

# Transforming Care Report



March 2020

**healthwatch**  
Walsall

## Introduction

Healthwatch Walsall is the independent voice of the public in the health and social care services. We collect feedback from the public of Walsall about their experiences of using health and social care services and use that feedback to work with service providers and commissioners to look at ways that services can be improved.

One of the ways that we collect feedback is to carry out focused projects looking at particular services or conditions. On this occasion we have carried out a project that looks at the experiences of people accessing services that support people with Learning Disabilities and/or Autism in the community.

## What we did

This project made use of surveys and focus groups. The surveys were made up of a short number of questions that were a mixture of multiple-choice questions and open text questions where respondents were able to expand on their answers.

The focus groups were designed to gain a greater understanding of the experiences of people with learning disabilities and/or autism and their carers in accessing and using services in the community.

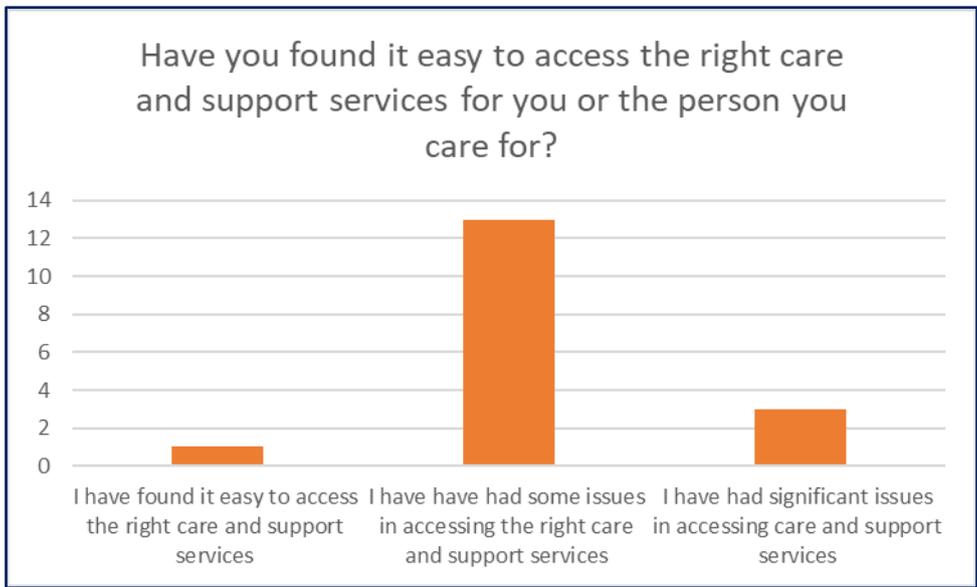
## Findings

There were a minimal number of survey responses with a total of 22 responses being completed. A total of 41 participants took part in the focus groups and additional feedback was also submitted by one support worker who had taken part in a focus group. Those who took part in a focus group were also able to complete the survey and therefore, there is the potential that participants in the project will have done both.

