

Experiences of post diagnostic services for Autistic people and people with ADHD – Kingston & Richmond

Engagement analysis report – July 2023

Introduction

This report details the findings of recent engagement with those who have lived experience of the post diagnostic services for Autistic people and people with ADHD. The engagement looked at both child and adult services in the boroughs of Kingston and Richmond. Insight will be used to inform a new pathway for post diagnostic services in both boroughs.

Methodical Approach

Outreach and focus groups

The work delivered through the Autism (NDT) Pathway Review has involved partners across the system and there has been ongoing engagement with service users through a number of focus groups. From information provided about experiences of service users attending the parent carer forums, Skylarks, Richmond Mencap, Fast Minds and ADHD Embrace the gap in post diagnostic support was raised and the need to gather wider feedback was identified. The aim of the survey was not only to capture the experience of people accessing both child and adult services, but to gather their views on how we can develop services moving forward. Through working with the focus groups, 7 questions were developed to find out what service users had experienced and how we could meet their needs better.

Survey

To ensure we heard from a range of people who had experiences of the post diagnostic pathway, we ran an online survey. The survey's aim was to build on what we have already heard from those who attended focus groups. The survey was uploaded to the Bang the Table site and, to reach a wide audience, was promoted through various channels including the SWL (South West London) ICB Autism (NDT) Pathway Review Steering Group including partners from across health, Kingston and Richmond Local Authority, education, voluntary sector, and people with lived experience. The survey was also sent out individually to Action Attainment, Richmond Borough MIND, Kingston and Richmond Parent Carer Forums, The Richmond branch of the National Autistic Society, Skylarks, Express CIC (Community Interpreting Certificates), ADHD Embrace and Fastminds.

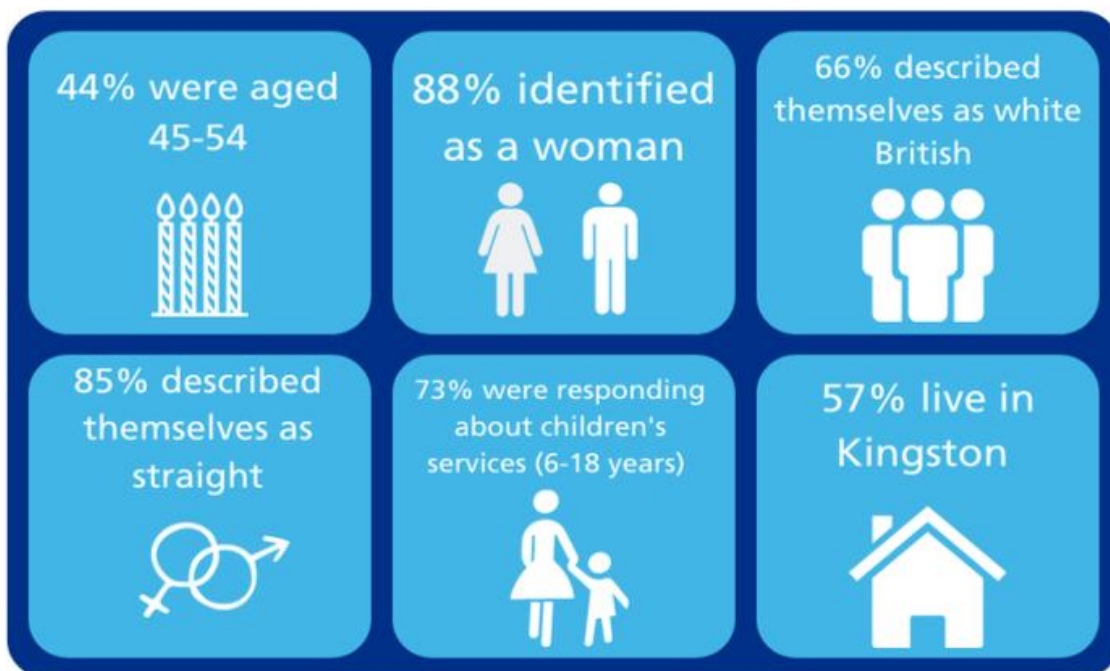
Respondents were asked, in free-text questions, what their experiences of post diagnostic support were, what was good about it and what did not go so well. They were further asked, as checkbox questions, how they found out about support available, what information they would have liked to have known, how best to receive information, and when best to receive support, post diagnosis, as well as asking basic demographic questions.

