

Healthwatch Kingston

Pulse Check report:

Neurodiversity and health and care services

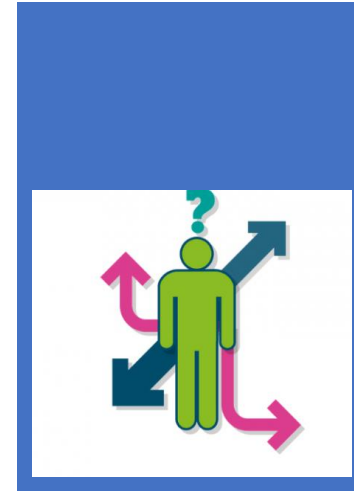
Survey and Focus Group - August and September 2021

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healthwatch
Kingston upon Thames

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1. About Healthwatch Kingston

Healthwatch Kingston upon Thames is your local health and social care champion. If you use GPs and hospitals, dentists, pharmacies, care homes or other support services in your area, we want to hear about your experiences. We are independent and have the power to make sure NHS leaders and other decision makers listen to local feedback and improve standards of care. We can also help you to find reliable and trustworthy information and advice. Last year, the Healthwatch network helped nearly a million people like you to have your say and get the support you need. Healthwatch Kingston upon Thames is part of a network of over 150 Local Healthwatch across the country.

We're here to listen to the issues that really matter to people in the Royal Borough of Kingston upon Thames and to hear about your experiences of using local health and social care services. We're entirely independent and impartial, and anything you share with us is confidential.

Healthwatch uses your feedback to better understand the challenges facing the NHS and other care providers and we make sure your experiences improve health and care for everyone – locally and nationally. We can also help you to get the information and advice you need to make the right decisions for you and to get the support you deserve.

It's really important that you share your experiences – whether good or bad, happy, or sad. If you've had a negative experience, it's easy to think there's no point in complaining, and that 'nothing ever changes.' Or, if you've had a great experience, that you 'wish you could say thank you'. Remember, your feedback is helping to improve people's lives. So, if you need advice, or you're ready to tell your story – we're here to listen.

2. Executive summary and recommendations

This report is the third from [Healthwatch Kingston's 'Pulse Check' engagement programme](#). Through the programme, we will work closely with Kingston's diverse communities: listening to people and gathering and reporting their experiences of health and social care services.

Through the Pulse Check programme, we will share people's experiences of local health and care services with commissioners and providers and encourage them to act on what matters to local people. We will also share these views and experiences with Healthwatch England and the Care Quality Commission.

This Pulse Check report is based on a survey of neurodiverse adults in Kingston carried out in April 2021. A total of 46 people responded to the survey and a further four people were interviewed over the phone as a requested [reasonable adjustment](#). Our Pulse Check survey builds on a Fastminds February 2021 review of Your Healthcare ADHD and Autism services in Kingston which collected feedback back from over 200 members of Fastminds (view slide set [here](#)) and made recommendations on ways services could be improved for neurodiverse people in Kingston on Thames. Their recommendations included a call for commissioners to develop a more holistic, joined up service.

Recommendations from our Healthwatch Kingston Pulse Check report should also be read in conjunction with recommendations in the [Healthwatch Kingston iCope Kingston service user review report: update](#).

**Healthwatch Kingston Pulse Check report:
Neurodiversity and health and care services**

RECOMMENDATIONS

WORKFORCE TRAINING

RECOMMENDATION 1 Health and social care service leads should commit to increasing awareness and understanding of neurodiversity across the commissioner and provider workforce to deepen understanding of the variety of ways neurodiverse people present. This includes the issues that arise from the ‘invisibility’ of these disabilities; the fluctuating nature of some symptoms and the disabling impact they have on people’s mental and a physical health and daily life. Impactful Neurodiversity workforce training should be co-developed and co-delivered with neurodiverse residents and tailored for both specialist and general health and care workforce, including clinicians and commissioners. [For ICS/CCG/Place leaders/RBK/Providers]

RECOMMENDATION 2 With neurodiverse residents, health and social care leads should co-produce a checklist of useful reasonable adjustments to make health and carer services properly accessible to neurodiverse residents and promote this check list to GPs and other health and care providers including mental health and diagnostic services. The training outlined in ‘Recommendation 1’ is one way to promote these useful reasonable adjustments across services. [For ICS/CCG/Place leaders/RBK/Providers]

JOINT (INTEGRATED) NEEDS ASSESSMENT

RECOMMENDATION 3 Public Health should conduct a comprehensive joint (integrated) needs assessment of neurodiversity in the Royal Borough of Kingston upon Thames. The assessment would gather data on the prevalence and number of adults with ADHD; improve data collection on autistic adults (building on the RBK Autism JSNA 2019) and assess the prevalence of commonly co-occurring conditions, mental health challenges and the health inequalities they experience. Public Health should use this data to create a specific neurodiversity chapter for the local JSNA to enable commissioners to understand the true scale of need for neurodevelopmental services in RBK and use this to leverage resources to design and commission sufficient, appropriate, integrated, and useful services to ensure neurodiverse residents can enjoy good physical and mental health. [For ICS/CCG/RBK Public Health and Place leaders].

COMMISSIONING

RECOMMENDATION 4 Commission a specialist pathway for neurodiverse people with functional mental health needs from a single lead provider. The provider must fully understand neurodiversity, how to provide tailored therapy for this complex group of patients and adapt appointment systems to accommodate the many challenges they face (e.g., executive dysfunction, emotional dysregulation, poor memory, and concentration). See also Recommendation 7 of [HWK's iCope Kingston service user experience report](#) [For ICS/CCG/RBK]

RECOMMENDATION 5 Autism and ADHD often co-occur with 28% - 44% of autistic adults also meeting the criteria for ADHD. Services should structure the adult neurodevelopmental assessment and diagnostic pathway so that the ADHD and Autism

teams proactively communicate, collaborate and cross refer. Collaboration would enable assessments to take place at the same time or in close succession rather than the current long waits between each. This would end the tortuous waits people experience securing a full picture of their needs and strengths as neurodiverse individuals. Similar cross referrals should be used for other mental health conditions (e.g., bipolar disorder and post-traumatic stress disorder) and other co-occurring conditions like Ehlers-Danlos syndrome, chronic fatigue syndrome, dyspraxia, dyslexia, and dyscalculia.

[For ICS/CCG/Diagnostic and mental health providers]

RECOMMENDATION 6 Taking account of the high heritability of both ADHD and autism, shorten the diagnostic process for people who have close relatives/children diagnosed with autism and/or ADHD. [For ICS/CCG/Diagnostic and mental health providers]

RECOMMENDATION 7 Commission an integrated autism and ADHD ‘aftercare’ service beyond diagnosis and medication reviews that ensures people receiving ADHD or autism diagnoses (or both) get psychosocial, occupational therapy/psychology and coaching to help them better manage their lives and stay well. [For ICS/CCG/RBK]

RECOMMENDATION 8 Commissioners to consider developing an integrated Neurodiversity One Stop Shop or Hub in partnership with peer support groups, offering a range of interventions from peer support and advice right through to referral for assessment, support, coaching, medication, benefits, signposting, advocacy, and employment support. [For ICS/CCG/RBK]

PEER SUPPORT

RECOMMENDATION 9 Commissioners should nurture a dialogue with Kingston's highly effective but over-stretched peer support group Fastminds. The dialogue should explore the best way to support and fund this voluntary group and provide resources to enable them to thrive, develop and continue to support neurodiverse residents and help shape local services. Commissioners should explore options for establishing and funding and developing a similar peer led organisation for autistic residents. [For ICS/CCG/Place leaders/RBK)

ACCESS

RECOMMENDATION 10 Urgently introduce text reminders for all patients using Your Health Care and all other health and social care services that currently do not use reminders and end the practice of closing cases after 1 or 2 missed appointments to make the service more accessible for neurodiverse patients. [For ICS/CCG/Place leaders/RBK/Diagnostic and health and social care providers]

3. Method

Healthwatch Kingston (HWK) worked collaboratively with [Fastminds](#), Kingston's peer support group for people living with attention hyperactivity deficit disorder (ADHD) and co-occurring conditions, to collect feedback on health and care services.