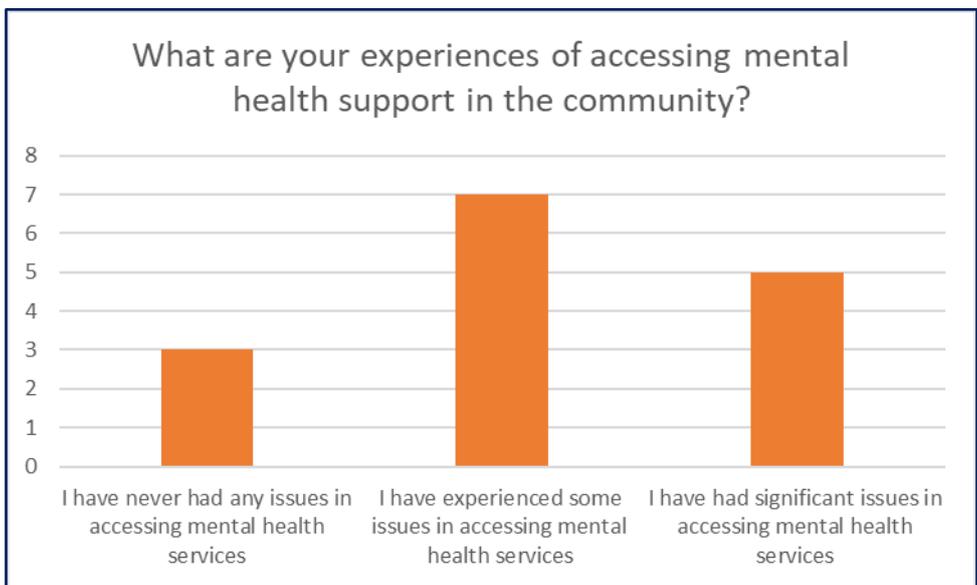
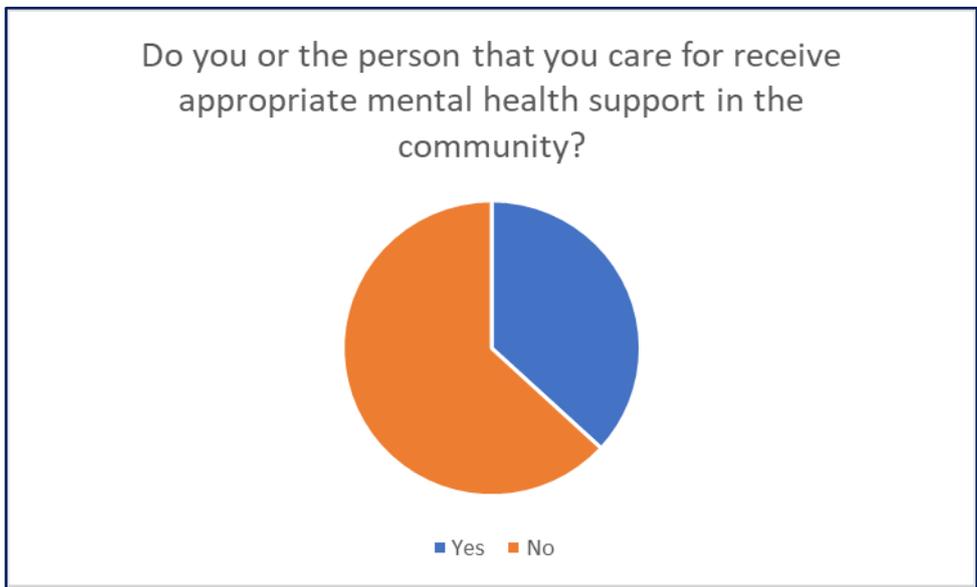
The survey asked respondents if they themselves had a learning disability and/or autism or if they were a carer for someone who had. Respondents were able to choose all the options that applied to them. Most of the responses came from people who were carers with six saying that they cared for someone with a learning disability and 14 saying that they cared for someone with autism. Two respondents to the survey said that they themselves had a learning disability.



Respondents to the survey were asked if they had found it easy to access the right care and support services. Of those that answered the question; one respondent said that they had found it easy to access services; 13 said that they had had some issues and three said that they had encountered significant issues in accessing services.



When asked if they or the person they cared for received appropriate mental health support in the community twelve of the respondents who answered the question said that they did not and seven said that they did.



Survey respondents were asked about their experiences in accessing mental health support in the community. Three respondents said that they had never had any issues accessing mental health support in the community; seven said that they had experienced some issues accessing mental health services and five said that they had experienced significant issues accessing mental health services in the community.