Survey results

Who we heard from

The survey ran from 18 May to 16 June and had 97 responses reflecting a robust level of participation (note that not every respondent answered every question). There was a fairly even split between the 2 boroughs and 1 respondent lived in another borough. Although 44% of people (42) who responded were aged 45-54, there was still a range of ages amongst the responses. 3 respondents were aged 16-17, 2 were 18-24, 10 were 25-34, and 9 were 55-64. No one over 65 responded.

Most people who responded identified as a woman (88%) and similarly, most respondents described themselves as straight (85%). Respondents identified with 11 different ethnicities, but the highest percentage was white British (62.6%). The survey was open to those who had experience of child and adult services. 89% were answering children's services, with 16% having experience of services for those aged 0-5 and 73% answering about services for those 6-18 years. 10 respondents answered about adults' services.



Summary

Headline findings from the survey respondents and the community outreach:

- Many of those who responded felt there was little, if any, support after an Autism diagnosis. This is for adults with Autism, and parents of children with Autism. The sentiment was they felt dismissed and alone after the diagnosis.
- A lot of those who felt they had some support did not feel it was enough, and had negative experiences, including long waiting times and a confusing system to navigate. They said they were also not advised about support through NHS services and felt it was up to them to seek it out using other channels.
- Respondents wanted to know any information that would have been helpful to them post diagnosis, as many were/are unsure where to go.

Detailed findings

Tell us about your experiences of post diagnostic support. What was good about the support?

What did not go so well?

The answers given to these 2 questions overwhelmingly pointed to the lack of support given after receiving a diagnosis. 45 of the 90 answers given to the first question expressed that there was no support given at all. Some answers did not expand past this, for example;

“It is non existent” and “Honestly, I can’t think of anything good”.

Multiple people felt, because of the lack of support, they were left alone to find out what was available. One person said;

“We had nothing but left to do our own research”.

Some were given leaflets as the only means of support/ signposting. Others commented on how much of a struggle this is because the system is not easy to navigate without professional help, with one person referencing the confusing jargon used. There were comments from those who felt dismissed by the paediatricians and psychotherapists who they did seek help from. One account said that they were told they would have to privately pay if they wanted any further support.

Other answers indicated that they were able to access some support but did not feel it was enough. This included;

- Access to medication. Many said they were able to get medication but that was the extent of the support.

“The medication is helpful however there has been no other support we feel we as a family have just been completely left to our own devices and think it's terrible that the support is so minimal”

- Some who were answering about services for children, had been referred to CAMHS (Child and Adolescent Mental Health Services). However, there is a lack of resources in CAMHS, with some finding they still had no support after being referred to them. This is after sitting on long wait lists. Some commented that there were no offers of therapy through CAMHS. A theme from all answers was a need for more provisions for therapy.

“We didn’t receive any other help from CAMHS at all. My son was only diagnosed when he was 7 years old, while problems were since nursery. Also, though he was referred to Emotional Health Support Service at CAMHS, he only got his assessed for support, and since that we haven’t had any support from them (a year later). No consultation about medication has been offered as well. There are no contacts whom I could ask questions.”

Although this person did not receive a prescription through CAMHS, a few others commented that the CAMHS pathway was how they got medication.

“CAMHS role in prescribing medication has been great. But there's nothing else available (e.g., therapy)”

- 12 parents who felt they had received some support said it came through their child's school, and not through NHS services.

“Only support received has been through my son’s primary and secondary school SEN department post diagnosis. There has been no other support offered. He got his ASD diagnosis in 2016. It felt like we were given a diagnosis then abandoned. No follow up or support coming to terms with what ASD means to him or us as a family. He is now nearly 16 and has not come to terms with his ASD. Even CAMHS didn’t help. We were just signposted to information. websites despite his mental health being affected during his teenage years”.