We developed an online survey promoted via the HWK newsletter, on our website and via social media. Fastminds shared the survey via its communication channels and promoted on its website. The survey sought people's views on access to services, the quality of those services and their experience of aftercare.

The survey asked respondents to select which services they wanted to comment on (multiple options) and asked them to rate their experience overall. They were also offered a free text box to comment in detail on their experiences of services.

We also carried out 4 in-depth phone interviews with residents who preferred to share their views in person as a reasonable adjustment and attended Fastminds review of local services in February 2021 (view slide set [here](#)).

4. Contextual information

a. About neurodiversity

Neurodiversity refers to a group of people with variations in their sociability, learning, attention, mood, and other mental functions. Neurodiversity refers to neuro-types that diverge from the 'neurotypical' majority. The term typically includes autistic people and people with ADHD (attention deficit hyperactivity disorder) ADD (attention deficit disorder) and Tourette's syndrome, dyspraxia/developmental co-ordination disorder, dyscalculia, and dyslexia. Some people believe it also embraces people with intellectual/learning disabilities. Some conditions can derail a person's ability to plan, organise and make decisions

and affect their mental health. Individuals who have these conditions are referred to as ‘neurodivergent’. The neurodiversity movement subscribes to the social model of disability, pushes for interventions and support that enables health and wellbeing, acceptance, and inclusion. They often reject the idea that neurodivergent people must be ‘fixed’ or ‘cured’.

b. ADHD and related conditions

The [NHS describes the symptoms/behaviours](#) of ADHD in two categories: inattentiveness (difficulty concentrating and focusing) and hyperactivity and impulsiveness. Many people will experience both. It says ADHD can be harder to diagnose in adults, especially women, but provides a list of signs on its website. UK practitioners mainly use the [ICD 11 definition](#) to diagnose people with ADHD.

Helpfully, Kingston’s ADHD support group Fastminds’ name is an acronym of common challenges people with ADHD experience and report. It describes the impact of the condition from their perspective. People with ADHD are often forgetful; achieve below potential; get stuck in a rut and can be time-challenged, motivationally challenged; impulsive; novelty-seeking; distractable and scattered. People with ADHD (and autistic people) can be especially vulnerable to abuse and exploitation and susceptible to trauma.

c. Autism and related conditions

The Diagnostic and Statistical Manual of Mental Disorders (DSM-5) is the most common diagnostic guide for mental health professionals, widely used in the US and influential in the UK. The manual defines autism spectrum disorder (ASD) as ‘persistent difficulties with social communication and social interaction’ and ‘restricted and repetitive patterns of behaviours, activities, or interests’ (including sensory behaviour), present since early childhood, to the extent that these ‘limit and impair everyday functioning’. An autism diagnosis also includes Asperger syndrome, childhood disintegrative disorder and pervasive disintegrative disorder (PDD-NOS) which are no longer listed as separate conditions in the diagnostic manual. The manual notes that 70% of the

time, a diagnosis of autism is accompanied by an additional condition or diagnosis, and 40% of the time by two or more additional conditions of diagnosis. Many people with an autism diagnosis regard it as a ‘neurotype’ not a mental health ‘disorder’ but many people experience mental ill health from being poorly understood and having to cope in a world designed by and for the neurotypical majority. Many people reject the expression ‘having autism’ or ‘ASD’ and prefer to describe themselves as autistic, on the autism spectrum or having Asperger syndrome. [More on co-occurring conditions here.](#)

d. Best practice

The National Institute of Health and Clinical Excellence (NICE) in 2012 published best practice [guidelines on the diagnosis of autism diagnosis and management in adults.](#)

NICE, published guidelines for [attention deficit hyperactivity disorder: diagnosis and management](#) in 2018. Health and care services are expected to follow these guidelines and adopt or adapt them for local use to improve care and patient outcomes.

e. Treatments

People with ADHD can benefit from medication although these do not suit all and work better if support and other therapies are provided alongside medication. Some people recommend [Body Doubling](#) as a useful tool for helping people to manage and complete their daily tasks. There is no specific medication to ‘treat’ autism.

Autistic people and people with ADHD and those with both conditions can frequently experience depression, anxiety and other debilitating anxiety-driven mental health conditions like obsessive compulsive disorder, hoarding disorder and substance misuse. They are more likely to be on more than one type of medications (polypharmacy) and therefore at risk of side effects from drug interactions (e.g., known interaction between the commonly prescribed antidepressant Sertraline and stimulant ADHD medication).

Some medications like antidepressants can help to reduce anxiety and improve persistent low mood and help with emotional regulation. Sometimes, more controversially, anti-psychotics are prescribed to tackle 'behaviours' that others find challenging.

f. Relevant national plans and priorities

The NHS Long Term Plan published in Jan 2019 sets out priorities for healthcare over the next 10 years and shows how the NHS funding settlement will be used.

[Chapter 3.31 to 3.36 of the NHS Plan](#) sets out aims to reduce health inequalities for autistic people and people with learning disabilities by tackling their over-medication and [promoting annual health checks](#). It wants to cut the number of autistic and learning-disabled people inappropriately placed in long stay psychiatric wards through building better community support and wider use of personal health budgets.

The NHS is currently piloting [a yearly check for autistic adults](#) although this is unlikely to be ready until 2023. The NHS Plan commits to jointly develop packages with social care, education and expert charities to support families with children who are autistic or who 'have other neurodevelopmental disorders including ADHD'. The plan makes no explicit mention of additional investment in services for adults with ADHD. Therefore, it is up to local areas to make services for these patients a priority.

In July 2021, the Government published its refreshed autism strategy: the [National Strategy for autistic children, young people and adults 2021-26](#) setting out its vision improving the lives of autistic people and steps national and local government, the NHS and others must take towards this within the first year of the implementation plan (2021 to 2022). Strategy priorities include supporting positive transitions into adulthood, supporting more autistic people into employment, tackling health and care inequalities for autistic people and building the right support in the community.

5. Health and care services in Kingston

Services for neurodiverse residents in Kingston are notable for their number and complexity.

Four different providers deliver the 'autism' pathway:

- Community Paediatric Services, Achieving for Children Kingston (children 0-5)
- Achieving for Children Kingston and Richmond (6-18)
- Your Healthcare (18+).

Your Healthcare also provides ADHD assessments and support.

iCope Kingston, the talking therapies service, is run by Camden and Islington NHS Foundation Trust.