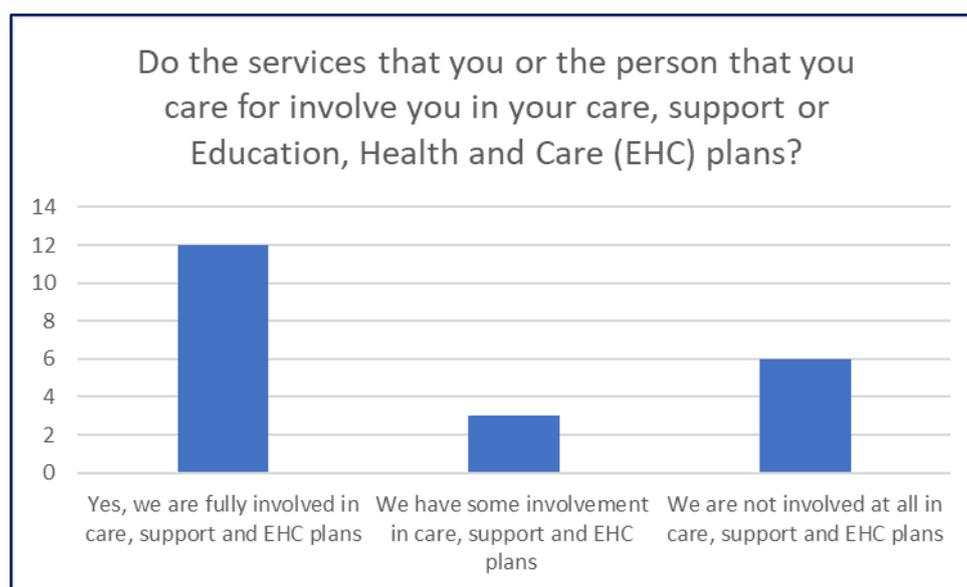
Feedback was provided from the focus groups and from the comments from survey respondents about access to CAMHS in particular, both before and after diagnosis. Experiences were mixed with some good experiences tempered with some poor experiences.

The time spent waiting to be seen by CAMHS was raised as an issue by parents of young people. For example, one participant in the focus groups told how they had waited for six months for an initial appointment with CAMHS when seeking a diagnosis for their child. They then went on to tell us how there had been numerous appointments before they got a diagnosis for their child and it had taken them 'writing a four page letter detailing day to day everything [they] go through; adding a threat that I'm going to make a complaint if somebody doesn't do something about this.'

One of the respondents to the survey said that it had taken 'a while to access CAMHS; had to wait until my child self-harmed'. During one of the focus groups we were told by a participant that their child had received a diagnosis when they had been an in-patient at a specialist hospital but that it has taken reaching crisis to get to that point.

Only being able to access services once the young person was in crisis was raised in the focus groups. They told how when their child had been in crisis they had called for an ambulance and been told to contact the crisis team. However, they said that there was no mental health crisis team for young people, only for adults and commented 'well yeah, there is a Crisis Team, but it doesn't deal with young people, only adults.'

It was felt by another participant in that focus group that crisis had to be reached before there would be any action by services to support young people with autism. They told how once their child had received a diagnosis of autism from CAMHS they were then left to fend for themselves. A lack of post diagnosis support was a theme that they returned to throughout the focus group commenting that 'I would have thought that once a child has accessed CAMHS and got a diagnosis there would be a support service there that they can access... once they've got a diagnosis there's a black hole until they reach crisis and then everyone jumps on board.'



Respondents to the survey were asked about their involvement in Education, Health and Care Plans (EHCPs). Twelve respondents said that they or the person that care for was fully involved in the plans; three said that they had some involvement and six said that they had no involvement at all.

Participants in the focus groups and respondents to the survey gave feedback on their experiences of accessing EHCPs.

Being able to access EHCPs was discussed in the focus groups and there was also feedback from the surveys. One parent told how they had tried to request an EHCP for their child themselves but only the school could do this and they had to ask the school to request and then continually chase them up for information on how it was progressing. Another who responded to the survey said that their 'youngest child had been denied an EHCP as the school strategies to meet [their] needs [but] I think [they] need this and I'm in school every day.'

One parent in a focus group told us that they had chosen not to pursue an EHCP because their child's needs were being met at school and mental health services.

Participants in the focus groups and surveys told of the waiting times that were involved in the process of obtaining an EHCP. One participant in a focus group commented that 'EHCP takes 26 weeks' but that it 'can be done in 10 weeks'.

Another said that it had taken 10 weeks. Being able to get an EHCP in the first instance was also an issue for one focus group participant who said that they had waited 'three months before they finally said someone was coming out to assess [them] but I haven't heard anything since.' For this participant the impact had been that their child had only been in school for around two days since their diagnosis the year before.

One of the survey respondents said that it had taken '9 months in total' to secure an EHCP and this had been their 'main difficulty'

One respondent to the survey commented on the outcome or process of the EHCP and they said that 'the EHCP does not meet [the] child's needs. The EHCP does not assess all needs and include them in the plan' which may suggest that they did not feel that they had been sufficiently involved in the decision-making process.