- Those who were offered support found there were long waiting lists for access to medication and therapy. This was frustrating for some after waiting a long time for diagnosis in the first instance.

Some answers revealed more positive experiences. One person answered that the voluntary sector training they had for parents went well. Another person who had had a positive experience cited that their child

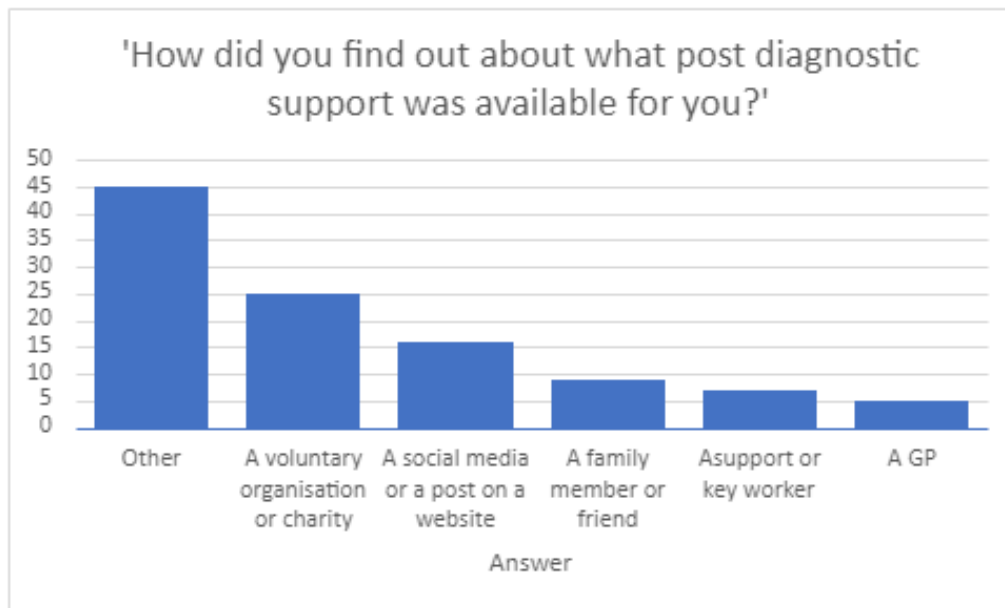
“Was referred to a number of specialists for further assessments which offered us more information and understanding of her support needs”.

6 people who had more positive experiences spoke of support from the Earlybird's course and ADHD Embrace.

The other questions were checkbox questions but gave the option for respondents to write free text answer as well. Respondents were able to pick more than one answer to the questions.

Question 4 asked **how did you find out about what post diagnostic support was available for you?**

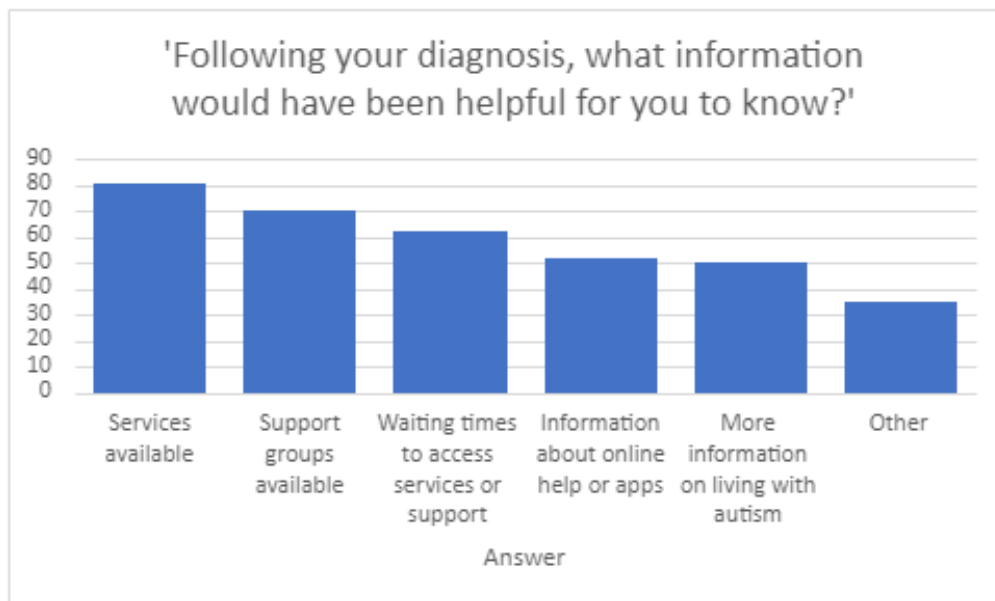
45 of respondents voted for “other” from the answers provided. The answers in the check boxes and free text mostly reflected the experiences given in the first 2 questions.