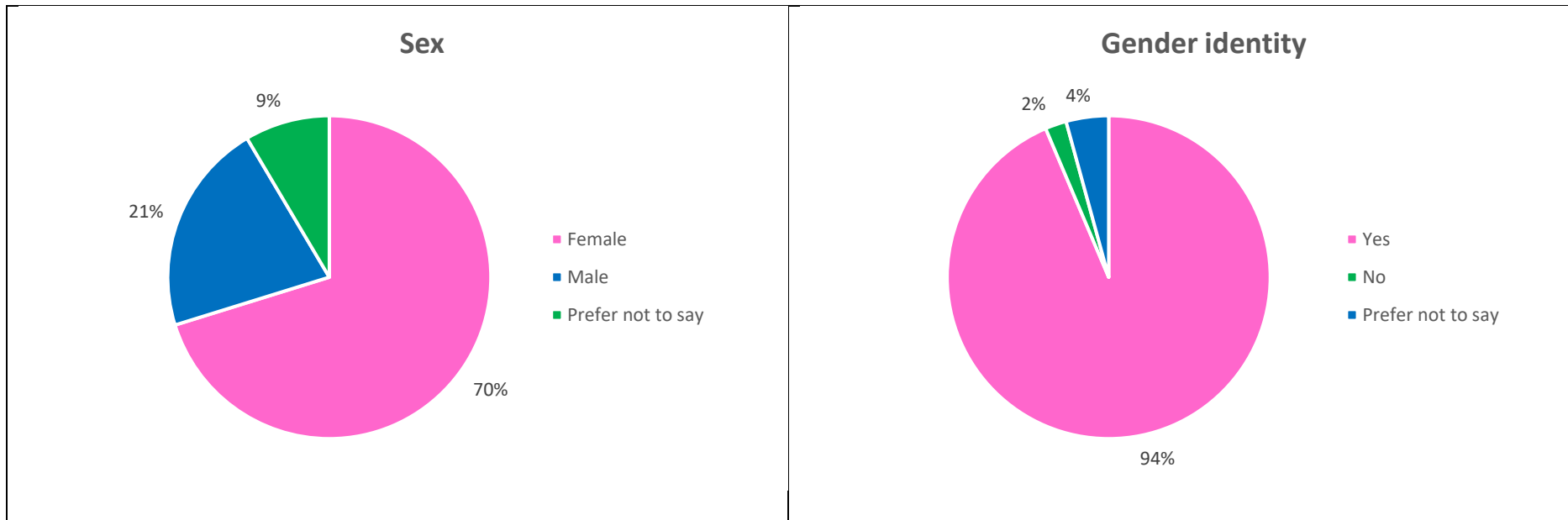
South West London and St George's Mental Health NHS Trust provides recovery and mental health services for adults with more complex mental health needs.

To find out about support available for people living with and affected by Neurodiversity in the Royal Borough of Kingston upon Thames, go to the [Healthwatch Kingston All About: Neurodiversity services](#).

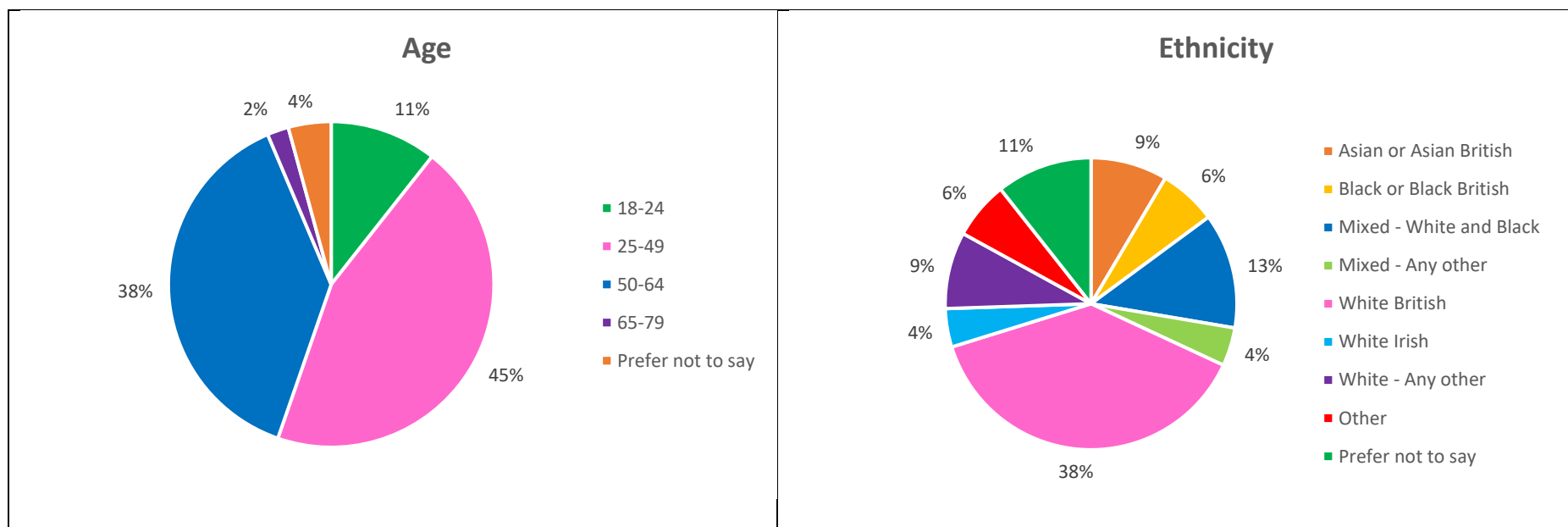
6. Who responded to our survey?

a. Demographics

In total 50 responded to our survey. 46 people completed the online survey and a further 4 people took part in phone interviews, requested as a reasonable adjustment. Of those who completed the online survey, 70% were female, 21% male and 9% preferred not to say. 94% stated they were same gender identify assigned at birth, one person has a different gender identity and one preferred not to say.



The vast majority, 83%, of online respondents were in the 25-64 age band with 45% aged 25-49 and 38% aged 50-64. Five people (11%) were aged 18-24 and one aged 65-79. Two people did not give their age. More than half (51%) of respondents were White, 9% Asian, 6% Black or Black British, 13% Mixed heritage (White and Black) and 4% other mixed heritage. 11% preferred not to state their ethnicity. Please note the charts are for online survey responses only.

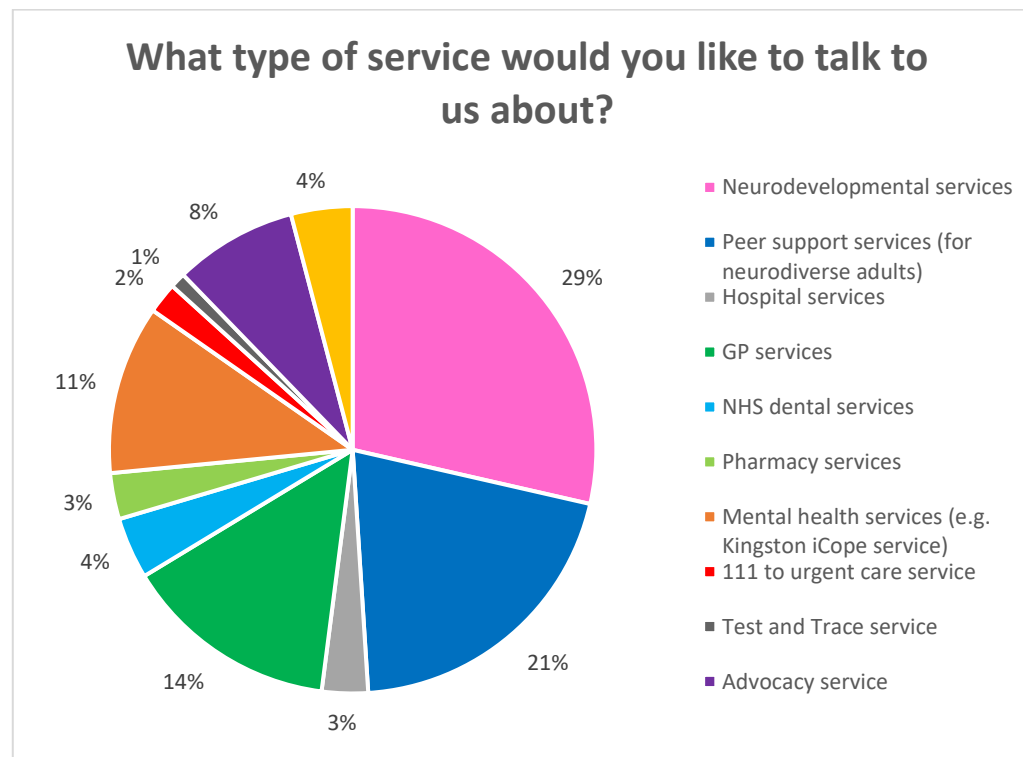


b. Limitations

We recognise online surveys have methodological limitations and total of 50 respondents is lower than we wanted. However, it is widely acknowledged surveys are a useful tool in gathering information in a timely fashion and providing us with a useful snapshot of views and qualitative patient experience at the time of the community engagement.

c. Which services did people comment on?

