makes us angry and sad'.

Other participants were more positive, one told us that the process 'helped my family's life', another advised that completing the process had 'made our negative family a better place', and that 'it made our parents' hearts a little less heavy', and another reported that they found the process to be 'very good', and that it has had 'a positive effect'.

2. Assessment and Referral was another commonly discussed theme, one participant reported to us that there are 'long waiting times for assessments and support', another told us that 'delays in assessment and implementation of support without the assessment caused huge amounts of stress and anxiety for my son and was detrimental to his health and wellbeing', another stated that 'there are too many procedures in this process', and someone else advised that 'I know very little myself, so I think the process is more complicated, because I really don't understand the policy'.

One participant advised that 'the evaluation was devastating and upsetting', another told us that 'I can't get help from anywhere and no one has met my child yet to even start any assessments', someone else told us that 'the CDC in Widnes have written stating they cannot give an appointment due to a backlog' and another reported that 'we had to fight for my child to be assessed' and that 'we flagged concerns at aged 2 and finally received his diagnosis at aged 7', they went further to add that 'once we had the diagnosis it felt like we were left to fend for ourselves with no direction to where we could get help or support'.

Other participants reported positive experiences, one told us that 'although it is troublesome, it is generally good' another advised that 'we are being seen promptly by clinicians regarding the EHCP process', and another advised that the 'referral was fairly quick (2 months to be accepted into pathway)' and that 'we had support from school SENCO which helped'.

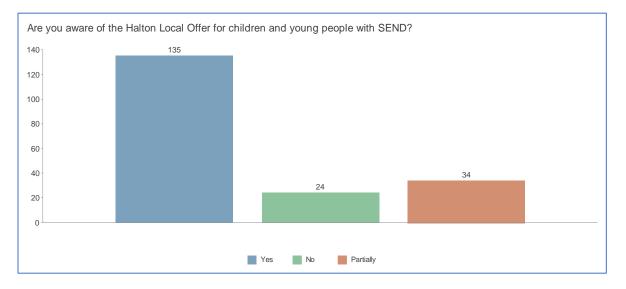
**3.** Family Involvement in the referral and assessment process was discussed by some participants, one told us that 'we've known for 7 years our child was SEND but no one wants to listen to parents', another reported that 'at first when I suspected autism in 2011 I wasn't believed and was made out to be an over protective mother', but that 'he received his diagnosis in 2019 after years of me asking for help', another advised simply that 'nobody listens to your concerns' and another informed us that 'both us as parents have had concerns for several years, but as my daughter is academically achieving ok we have been told she doesn't meet the threshold for referral' they went on to advise that 'subsequently we have paid to have her assessed privately and she has both ASD and ADHD'.

**4.** Education was another theme that emerged from the feedback, one participant told us that 'the longer this takes the more education he is missing', another stated that 'my child is 14 years old' and has 'missed nearly 3 years of school', another reported that 'my child's education suffering even further because the correct support is taking longer and longer to be put in place', and someone else informed us that 'school has not implemented care plans properly'.

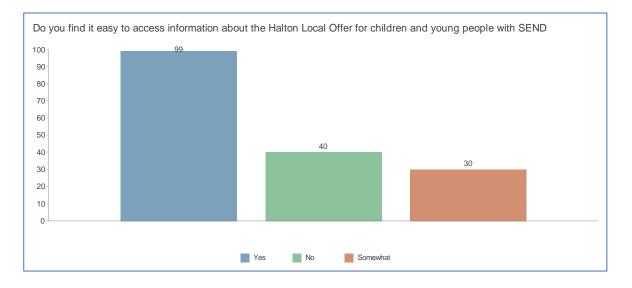
**5.** Support, Advice and Guidance was another theme that was discussed by participants, one person told us that they have 'no support, no direction', another stated that they are 'still awaiting things to kick in', another informed us that 'when you get a diagnosis everyone vanishes and you are left with no help', and someone else told us that they found the process to be 'very stressful', that there is 'no communication' and that parents are 'made to feel like an inconvenience', and finding that there is 'no support until diagnosis'. It is interesting to note the contrast in opinion of support that is available, one person advised that there is no support until diagnosis, whilst another reported that all support disappears when diagnosis is received.

6. Services were discussed by some participants, one stated that 'referrals made for inappropriate services despite being informed' and that there are 'gaps in services and provisions', another told us that there is a 'lack of training in children's services team and understanding of children's disabilities', someone else advised that there is a 'lack of communication between services and recording of information', that there are 'disjointed services', and 'barriers to services', and another felt that 'the whole process should have one case worker who oversees and communicates with professionals and the family'.