In the free text answers, many said they did not have any support, or that they sought support from their schools or through their own research (e.g., searching on the internet).

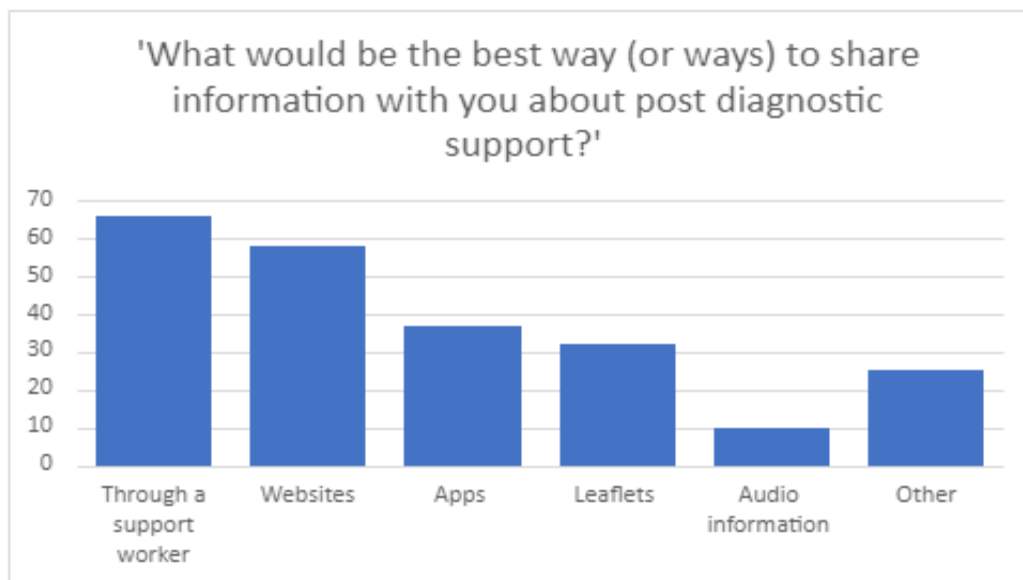
3 respondents said that they looked to other parents of SEND (Special Educational Needs and Disabilities) children for advice. Other themes that came up in the free text answers were finding out about support from the diagnosing clinician or in the diagnosis letter, through Speech and Language Therapy (SALT) and 2 were contacted by Achieving for Children.

For question 5, **following your diagnosis, what information would have been helpful for you to know?** there were 95 respondents, but many respondents voted for multiple answers, indicating that there are many areas where information for post diagnostic support is not available.



81 respondents would have liked to have known about “*services available*”, which is also reflected in 14 free text answers to this question which suggested they wanted more advice about the support available to them. There were suggestions in the free text answers as to what else would have been helpful. 6 answers indicated that having more access to professionals after diagnosis would help ease anxieties around the diagnosis and in emergencies. 8 answers specified that there needs to be more awareness of what mental health support is available to help people navigate their diagnosis. It was also flagged that there is lack of support to help children in the academic system, especially in periods of transition.

The answers to question 6 (**What would be the best way (or ways) to share information with you about post diagnostic support?**) indicated that there are a wide range of ways respondents wanted to receive the information. Relative to the other questions, the answers were voted for a fairly similar number of times.