Most survey respondents had used more than one service. 29% had used neurodevelopmental services; 20% peer support (including Fastminds); 14% general practice; 12% mental health services and 8% advocacy services.

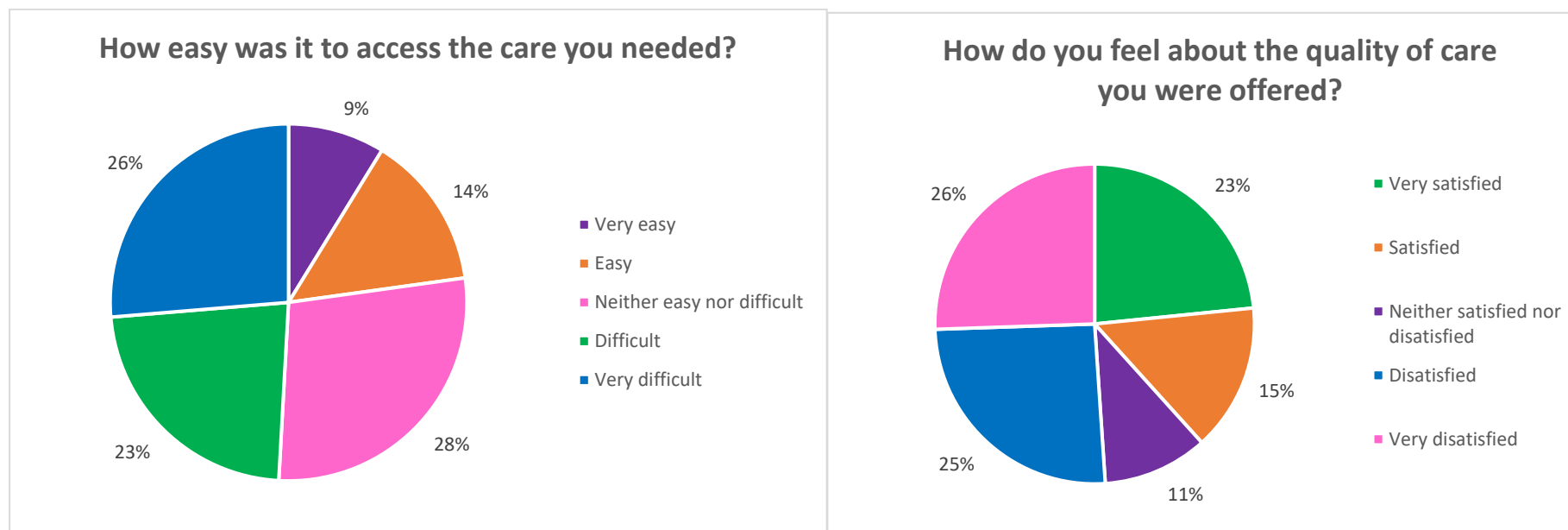


d. How easy did they find accessing these services?

Almost two-thirds (61%) of respondents said they found it difficult or very difficult to access the care they needed while just over a quarter (26%) found it easy or very easy to access the care they needed.

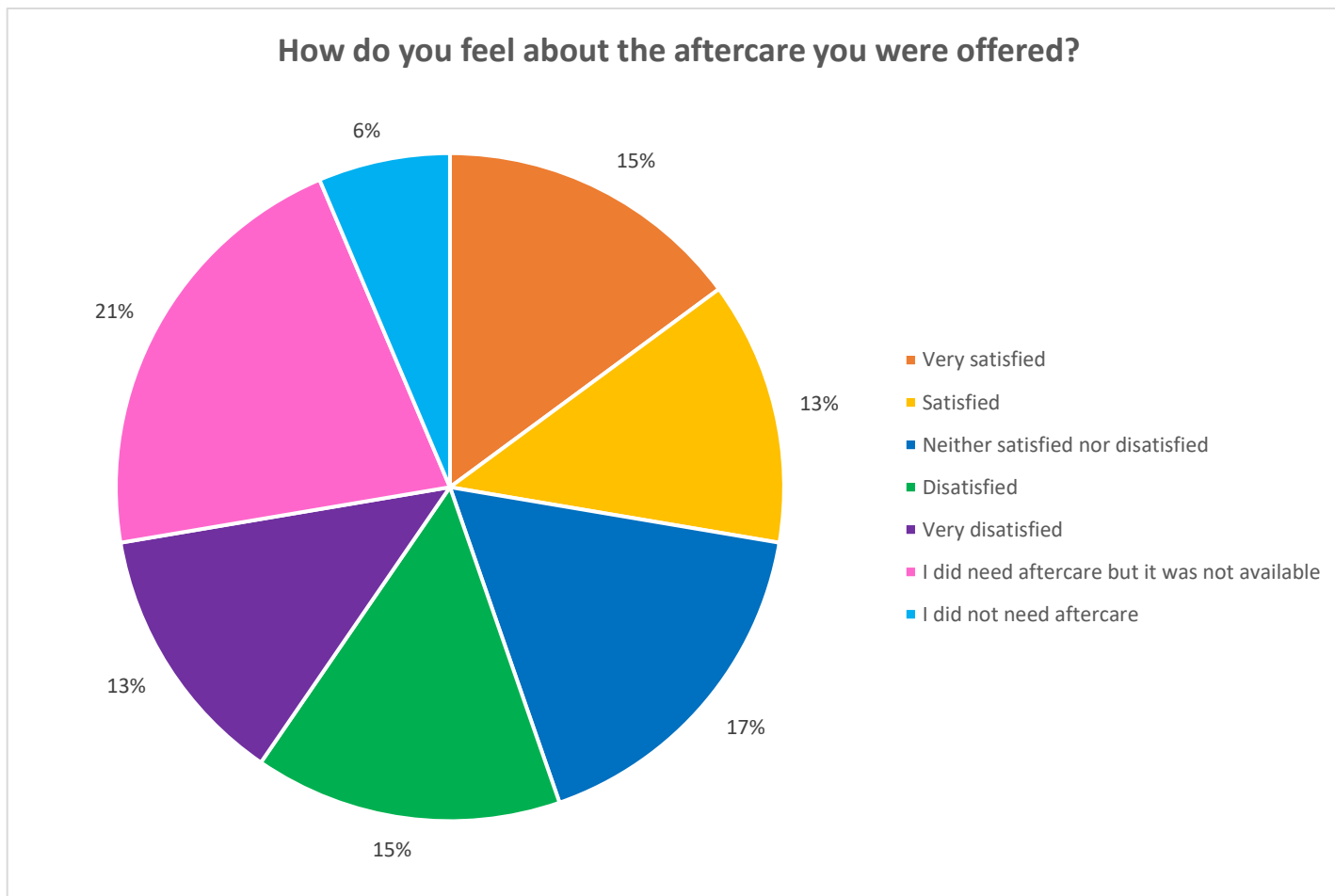
e. What was the quality of care they were offered?

Just over half (54%) of respondents were dissatisfied or very dissatisfied with the care they were offered while over a third (37%) were satisfied or very satisfied with their care.



f. What was aftercare like?

A fifth of respondents (22%) felt they needed aftercare, but this was unavailable. More respondents (29%) were satisfied or very satisfied with their aftercare compared with 26% who were dissatisfied or very dissatisfied.