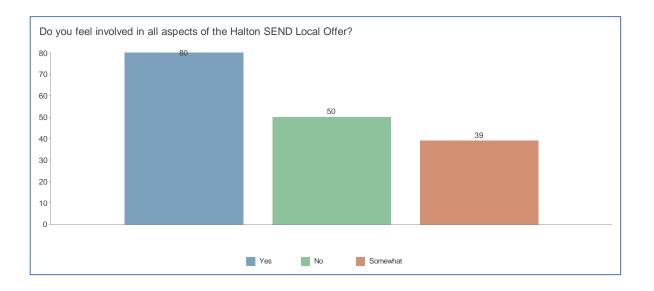
Question 9 asked participants if they were aware of the Halton Local Offer for children and young people with SEND, 135 people selected *Yes* as a response, 24 people selected *No* as a response and 34 people reported themselves to be *partially* aware of the Local Offer.



Question 10 asked participants if they find it easy to access information about the Halton Local Offer for children and young people with SEND. 99 people selected **Yes** as a response option, 40 people selected **No**, and 30 people selected that they find it **Somewhat** easy to access information.



Question 11 asked if participants felt involved in all aspects of the Local Offer, 80 people selected *Yes*, 50 people selected *No*, and 39 people felt they were *Somewhat* involved in the Local Offer.



**Question 12** asked participants how they would like to receive information about the Halton Local Offer. Five main routes of communication were identified, these have been represented in the chart below with the number of participants who listed each communication type.



**Question 13** asked participants how they would like to be involved in the Halton Local Offer, and feedback was analysed thematically, and four themes emerged from the feedback.

**Communication and Information** was the most commonly discussed theme, one participant told us that 'I enjoyed a zoom where there was instructions on how to get the most from the local offer and would like something like that again', another stated that they 'would like to know what the local offer is', another advised that they want 'information to be easier to access', another told us that 'I would like to fully know what help is available for send children and what support is offered', and someone else stated that they want 'relevant and up to date information to access on the local offer' but that there should be by 'other means of accessing information other than via computer/web'.

One person suggested that 'regular newsletters/roundups of local events and support would be beneficial', others simply stated that 'email' would be their preferred way on receiving communication and information, and some advised that having information available on 'Facebook' or 'via social media page' would be better than 'having to search stuff on the Halton local offer site'.

**Family Involvement and Expertise** was another theme that emerged from the feedback, one person felt that 'more input from users should be sought', another stated that the ability to 'give views and feedback on services is required', someone else advised that 'more consultation with parents' is needed, and someone else stated that they would 'like to be involved very much in the Halton SEND Local offer'.

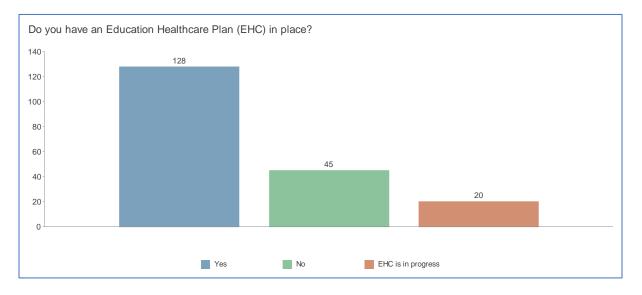
Others suggested ways that they could be more involved, one person felt that 'regular meetings' would be helpful, someone else stated 'I have attended a meeting and feel that I could be involved if I wanted to', someone else advised that they would like to 'participate in groups and receive regular information', and another reported 'I am involved sufficiently'.

**Support Services and Groups** was another theme that was raised by responses, one participant told us they felt that 'involving the parent carers forum via zoom meetings is a good way to get more information and to open up communication between the LA and the families that need support', another felt that there should be 'easy access to services and signposting', another advised that there should be 'collaborative working practice with ALL services/professionals involved' which would 'reduce the impact on family of repetitive communication of needs' another advised that they would like to be 'given some advice & guidance on what services there are specifically suited to my child's needs', whilst another stated that 'I have found Halton SEND a very helpful service who have signposted me to other useful services'.