Survey respondents were asked if they had any needs that were not met by services within the community. One respondent said that their needs were fully met by community services. Seven said that most of their needs were met; seven said that some of their needs were met and seven said that their needs were not met by community services.

For participants in the focus groups being able to access social activities was a key topic of discussion. This ranged from activities that could be undertaken by those who had care packages and enabled them to go out in the day to social activities that families could take part in.

Service users told us about a range of activities like, swimming, bingo, discos and parkrun that they received support to attend. However, care providers spoke about the difficulties of going to activities in the community at certain times because of the costs increasing with one saying 'if you're on a budget, in the school holidays it's double. So, then that chucks them out of their routine.'

Paid care providers spoke about how they were developing services based on feedback from families, that would provide a youth club in the early evenings and social activities such as parties that they could attend as families as 'they feel that they can't...if you've got someone who's highly autistic, they can't go to a normal pub or disco because it's too much.'

Not having enough information about what services are available to them was raised within the focus groups. One participant told how their adult dependant had finished full time school some years previously and after that they had been left with nowhere to go. Although they were now accessing services this was because they had 'happened' upon the services of Mencap. They explained how as a result they felt that they had 'let down' their dependant because they were so 'ignorant' of what was available.

A lack of information about services that were available was echoed by participants in other groups with attendees of one group being unaware of support that was available to them as parents with one saying 'to be frank with you...there isn't really, unless you know otherwise, a forum for parents. The parents of children with autism. There isn't that forum for us to meet as parents.'

Wider support for carers was also raised by one participant who was the carer for their adult dependent saying that they had accessed a course for carers through the local authority but they were uncertain whether they were registered as a Carer saying that 'although I am contacted by the doctor and I have been on a Carers course with Walsall Council, I've got no information, no written evidence that I am [their] Carer.'

A group made up of paid support workers at a day centre spoke about the difficulty of service users being able to access reviews if their needs changed. One of the issues that was discussed in relation to accessing reviews related to a lack of continuity of social workers. Paid carers spoke about how there was no ongoing contact with a social worker once they have their care package commenting that 'you used to have a social worker and that social worker was for life; it isn't now. It's until they've done the package and that's it.' They went on to say that families would say to 'get on the phone to [the social worker] tell them we need a review. And, I'm like, you haven't got them anymore. And this is so hard for them to understand.'

It was also discussed that the social workers involved were no longer specialists in learning disability and as such it was felt that there was a lack of understanding of the needs of the service users with one participant commenting that 'they're not specialists anymore... social worker hasn't done anything with learning disability... if you've got a social worker who doesn't understand the needs of someone with learning disabilities it's not a very good start.'

For one parent of a young person with autism it was also raised that having a social worker opened access to other services with them commenting that 'if you haven't got a social worker or if they haven't got an EHCP then you cannot access any support services for a young person in Walsall.'

Care providers attending a focus group spoke about the transition from children's services to adult services. They said that there was a lack of preparation for the young people moving between services. One participant said that 'transition is a major problem and has been for many years. There is no proper transition from children to adult services.'

As a care provider they were seeking to work with the local school to develop an approach to transition to adult services as they pointed out that 'at 18, the respite has to change; at 19 they are leaving school. Going to another new place, whether that's college, whether that's a day centre, they're moving on. So, in that period of two years you've had to leave the school where you've been for the last 15 years, you're having to change your respite and you're having to change your placements.'

One of the parents taking part in a focus group commented that 'after 22 you go to adults support/health and that means you have nothing unless you have a care plan.'

## Conclusion

There were a relatively small number of respondents to the survey and participants across the focus groups. However, it has been possible to identify some themes from the feedback.

Access to CAMHS for assessments and for support post-diagnosis for those that receive a diagnosis of Autism Spectrum Disorder was raised as an issue by some parents. It was felt by some that there needed to be a crisis situation before there was sufficient intervention and a multi-agency response.

Accessing Education Health and Care Plans was an issue for parents with difficulties getting schools to request them and long waiting times for assessments. This was impacting on access to education and other services for some people. Involvement in the decision-making process was less commented on, possibly because the feedback received was from parents who were still waiting to access assessments for their children.