7. Key findings

- A. WHAT NEURODIVERSE PEOPLE WANT** Neurodiverse people in Kingston told us they want to be accepted, understood and get the right support. A dominant theme was the pressing need for services to provide useful, reasonable adjustments. People told us they needed help to manage appointments, welfare benefits and form filling. They said they would also benefit from in-work support. Access to Work, mentoring, occupational psychology, or life coaching can all be useful. People also shared that they needed access to for appropriate therapies, medication, and peer support. We learned that autism or ADHD-informed occupational therapy, for example, can help people to develop strategies for everyday life and staying healthy and task completion.
- B. HEALTH INEQUALITIES** Autism and ADHD are life-long conditions and tend to run in families. They persist into adulthood and, without the right type of care or support, can significantly impact on a person's mental and physical health, work, education, and relationships. As one survey respondent put it: their '*wheels came off*'. Many neurodivergent adults experience economic and social exclusion.

Studies show autistic people without an intellectual disability are at higher risk of mental health problems than the general population, including higher than normal suicide rates. On average, they die 12 years earlier, with suicide the greatest cause of premature mortality. Data from the ONS suggest autistic people have the lowest employment rates of all disability groups (ONS, February 2021).


- C. DIAGNOSIS and NEURODEVELOPMENTAL SERVICES in KINGSTON** People with ADHD and autism are typically diagnosed as children in paediatric or child and adolescent mental health services (CAMHS). Some are diagnosed later in adult mental health services or (increasingly) in specific adult neurodevelopmental services. Adult neurodevelopmental

services in Kingston are provided by the community services community interest company [Your Healthcare](#). The service provides autism and ADHD assessments as well as integrated services for people with a (global) learning disability. 29% of our survey respondents had used their autism and ADHD services for assessment, diagnosis and/or treatment. The waiting list for assessments is long. Due to long local waiting lists, the peer support group Fastminds may encourage some people to apply for a diagnostic assessment using [Patient Choice via Psychiatry UK](#).


Autism and ADHD are ‘invisible’ disabilities, so it is vital health and care professionals, especially neurodevelopmental services, have up to date knowledge and understanding of how people present, the range of co-occurring conditions, and how to make their services accessible. Some people faced long waits for assessment. Some described their deteriorating mental health while waiting.

 *I am struggling with my mental health and waiting for assessments nothing offered to help.”*

One person interviewed over the phone with a history of trauma and anxiety, was rejected for an assessment:


 *I am on the spectrum. When I was trying to get a diagnosis, the NHS local services turned me down. I think I have autistic burnout. I am always knackered.”*

The same person turned online to get a private ADHD diagnosis:

 *The NHS are not equipped to meet my needs. I used [ADHD 3600](#) to get diagnosed due to waiting times with NHS.”*

During a telephone interview a participant told us they were still waiting for an NHS appointment for assessment. They contacted Your Healthcare in February 2020, a letter was sent in June 2020, and they had heard nothing since.

Several people felt compelled to pay for a private diagnosis because of assessment waiting times while at least one found assessment cursory:

 *I have dyspraxia, ADHD, and Asperger traits diagnoses. I had a 10-minute chat with a psychiatrist [who] said Asperger traits. Diagnosed with dyspraxia privately. Diagnosed with ADHD privately.”*


Long waiting times for assessment were a common theme:

 *No-one to talk to about getting an Autism assessment quicker - long waiting lists.”*


And:

 *I am struggling with my mental health and waiting for assessments nothing offered to help.”*

Long waits for therapy were experienced too.

 *I understand Covid must have made it more difficult for Neurodevelopmental services to get to their patients quickly, but the wait was ridiculously long.”*


D. AFTERCARE 29% of respondents were satisfied or very satisfied with the aftercare they received however a fifth said they needed aftercare but were not offered any. This suggests not all the adults who need support after diagnosis are receiving it, while others say they are not even getting regular medication reviews. Others were frustrated at the piecemeal approach to diagnoses in the neurodevelopmental service. As one respondent put it:

 *Left after diagnosis with no support, only follow up once a year for medication. No one to talk to about getting an autism assessment quicker or the long waiting lists.”*

Another said:

 *The waiting list for the Autism assessment was extremely long. Over a year. The assessment was thorough, but there was no aftercare. I had one session afterwards and was meant to have another with my Mum but that has not happened.”*

Others couldn't access reviews because they found appointment systems inaccessible. One said:

 *I find it difficult to get appointments as my meds have sedatives in them so I wake too late to make GP appointments and upon trying to do it at reception wouldn't work on the system. So, a year and half down with no mental health review.”*

E. MENTAL HEALTH Many respondents reported experiencing mental distress. Some people faced long waits for formal diagnostic assessments or therapies. Others felt abandoned or alone after diagnoses because of a lack of post diagnostic support. They interacted with different mental health services in different ways: referral for assessment and

diagnosis; post diagnosis medication; help with anxiety and depression (Kingston iCope); and longer-term involvement with secondary mental health services like the community mental health team. During the phone interviews, people often referred to services nonspecifically as ‘they’ or ‘them’, including mental health services. People were often unclear which service they were using. This not only demonstrates the memory and cognitive issues neurodiverse people frequently experience but it also illustrates the confusing and fragmented nature of local services used by this group.


- F. **MISSED OPPORTUNITIES, MISDIAGNOSES, TRAUMA** Two respondents had been in contact with various mental health services over the years due to depression, breakdown, or self-harm. They were frustrated that mental health practitioners never suggested they were screened for autism, ADHD or both when they presented with depression, OCD or other mental health conditions.




...I was on the verge of losing my job 2 years ago at the age of 34, because I was suffering with undiagnosed ADHD and had a meltdown at work. I've been living in the Royal Borough of Kingston upon Thames for over 10 years now and never did my doctor recognise that I had ADHD. They recognised I was suffering with depression and anxiety, which was stemming from my undiagnosed ADHD.”

It is possible some late diagnosed neurodivergent people experience mental health crisis or Post Traumatic Stress Disorder (PTSD) in adulthood partly due to being rejected, misunderstood, or labelled ‘difficult’ through their childhood and teens. One young person sectioned as a child and rejected by their family went on to experience sexual abuse in a relationship. Mental health services had diagnosed them with a personality disorder. It took a long time

before the diagnosis was finally corrected to autism and ADHD. One person thought disjointed and inaccessible mental health and diagnostic services were a contributory factor in neurodiverse people developing mental health problems.

 *There is a lack of cohesion or forethought, and a lot of people are probably really struggling with their mental health because they think they are broken when they are neurodiverse.”*


Another found it strange that practitioners diagnosing ADHD did not feel the need to screen for autism at the same time and vice versa.


 *I do find it odd that one service is not connected to the other. Should practitioners not know more about other conditions in case they spot something more and then refer the patient to that service? For example, see the ADHD service and then they may pick up autism and have you already in the system without you having to refer yourself and to have things more streamlined. Or maybe have it in one go assessment after another since its highly possible those with ADHD have autism.”*

G. NEURODIVERGENT PARENTS/CARERS Autistic/neurodivergent carers of children with similar conditions told us they face a double burden of stress and anxiety managing their own and their children’s conditions. Both autism and ADHD often runs in families (genetic or heritable), so it seems logical that diagnoses should be more straightforward for people when family members or relatives have diagnoses.

H. CHILD AND ADOLESCENT MENTAL HEALTH SERVICES (CAMHS) A mother described CAMHS losing the emergency referral from Kingston Hospital after her child's attempted suicide. She said Kingston Hospital also failed to carry out a promised full mental health assessment on her daughter. However, the parent was happy with another CAMHS professional who conducted assessments of three sessions to help them with difficulties at school '*which was really good*'.

High quality, responsive CAMHS and neurodevelopmental services for children with better screening would ensure more neurodivergent people enter adulthood and transition into adult health and/or care services with the support they need and better understanding of their strengths and difficulties. It is also likely to reduce the trauma from being misunderstood by family and friends and schools or mislabeled by services.