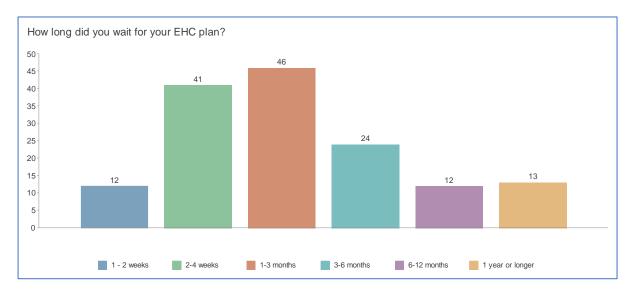
Local Offer Website was discussed by some participants, one stated that they would like to 'see more up to date information published', and 'more from parent and carer forum as they are in the leisure section' but that instead 'need to be in educational section too' so that the information 'does not get lost'. Another person told us that they would like to see 'easier to read and more up to date information' and that the website is 'hard to navigate and most information is incorrect and outdated', another reported that 'the local offer site is confusing at best', and someone else told us that 'it should be easier to navigate, I didn't know anything about it and had to find all the info myself'.



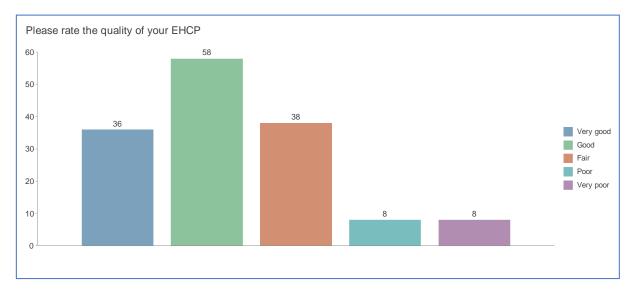
**Question 14** asked participants if they have an EHCP in place, 128 people responded *Yes*, 45 reported that *No*, they did not have an EHCP in place, and for 20 people the *EHCP was in progress*.



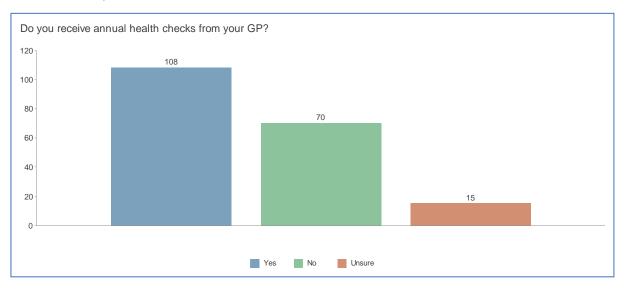
Question 15 asked participants how long they waited for their EHCP. 12 people reported that they waited for *1 to 2 weeks*, 41 people stated they had waited *2 to 4 weeks*, 46 people reported that it took *1 to 3 months*, 24 people advised that they waited *3 to 6 months*, 12 people reported it took *6 to 12* months, and 13 people reported that it took *One year or longer*.



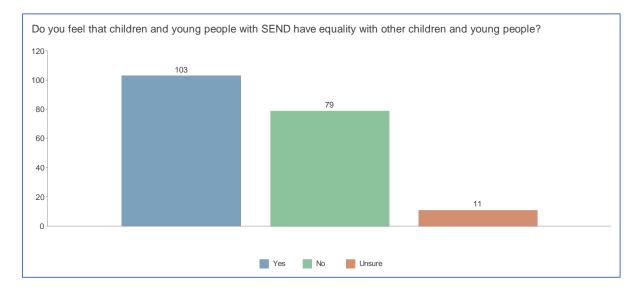
Question 16 asked participants to rate the quality of their EHCP. 36 people rated it as *very good*, 58 people rated it as *good*, 38 people rated it as *fair*, 8 people rated it as *poor*, and 8 people rated it as *very poor*.



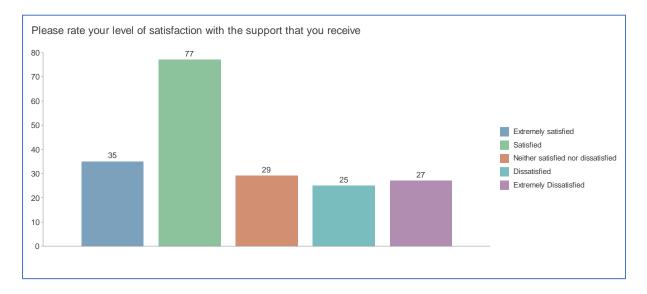
**Question 17** asked participants whether they receive annual health checks from their GP, 108 people selected *yes*, 70 people selected *no*, and 15 people were *unsure* if they receive annual health checks or not.