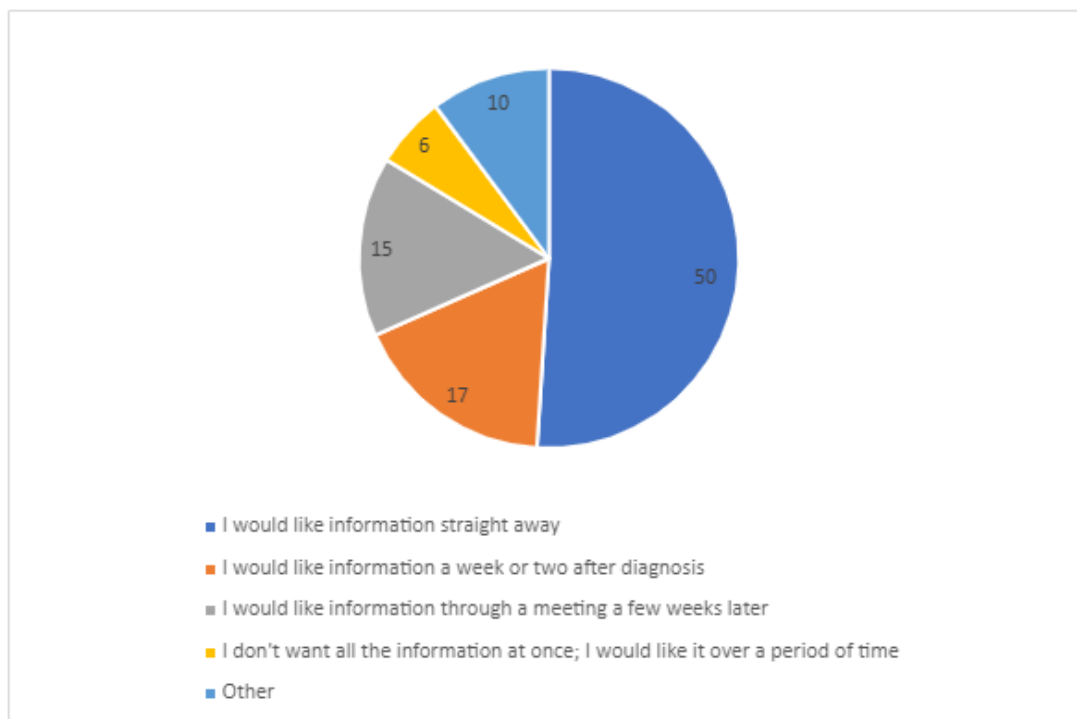


The other suggestions included information at GP surgeries, a booklet compiled with all local information, anything in writing e.g. emails/ texts (this was suggested by many but one person said it easier to translate if English is a second language), more information through schools, a clearer AFC (Achieving for Children) website, interactive apps / online services and workshops (online or in person). Other comments wanted the sharing of information to be more regular, and not 'dumped' on people in one go.

One response to question 5 asked for a change in support, rather than just the information -

"None, because nothing available is of much use. We need SALT, not a coffee. And the support available is not compatible with normal working hours. I can't take a pay cut to go for coffee, or for AFC to tell me how I can help myself. That just isn't helpful".

Question 7 - We understand that the diagnosis process can be overwhelming. When would be the best time to share information about post diagnostic services?



There were a few free text answers to this question giving suggestions about when information could be shared to parents of children with autism. One person responded

“Information should be provided at intervals, particularly at key education transition points, and ideally through discussion with the family and the individual with an autism diagnosis. Information should be tailored to the age group and stage of education.”

Whilst others thought information and support should be available on request, a main theme in the answers was having regular follow ups post-diagnosis or having a person to contact.

Conclusion

Those engaged felt there was little, if any, support after an Autism diagnosis and those who did receive some support felt it did not go far enough. Respondents want to know any information about available services, as many felt they had nowhere to go. Patient engagement on experience of the Autism pathway will be used to inform a review of the post diagnostic services in Kingston and Richmond.

Acknowledgements

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