 *I've been through counselling and mindfulness through mental health services, starting 13 years ago, I was referred for ASD assessment four years ago and I have just recently been diagnosed with ADHD. However, there seems to be no neurodiversity screening in place when you are first referred for mental health support."*

 *I was diagnosed 3 years ago with ADHD after being passed around mental health services. I am on the waiting list for an autism assessment and told the waiting list is very long, ...I have no support and wouldn't know where to access it, just been left alone to cope. I also have to try and support my 30-year son who has ADHD and autism, which led me to a breakdown 1 year ago, ...having to be taken to hospital, give up work and still waiting for trauma therapy at the Maudsley 2 years on. I feel abandoned and very alone."*

- I. **COMMUNITY MENTAL HEALTH TEAM** A 20-year-old with a history of abuse and involvement with mental health services since childhood felt the Community Mental Health Team, provided by South West London and St George's Mental Health Trust, had 'discriminated' against her autism by discontinuing their support and discharging her in 2020.




I was overdue a review. I asked for a review with a link worker. I told the GP I was getting nowhere with support. The social worker and psychiatric professionals arranged a meeting without a person to support me. The Link worker sent a text saying your meeting was arranged. I turned up and there were too many people in the room. I felt overwhelmed and they ignored my requests. It felt like a blaming game. The social worker and GP did not agree with each other.”


The respondent felt they were offered the wrong type of mental health support.





I needed support for PTSD [Post Traumatic Stress Disorder] and EUPD [Emotionally Unstable Personality Disorder].”

- J. **KINGSTON iCOPE and TALKING THERAPIES** Four survey respondents specifically commented on iCope, Kingston IAPT/talking therapies service. Comments made by respondents were clearly negative. All suggested the service was too insubstantial to meet their mental health needs and inaccessible as they were quickly removed from the service if they missed an appointment. This is what people said:


 *I...was given group therapy. I didn't get anything from it. I forgot to go to an appointment and was discharged the same day, they did not send a reminder. I was made not to feel like a person just a number. The iCope service is poor. They gave me a handbook to try and help but I need proper support.”*

 *I feel very let down by iCope and am seeking support to make a complaint about the way I have been treated, including being called repeatedly to be offered an appointment with the wrong type of therapist, not having my notes updated for over 6 months despite being informed that they had been.”*


 *iCope waiting times are also very long and then you don't really get many sessions either. They mainly focus on CBT which does not work for me. I can't get into the deeper issues I have because there is such a limited amount of time.”*

 *I made a self-referral for talking therapy. They said I have autism.” (May 2020) I am pushed from pillar to post - just want to be happy. My case is now being raised high up with South West London and St George's Mental Health Trust.”*

Others referred for group therapy found the sessions unhelpful:

 *I was given only three sessions of group therapy via Zoom and told to print out a handbook beforehand. I looked through this handbook and then once I was on the Zoom meeting, I found it really basic. None of the group really spoke much. It was mainly just the hosts that were talking and to me, all we did was sit through a talk about the very handbook I was sent. It just seemed a little silly.”*

We learned that neurodevelopmental services also discharged another patient after they missed their second appointment:

 *For a department meant to be trained in ADHD, I would have thought that it would be understood that we're not great at keeping appointments and we are forgetful. I forgot to attend my second meeting and within hours of realizing I forgot, I was already sent an email from Neurodevelopmental services, telling me they had discharged me because I didn't attend the second session!”*

The patient said they were left angry and confused about why the service had discharged them so quickly.

 *I lost all faith in the support of neurodevelopmental services. It seems it's more about ticking off boxes, rather than actually making the patients feel understood and supported.”*

A different patient, who had a good experience of diagnoses and support with medication, noted the lack of therapeutic support through the iCope Kingston service:



Good service with regards to assessment, diagnosis, titration and annual reviews. But medication only helps so much in my experience. Would have been great if there were also services in the form of talking therapies, CBT, coaching etc.”

K. **FASTMINDS (PEER SUPPORT)** Fastminds is a not for profit, user-led organisation that offers advice, information, peer support, peer advocacy and signposting to people with ADHD and co-occurring conditions in Kingston. It survives on charitable donations and is currently not commissioned by or in receipt of grants from RBK nor SWL CCG. The group is led by two volunteers and demand for their support and advocacy is growing.

A total of 23 respondents mentioned Fastminds. The comments were all positive, typically praising the peer support service for being helpful, supportive, knowledgeable, compassionate, responsive, and caring. Some credited the organisation with giving them the confidence to ask services for the help they needed. Others liked the way the group had helped them as a newly diagnosed person.

The Fastminds website was described by one person as, ‘easy to find’ and ‘they got back to me really quickly.’


Others sought a diagnosis only after contact with the group. Comments typically included superlatives like ‘amazing’ ‘brilliant’ and ‘fantastic,’ ‘lovely’ and ‘great’.

Respondents appreciated the range of help provided by Fastminds including help with referrals, form filling, answering questions about medications, coaching and advice on sleep and other therapies. One person mentioned the ‘welcoming’ WhatsApp group started during the Covid-19 lockdown.



Some saw the group as a lifeline a key part of being able to cope:

 *It [Fastminds] really kept me going, it kept me fighting” and,*  *It [Fastminds] helps with my life.”*

For others it was a key staging post on their journey to self-understanding and diagnosis:

 *It took a near stranger [the founder of Fastminds] to point out I had ADHD because she had it herself and saw the wheels coming off. It wasn’t the doctor that saw my ADHD but a near stranger...who referred me to get an assessment.”*

A member of Fastminds described it as a:

 *A safe place where we can feel accepted for who we are.”* while another stressed,  *It’s important to be understood and valued as a member of a community.”*


Both comments highlight the alienation neurodivergent people can experience and the relief at finding a place they can be themselves.

One person described Fastminds as: *'filling gaps in service provision'* with support, access to disability information and *'soft advocacy.'* While peer support was *'much needed'* in Kingston, the respondent felt *'peer support groups shouldn't be having to do so much work,'* work that should be done by funded health and care services.


- L. **GPs and PRIMARY CARE** General practice is the gatekeeper and coordinator of most care for patients including those who are neurodiverse. Comments from our survey suggest that GPs do not fully understand conditions like ADHD or autism or the range of challenges these patients experience trying to access their services. Comments suggest GPs do not make the reasonable adjustments necessary to ensure their service is accessible to neurodiverse patients. One respondent was unequivocal in their praise for their GP:


 *My GP is fantastic. All at the practice are."*

But others shared negative experiences of general practice. One found their GP wanting to help them secure autism and ADHD assessments, but they were confused or unaware of local pathways.

 *I needed assessment for Autism and ADHD. My GP was not trained about either and didn't know how or where to refer me for autism...but wanted to help. There's nowhere local for adult autism. I found options like the Maudsley, and she referred me, but we never got an ok from local health commissioners. I also needed ADHD assessment and was referred to the service at Surbiton Hospital."*


Two patients failed to get an appointment because of their GPs' insistence on initial phone consultations.

 *[It] took about a month to get a doctor's [GP] appointment. They didn't call me. I get super anxious and seeing as they only do calls at the moment. I had to bear the panic attack. I feel let down and overwhelmed at doing it all over again. On the app I cannot book a double appointment which is recommended by my GP and in reasonable adjustments which is not well known about. I am unable to be independent because I don't use the phone."*


 *Contacting GP is hard, I have an app to make an appointment, but I can't book a double appointment, a reasonable adjustment. Phone calls cause me to have panic attacks, so this is a barrier to getting health care. With multiple health problems, it is a minefield. I could do with a care-coordinator that works across all health, primary and secondary services. Someone who knows the systems. When things are too complicated, I shut down and don't function."*

The common process of GPs asking patients to call the surgery on the phone early in the morning to make an appointment was also noted as a barrier (see page 23 of this report).