**Question 18** asked participants if they feel that children and young people with SEND have equality with other children and young people. 103 people selected **Yes**, 79 people selected **No**, and 11 people were **Unsure** if there is equality or not.



**Question 19** asked participants to rate their level of satisfaction with the support that they receive. 35 people told us that they are *extremely satisfied*, 77 people felt *satisfied*, 29 people reported they were *neither satisfied nor dissatisfied*, 25 people told us they were *dissatisfied*, and 27 people felt *extremely dissatisfied* with the support that they receive.



**Question 20** was an open text question that asked participants to tell us anything else they would like us to know about their experiences or level of satisfaction. The feedback was analysed thematically, and **three themes** emerged from the feedback.

1. The Local Offer was the most commonly discussed theme by participants, one person told us that there is 'a total lack of assessment and diagnosis and then further support', another reported that they had been 'made to feel like a failure as a parent and fight barrier after barrier', someone else advised that 'overall the quality of assessment and additional support in the borough is extremely poor', another stated that 'aside from a phone call with repeat advice I don't feel any services have fulfilled my child's needs', and another told us that 'I believe children should be seen with a lot more urgency while they are awaiting to be assessed they are struggling daily which is effecting their education and mental health'.

Others were positive about their experience with The Local Offer, one told us that 'I'm satisfied in every way', another advised 'I'm pleased with how quickly the process went down', another reported that 'I'm happy with the care I'm getting', and someone else told us that 'the SEND service is very good'.

2. Support was another commonly discussed theme, we were told by one participant that there is 'no support' and that families are 'constantly pushed from one person to another', another person advised that 'services in Halton are poor', and that 'the only good thing is the parent carer forum', someone else told us that 'some support for the children' would help greatly' as well as the 'ability to access support before diagnosis'. Another participant stated that 'I know there are a lot of children with SEND needs but, children are missing out on important help and support as the process just takes far too long', another reported 'children receive a diagnosis and are left to deal with it' and someone else told us 'I have had no support'.

Others were positive about the support that they had received, one person told us that 'it helped our family, it helped solve the problem', another advised that 'I've had a lot of help and I feel really good about it', and another stated that 'I am very satisfied with the help for us, which is a great encouragement for my disabled children'.

3. EHCP and Education was another theme that emerged from the feedback, one person told us that 'I have 2 children with EHCP's, I feel one is much more comprehensive and explanatory than the other, same with the advisors they had', another parent advised that 'all professionals give their recommendations for the child but school do not have the manpower or funds to put in to place, so child goes without', anther told us that they have a 'lack of support from the school'. And someone else reported that 'when the EHCP was compiled school were mindful of only stipulating support they felt they could meet and not support that was actually based on need'.

Other had more positive experiences with EHCP and Education, one person told us that 'we have been lucky to have a knowledgeable and pro-active teacher in my child's (mainstream) class this year, so we have received some support direct from the school and are now getting a school nurse involved to do some work with our daughter', another told us that 'after diagnosis, they were very active in making the EHCP', and someone else told us that their 'experience of school / nursery support and EHCP have been positive so far'.

#### Conclusions

The feedback received from all participants was very mixed in terms of experience and sentiment towards referrals and assessments, additional support, the Local Offer, and communication and information.

Throughout this feedback however, it is important to note that there were positive examples of experiences of assessments and additional support, and the implementation of all aspects of the Local Offer.

As the feedback regarding waiting times for assessment show, assessments could take weeks, months or up to one year or more to take place once the referral has been made, with the same being shown when awaiting additional support to be in place. Participants referred to delays and long waiting times that they felt were unnecessary, and which often had a family wide impact.

In terms of services working together there was a general agreement that patient information, case histories and care plans are not communicated well between services of different disciplines, and that often parents or carers have to tell their story repeatedly to different professionals. Utilising different software systems, lack of staffing, lack of adequate resources, and a lack of staff knowledge, were mentioned as reasons for this, but many felt that there were gaps in services, barriers to accessing services and that services were disjointed.

Feedback about the Local Offer website was largely negative, and users found it to be too difficult to navigate, not relevant or up to date, confusing, and not easy to read and understand. Advice from professionals suggested that digital access, digital skills, and literacy skills were barriers for people in accessing the information on the Local Offer website.

Communication and Information was another issue raised by participants. Many people felt that they were not kept informed about the assessment and additional support process as they would have liked to be, and that services did not communicate with them with regard to progress and expected waiting times. Some also reported a lack of information about what support was on offer, what services were involved, and the procedures and protocols of the Local Offer.