Access to social activities was a topic of discussion from participants who had LD and also parent carers and paid carers. Whilst those with LD were generally happy with their social activities and the support that they received to access them, it was felt by paid carers that there was a lack of activities for families and young people. The costs of activities were also raised as some commercial activities were higher priced in the school holidays and this was a barrier to access for service users.

Having access to information on what services were available for both those with LD and/or Autism and their Carers was seen as a gap, including support groups for parents and carers. This was also the case with moving from children's services to adult services.

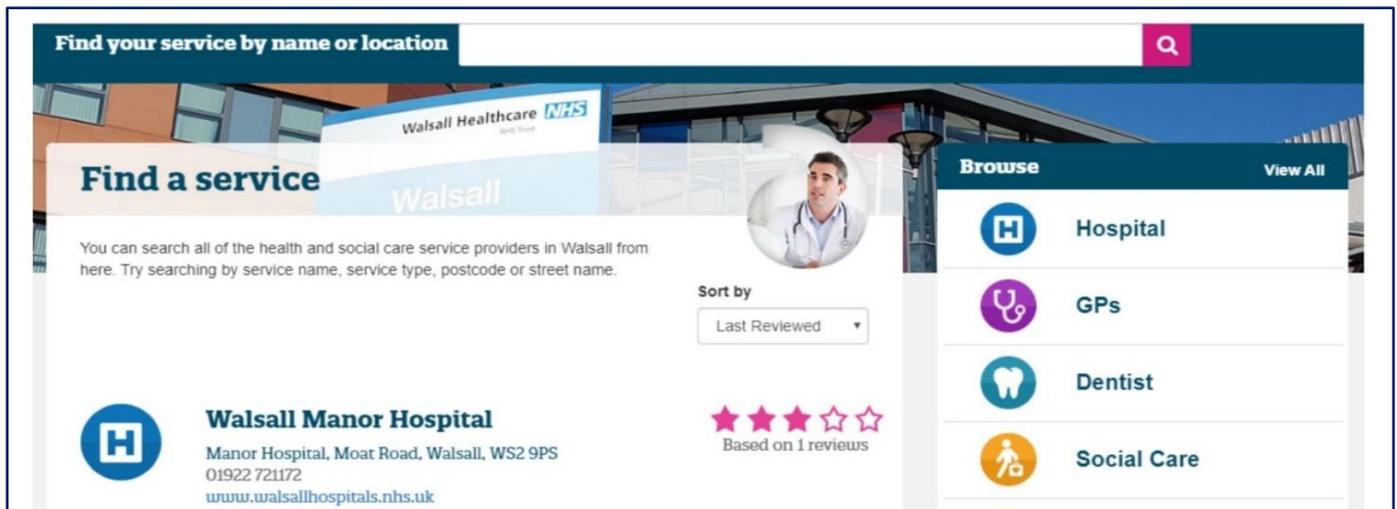
Having a social worker was seen as a means of accessing services but continuity of social workers was seen as a problem, alongside the knowledge that social workers have of LD in particular. As social workers move on from the service users once their support has been agreed this meant that when needs changes outside an annual review cycle it could be difficult to access a new assessment.

## Recommendations

- Easier access to CAMHS assessments for clients and families
- Families should be able to access EHCP assessments more timely.
- If possible, an assigned social worker should remain with the same client through their journey to give continuity, assurance and development opportunities for clients.
- Specialist training should be delivered and mandatory for social workers around autism and learning disabilities training.
- Consult with carers and clients with learning disability/and or autism to identify style and formats of information that advises them of their care.
- Increased opportunities for external social activities be more available, especially for adults who may have reduced access to services such as when a child or adolescent.
- Commissioners and Professionals have in place an intervention strategy to avoid or reduce service user(s) issues escalating to crisis points. Management rather than reaction.
- Greater engagement and involvement of co-produced services should take place between service commissioners, providers and professionals with individuals and families to ascertain needs and develop delivery to meet them.

If you have any NHS or Social Care service experiences that you wish to share, you can visit our online 24/7 Feedback Centre. Whether it's a: compliment, concern or complaint.

Link: <https://healthwatchwalsall.co.uk/services/>



## DISCLAIMER

Please note that this report only relates to findings we observe on the specific date of our visit. Our report is not a representative portrayal of the experiences of all residents and staff, only an account of what was observed and contributed at the time.

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Walsall

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