Another patient, a parent with ADHD who has children with ADHD, described the challenge of having to use the practice phone menu system:

 *I do not have the executive functioning ability to register my and my children's results by phone. There are too many menu options before you get to the place you can register the test and I lose focus before I get to the end and press the wrong buttons and have to start again.”*

Lack of understanding and failure to make suitable reasonable adjustments was another theme:

 *GPs at [practice names provided] are not responding to requests to make disability accommodations. They are impatient during consultations with people who need to take longer to explain themselves. They make judgements based on stereotypical views of people with neurodiverse conditions, namely that their problems are mainly related to psychological difficulties in the first instance.”*


Lack of awareness among GPs and other doctors can delay a diagnosis, prolong someone's mental distress, and therefore stall the process of people beginning to understand their strengths, needs and difficulties. Sympathetic support at this early stage can reduce the risk of unemployment and even suicide.

 *These conditions are so misunderstood by the world at large. Not even GPs nor psychologists seem able to spot the signs...a lot of people are probably really struggling with their mental health because they think they are broken when they are neurodiverse.”* Another said:

 *Very hard to have ADHD detected. It was detected because I had to push the GP.”*

Others highlighted process failures and lack of responsiveness to complaints.

M. IMPACT of INACCESSIBLE or DISORGANISED GENERAL PRACTICE on NEURODIVERSE PATIENTS While process/ system failures can create a poor experience for all patients, they can be especially distressing for patients with mental health problems and can compound those problems:

 *The GP surgery keeps under prescribing my bipolar meds. After putting a repeat prescription for 200mg and 25mg to make up a daily 250mg they have failed to pass on to the pharmacy to give correct dosage. This has happened more than 5/6 times with a monthly repeat of me chasing the correct dosage. Several times I’ve been left 2 to 3 days without my full dosage which is disruptive and can trigger an episode. I’ve put in a complaint over 3 weeks ago and complained every time and they are dismissive saying always ring and chase it ASAP. It really isn’t my responsibility to make sure their systems and processes work when I email a repeat prescription a week before I need the meds!”*

Another autistic respondent described their medical centre as ‘chaotic.’ They were particularly upset when the practice failed to advise them in advance that their GP, the one they were due to see, was unwell. Predictability can be very important for autistic patients it is vital they are told of, and have time to process, any changes in advance.

 *They could have handled that better.”*

Another autistic patient diagnosed with ADHD, and PTSD with a history of domestic sexual abuse and suicide attempts from childhood, described the difficulty of finding a GP to accept them on their register when they moved to a hostel in Kingston to flee their abuser.


- N. REPEAT PRESCRIPTIONS, MEDICATION REVIEWS and PHARMACIES** One respondent encountered repeated problems collecting medication from the pharmacist due to scripts not being ready or incomplete. They were also unhappy about the brand of medication changing.

A visually impaired neurodiverse single parent of a neurodiverse daughter described significant problems and confusion trying to order their respective repeat prescriptions for ADHD medication from the GP surgery. Issues have left them both without medication, *'on a number of occasions.'* This is distressing for both, as her daughter cannot sleep without the medication. The problem was compounded by the practice not telling her the prescriptions had been rejected.




I get so stressed about ordering the meds now, I have to get my support worker to do it...I can't use the NHS app. I email my prescription to the surgery for ADHD controlled meds. On other occasions the prescriptions from the surgery have been rejected as I ordered too early...I always send two emails, so they don't get confused. The practice said they had only got one. They said on the records I'd not had these meds since 2019. This was wrong. The doctors are lovely...but as a neurodiverse person with autism and a visual impairment, the processes is terrible."


She also found the annual medication review forms *'confusing, visually stressful and inaccessible.'* Others wanted more frequent medication reviews. A respondent still waiting for an autism assessment said:

 *My Dr does not understand ADHD and I'm taking Sertraline for my mental health as well as 2 ADHD medications which do not work great with me, I only have a review 1 time a year when I should be checked for weight, blood pressure etc every few months."*

O. ADULT SOCIAL CARE SERVICES Only one respondent with complex mental health needs and history of domestic abuse mentioned social care services. Her comments were negative. This may be because the threshold for access to statutory social care services is high. A refuge worker had arranged a MARAC (multi-agency risk assessment conference) meeting for her and re-referred her for a social care assessment:

 *Because of my current health issues...and my mental health in general because everything is becoming increasingly overwhelming and increasingly difficult to cope..."*

She also reported delays in her integrated care assessment:

 *The new social worker had to start over and have a new advocate from Kingston Advocacy Group. Kingston council say they are not responsible for me, due to me sofa surfing outside of Kingston, they have now delayed the appointment. I was getting one session a week from a decluttering service - but sadly it's*

not complete yet. Social services are closing my case without welfare checks. Several organisations have raised safeguarding alerts.”

- P. ADVOCACY** Eight people in the survey had used advocacy services though it is unclear whether this was statutory advocacy or peer and community-based help to complain or communicate with services. One person eligible for mental health advocacy could not secure advocacy for their complaint about the Community Mental Health Team discharging them during the pandemic and failing to liaise properly with the GP over medication. Another felt general advocacy in Kingston was limited to people with ‘higher support needs.’ Another praised Fastminds ‘soft advocacy.’



It’s difficult to get support to engage with social or council services if there is a problem. Citizens Advice Kingston offer good support but people with neurodiverse conditions often need help to access their services because of difficulties focusing on the details of complaints/problems, managing complex written information and feeling confident to engage with strangers.”

8. Recommendations with commissioners' response

Healthwatch Kingston invited a formal response from the South West Kingston Clinical Commissioning Group. The following commissioners contributed to this feedback:

- **Nigel Evason, Head of Mental Health, Learning Disabilities and Children & Young People for Kingston, SWL Clinical Commissioning Group**
- **Rachel Rowen, Transformation Lead for Kingston, SWL Clinical Commissioning Group**
- **Rachel Oostr, Project Lead for Neurodevelopment Pathways, Kingston, SWL Clinical Commissioning Group**

We welcome the report from Healthwatch Kingston which is both informative and very timely. We appreciate that Healthwatch has acknowledged the limitations of the report, however the recommendations are very helpful.

Kingston commissioners in collaboration with stakeholders have agreed to complete a mapping and review of all neurodevelopmental services within the borough. Our aim is to have clear pathways for pre and post diagnostic services (all commissioned services to be working in a seamless and consistent way) with the engagement and support of the wider system and to push for an autism friendly borough with health services supporting this at the centre. A dedicated project manager has been recruited to support the transformation, working across agencies to review the existing pathways for all ages. Through redesigning the pathway and service specifications outlining standards we will develop a consistent health model and develop an offer to support the wider Autism, NDT and intellectual disability strategies and plans for both boroughs.

Progress to date

Autism (NDT) Pathway Review

- We have developed a Kingston and Richmond Autism (NDT) Pathway Project Oversight Group - Agreed remit and group membership
- Completed a service mapping to review the pathway for Autism (NDP) for all services across Kingston and Richmond and understand what is working well and what the current challenges are within the system.
- Completed a data mapping to understand the latest activity, demand and capacity to capture increased pressure in the system
- Captured service user and PCF experience of the pathway and liaised with Lead Engagement Manager Kingston and Richmond to understand how we can work with service users in codesigning the pathway.
- Gathered best practice models across the UK to feed back any different ways of working to the group
- Set up workshop with partners to capture short, medium, and long-term goals

Next steps - Priorities for 22/23

- Continue Autism / NDT Pathway redesign
- Continue PBS model rollout with training
- Develop a model of accredited workforce training to upskill staff within teams to support the diagnostic pathway

- Community Support- increase provision of psychology within LD Autism local services (CAMHS tier 2)
- Implement Key Worker Pilot following the roll out in Sutton and Wandsworth
- Intensive Crisis Support - Develop model for enhanced, intensive and crisis community support across Kingston and Richmond: The Model will consist of two parts:
 - People with autism and but no Learning Disability
 - CYP with moderate to severe LD
- Mental Health support for CYP/ people with autism without an LD diagnosis - Develop role/ function of Care Coordinator and psychiatry input
- Annual Health Checks (14 years+) - Improved uptake and quality of the Annual Health Check in primary care and completion of health action plans
- Supporting Parents and Carers of CYP or people with autism - all ages
- Continue with Enhance Register Meetings to identify adult at risk of hospital or placement breakdown.
- Continue to engage the system in attending CETR meeting for people in hospital and in community setting at risk.
- Dose of Nature to provide nature alternative to medical interventions for people with Autism across Kingston and Richmond 22/23.
- Review of how Your Healthcare staff work collaboratively across the Neuro-developmental teams (LD/Autism ADHD) to provide seamless care and support