Family involvement and expertise were also raised throughout the project, and participants felt that the views of young people and their families should sought by professionals of all disciplines, and that the information that they add should be taken more seriously for assessments, care planning or EHCP's.

There was also a strong indication that people would like to be more involved in the Local Offer through providing feedback, attending meetings or being involved in consultations, but many don't know how to access this, some however reported that they already attend meetings and give regular feedback and are satisfied with the amount of involvement hat they have with the Local Offer. This shows that the opportunities for involvement in the Local Offer are there, but there is a lack of information on how to access it.

Education and EHCP's were discussed by many who had difficulty accessing appropriate educational settings and the suitable support whilst at school, whilst awaiting diagnosis or additional support to commence.

Many discussed the wait times for an EHCP to be put in place following assessment, with waiting times ranging from a few weeks to 1 year or longer. Other issues that were raised were consistency of EHCP, quality of EHCP, young person and family influence in the creation of the EHCP, and a lack of resources within schools to provide adequate support which leads to ineffective EHCP's.

#### **Recommendations**

- Improve Assessments:
  - a Review the delays and waiting times for assessments and additional support.
  - b Review consistency of access to support for young people, their parent or carers throughout and beyond the assessment process.
  - c Ensure assessment procedures allow for family expertise to be a core element of assessments.

**2.** Improve Joint Working Protocols:

- a Ensure joint-working protocols are in place in all services and disciplines involved in the Local Offer.
- b Monitor joint-working protocols to ensure they are being followed by all services and disciplines involved in the Local Offer.

**3.** Refresh and redesign the SEND Local Offer website:

- a to make it more user friendly in terms of ease of use, navigation to relevant information and levels of literacy used.
- b Involve parents and carers in designing a Local Offer website which responds to their needs better. A redesign should take account of a range of access needs (e.g., pictures may help some groups but may be problematic for others without a description) and ways of presenting information which is navigable by people with a range of additional needs, including sensory impairments.
- **4.** Improve family involvement in the Local Offer by promoting the different ways that people can get involved through digital and non-digital means.
- 5. Design a broader approach to communicating the Local Offer information in a more user-friendly way with non-digital options that are accessible to people who do not have digital access or skills.
- 6. Improve communication between professionals and between professionals and young people/parents/carers.
- 7. Demonstrate clear processes for promoting and signposting to groups who can have a role in supporting young people, parents, and carers, throughout the process.

- 8. Education and Healthcare Plans (EHCP)
  - a Improve the timeframe for EHCP creation.
  - b Improve the consistency and quality of EHCPs to include specific/quantifiable support which can be easily monitored and evaluated. This will enable parents/carers to have a better understanding of what support is in place and who is responsible for delivering it.
  - c Ensure that EHCPs are meaningful to children/young people. Provide a way for young people to provide feedback about whether EHCP actions, or support plans, are working well for them or not.

#### **Report responses**

#### Halton SEND Parent Carers Forum

'At Halton SEND Parent Carers Forum we say, 'Your voice counts' and it was wonderful to see so many families with SEND get involved with the Healthwatch survey and have their voice heard. The data has identified and evidenced areas for improvement and it is now vital that the recommendations, from the Healthwatch project will be followed. This will help enable better support, services and lives for those with SEND living in Halton.'

Halton SEND Parent Carers Forum (HSPCF) - <u>www.haltonsendcarersforum.org.uk</u>

#### **Denise Roberts**

NHS Cheshire and Merseyside's Place Associate Director for Quality and Safety Improvement for Halton and Halton SEND Partnership Board Chair

"We welcome the findings of the report and would like to thank our Healthwatch Halton colleagues for compiling the report and all those who gave up their time to share their experiences.

"We're aware of the challenges many children, young people and their families with special educational needs and disabilities (SEND) experience, and the report's findings show the impact that any additional barriers can have on their day-today life.

"While we are already in the process of addressing many of the challenges, the Halton SEND Partnership Board is committed to reviewing all the recommendations and working with partners across Halton to address them appropriately.

"As One Halton, the council, NHS organisations, GP practices and voluntary organisations are working together to make the health and care system work better for Halton's residents - working as one to join up services, share ideas and resources and tackle the borough's biggest challenges."

#### Acknowledgements

This report could not have been produced without the input and support of many individuals and organisations.

Thanks to all the children, young people, parents, carers, SEND practitioners, service providers and commissioners who took the time to share their stories, experience and information via surveys and focus groups. Their contributions were anonymous, but their input was crucial.



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