WORKFORCE TRAINING

RECOMMENDATION 1 Health and social care service leads should commit to increasing awareness and understanding of neurodiversity across the commissioner and provider workforce to deepen understanding of the variety of ways neurodiverse people present. This includes the issues that arise from the ‘invisibility’ of these disabilities; the-fluctuating nature of some symptoms and the disabling impact they have on people’s mental and a physical health and daily life. Impactful Neurodiversity workforce training should be co-developed and co-delivered with neurodiverse residents and tailored for both specialist and general health and care workforce, including clinicians and commissioners. **[For ICS/CCG/Place leaders/RBK/Providers]**

CCG Response

Across the system the CCG is already supporting elements of training e.g. BILD Training, however the CCG is committed to working with partners to expand this offer to the workforce during 22/23.

RECOMMENDATION 2 With neurodiverse residents, health and social care leads should co-produce a checklist of useful reasonable adjustments to make health and carer services properly accessible to neurodiverse residents and promote this check list to GPs and other health and care providers including mental health and diagnostic services. The training outlined in **Recommendation 1** is one way to promote these useful reasonable adjustments across services. **[For ICS/CCG/Place leaders/RBK/Providers]**

CCG Response

The CCG are committed to work with partners to identify named leads and the best forum to take this forward.

JOINT (INTEGRATED) NEEDS ASSESSMENT

RECOMMENDATION 3 Public Health should conduct a comprehensive joint (integrated) needs assessment of neurodiversity in the Royal Borough of Kingston upon Thames. The assessment would gather data on the prevalence and number of adults with ADHD; improve data collection on autistic adults (building on the RBK Autism JSNA 2019) and assess the prevalence of commonly co-occurring conditions, mental health challenges and the health inequalities they experience. Public Health should use this data to create a specific neurodiversity chapter for the local JSNA to enable commissioners to understand the true scale of need for neurodevelopmental services in RBK and use this to leverage resources to design and commission sufficient, appropriate, integrated, and useful services to ensure neurodiverse residents can enjoy good physical and mental health. [for ICS/CCG/RBK Public Health and Place leaders].

CCG Response

The CCG would be happy to support the direction of Public Health in how they wish to progress this recommendation.

COMMISSIONING

RECOMMENDATION 4 Commission a specialist pathway for neurodiverse people with functional mental health needs from a single lead provider. The provider must fully understand neurodiversity, how to provide tailored therapy for this complex group of patients and adapt appointment systems to accommodate the many challenges they face (e.g., executive dysfunction, emotional dysregulation, memory, and concentration). See also **Recommendation 7** of [HWK's iCope Kingston service user experience report](#) [for ICS/CCG/RBK]

CCG Response for 4, 5, 6, 7, 8 and 9

We have started to review our current pathway provision with RBK and our Mental Health and Neuro-developmental providers which will inform a range of options to improve service provision (see introduction section of this report). This will enable us to work more collaboratively and allow us to be much clearer about the offer across for people with neurodiversity in Kingston.

RECOMMENDATION 5 Autism and ADHD often co-occur with 28% - 44% of autistic adults also meeting the criteria for ADHD. Services should structure the adult neurodevelopmental assessment and diagnostic pathway so that the ADHD and Autism teams proactively communicate, collaborate and cross refer. Collaboration would enable assessments to take place at the same time or in close succession rather than the current long waits between each. This would end the tortuous waits people experience securing a full picture of their needs and strengths as neurodiverse individuals. Similar cross referrals should be used for other mental health conditions (e.g., bipolar disorder and post-traumatic stress disorder) and other co-occurring conditions like Ehlers-Danlos syndrome, chronic fatigue syndrome, dyspraxia, dyslexia, and dyscalculia. **[For ICS/CCG/Diagnostic and mental health providers]**

RECOMMENDATION 6 Taking account of the high heritability of both ADHD and autism, shorten the diagnostic process for people who have close relatives/children diagnosed with autism and/or ADHD by of familial neurodiversity during assessments. **[For ICS/CCG/Diagnostic and mental health providers]**

RECOMMENDATION 7 Commission an integrated autism and ADHD ‘aftercare’ service beyond diagnosis and medication reviews that ensures people receiving ADHD or autism diagnoses (or both) get psychosocial, occupational therapy/psychology and coaching to help them better manage their lives and stay well. **[For ICS/CCG/RBK]**

RECOMMENDATION 8 Commissioners to consider developing an integrated Neurodiversity One Stop Shop or Hub in partnership with peer support groups, offering a range of interventions from peer support and advice right through to referral for assessment, support, coaching, medication, benefits, signposting, advocacy and benefits and employment support.

[For ICS/CCG/RBK]

PEER SUPPORT

RECOMMENDATION 9 Commissioners should nurture a dialogue with Kingston’s highly effective but over-stretched peer support group Fastminds. The dialogue should explore the best way to support and fund this voluntary group and provide resources to enable them to thrive, develop and continue to support neurodiverse residents and help shape local services. Commissioners should explore options for establishing and funding and developing a similar peer led organisation for autistic residents. [For

ICS/CCG/Place leaders/RBK)

ACCESS

RECOMMENDATION 10 Urgently introduce text reminders for all patients using Your Health Care and all other health and social care services that currently do not use reminders and end the practice of closing cases after 1 or 2 missed appointments to make the service more accessible for neurodivergent patients. [For ICS/CCG/Place leaders/RBK/Diagnostic and health and social care providers]

CCG Response

Many services across health and social care are already using text messaging, and we would be happy to support an approach across all providers.

9. Conclusion

People who are neurodiverse experience a range of difficulties including with focus, task completion, anxiety, concentration, and information processing. They can experience sensory overwhelming and mental ill health. These difficulties and disabilities may be invisible, but they can be debilitating and significantly impair someone's ability to cope with everyday tasks that many neurotypical people take in their stride. This survey has shown that health services, including GPs and even neurodevelopmental services, still have a long way to go to become truly accessible for these patients.

Long waits for autism and ADHD assessment suggest that services lack capacity to meet demand. Commissioners therefore need to develop a better understanding of autism and ADHD prevalence in Kingston so services can be expanded and funded to meet actual need.

Therapies currently available to these patients are insubstantial and insufficiently autism- or ADHD- informed or adapted to be useful to neurodiverse residents. Few autistic people find group therapy helpful, for example, particularly if they struggle with social communication difficulties and turn taking. Due to poor organisational skills and memory issues, patients with ADHD and autism too easily fall foul of the 'one missed appointment and you are discharged' rule. This all clearly points to the need for Kingston to commission a specialist therapy service for neurodiverse people.

Noting the response from Commissioners, Healthwatch Kingston will monitor progress against the response provided.

Thank you and next steps

Healthwatch Kingston would like to thank everyone that has shared their experiences with us. Everything we say and do is informed by what local people tell us. We will publish this report on our [website](#) and share with Healthwatch England, the Care Quality Commission, the Royal Borough of Kingston upon Thames, South West London Clinical Commissioning Group, Your Healthcare, the Voluntary and Community sector in Kingston and other stakeholders.

Healthwatch Kingston will work with commissioners and RBK public health to convene a Kingston Pulse Check follow-up workshop with providers of services for neurodiverse residents in the Borough, to ensure that all stakeholders have a chance to respond to and benefit from this community engagement report.





Tell us what you think about NHS and social care.

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