

By

**Members of the Fastminds Adult ADHD Support Group** 







25<sup>th</sup> February 2021



### **PURPOSE OF MEETING**

- Introduce Healthwatch Kingston role & responsibilities
- Outline changes Fastminds Members in Kingston would like to see made, and why
  - Yourhealthcare ADHD Service, Autism Service
  - For another time:
    - NHS GPs, psychological services, etc
    - RBK Social care services
    - Other
- Example of a successful ADHD/Autism service model





#### WELCOME!



**Stephen Bitti** Chief Executive Officer

Tony Williams Mental Health Group Lead

www.healthwatchkingston.org.uk/





About Healthwatch

Kingston-upon-Thames



They're here today because they want to better understand and engage with their local community, and track changing behaviour over time

- They are the independent champion for people who use health and social care services
- They are Healthwatch branches all over England
- They have the power to ensure that the government and those running the services hear what you think and take action based on people's needs
- They can help you find general advice, the services you need, make a complaint about health and social care services in Kingston-upon-Thames
- How Healthwatch can help you find the info you need YouTube Video <u>https://youtu.be/9-O5yJSIPQ4</u>

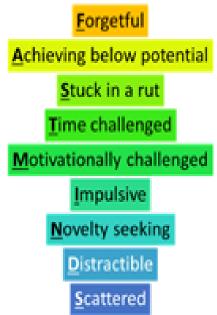


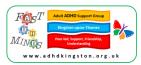
# About the Fastminds Adult ADHD Support Group

We're a not-for-profit peer-led support group that was founded in 2013, with the aim of offering assistance to individuals aged 18+ in Kingston-upon-Thames and the surrounding areas

#### Our aims are to:

- Promote and protect the physical and mental health of adults affected by ADHD (whether formally diagnosed or not) in Kingston and surrounding areas, and improve their quality of life
- Promote social inclusion among adults with ADHD
   (whether formally diagnosed or not) in Kingston and
   Surrounding areas, by providing education and
   information; advocacy and general support, and
   recreational facilities and opportunities for those with ADHD.
- Raise public awareness of the issues affecting those with ADHD.





#### **Neurodevelopmental**

Attention Deficit Hyperactivity Disorder (ADHD/ADD), □
 Autism/Asperger's (ASC/ASD), Dyslexia,
 Dyspraxia (Developmental Co-ordination Disorder - DCD),
 Dyscalculia. Tourette Syndrome (TS),
 Learning disabilities

#### We're EXTREMELY vulnerable to

Adverse Childhood Experiences (ACEs); adult abuse (eg. sexual, psychological, physical, financial, coercion, neglect); issues with housing, relationships, employment (long-term unemployment, multiple jobs), education (low attainment), addictions and self-harm, increased risk of accidents (eg. driving), eating disorders, criminal convictions, chronic disorganisation, hoarding behaviours; Infection; mental & physical health problems



People with Long COVID may have symptoms similar to ADHD

# About Adverse Childhood Experiences (ACEs)



ACEs are experiences that children have, that impact negatively on later childhood and adulthood

The chronic toxic stress from ACEs can impact on both brain and physiological development

Domestic violence, abuse, neglect, Mental illness, homelessness, incarceration, parental separation/ divorce, substance misuse

Children who experience four or more ACEs have been found to be:

- 8 times more likely to have committed acts of violence between the ages of 18 and 69
- 30 times more likely to have made a suicide attempt
- 41% more likely to experience low mental well-being



### Typical comments from Fastminds Members

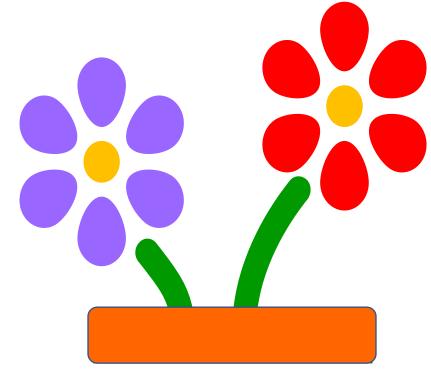


"Over the last year I have felt judged , belittled, patronised, and found the whole process completely re traumatising.

I was originally referred to icope following a referral from the NHS mental health trauma team who after assessing me felt my case wasn't extreme enough for the their service but did diagnose an anxiety disorder and PTSD symtoms and assured me that I could access EMDR trauma treatment through icope.

I did not want to be referred to icope as I had already had a negative experience with them approx 6 years ago when asking (and being ridiculed) for a mental health assessment. Due to that experience I was put off asking again until my mental health became so fragile that I sought the help of Fastminds and with the help of Sheena was able to self refer for an assessment for adhd"





# What's working? & Positive Impacts







# **Fastminds Adult ADHD Support Group** What's working?



#### **Members**

- Noticeable increase in requests to join Fastminds many from outside the Borough of Kingston
- Some members have adapted well to Zoom, incl. Virtual talks/ presentations - introduced Members to ADHD coach, neurodiverse therapist, sleep video etc – Dyspraxia expert soon....

#### **Other ADHD Support Groups**

- Some Fastminds Members have joined other ADHD Support Groups they say like it that Fastminds is more intimate than bigger groups
  - There can be up to about 50 attendees per Zoom session, with several separate virtual chat rooms for different topics (which can be useful if members are looking for specific advice)
  - Share information learned from attending other Support Groups with Fastminds Members (mainly via WhatsApp groups, if they're on them – eg. "<u>Right to Choose</u>"



# Fastminds Adult ADHD Support Group What's working?



#### Organisation

- Sheena receives support from Cherry Rudge (Trustee since March 2020), the group and members virtually on a daily basis.
  - Sheena and Cherry are both Time To Change Champions
- Trevor Rudge became Treasurer in 2020.
- Between us we have a lot of Neurodiverse experience
- Fastminds Member volunteer hosts Zoom meetings if Cherry or Sheena unavailable

#### Infrastructure

- Private donation received to pay for 1 year Zoom
- Website transferred from old version to new platform
- Policy documents gradually being updated eg. Privacy Policy
- Good Neurodiverse friendly contacts made for possible admin support & marketing (incl. automating Membership form, etc)
- Fastminds branding improved logo updated



# Fastminds Adult ADHD Support Group What's working?



#### Communications

- Social media
  - Facebook & Twitter names aligned
  - Being updated more regularly
- WhatsApp groups (Notices & Social) working well (not all members)
- Member's Newsletters being sent out more frequently (Mailchimp)
- Mailchimp proving very effective
  - People able to unsubscribe from mailing list by clicking button, which automatically links to Mailchimp
- Emails via website being checked more regularly (forwarded to Sheena's personal email address)
- Noticeable increase in enquiries & requests about Fastminds





# Fastminds Adult ADHD Support Group Positive Impact



#### **Fastminds Members have:**

- Increased awareness and understanding of ADHD/ASC Dyspraxia,
   & associated conditions, coping strategies & pathways to support
- Gradually gained confidence:
  - To ask questions, support each other eg. keep them on track; share experiences - links to ADHD-related topics; speak up to get needs met by medical & other services – and complain if necessary;
  - From having sessions with **private ADHD coaches**
- Been diagnosed with additional neurodiverse conditions
- Been fast-tracked to PsychiatryUK via "<u>Right to Choose</u>"
- Made use of "<u>Access to Work</u>" (if applicable)
- Enjoyed more self-care eg. Technology-free time
- Donated money to Fastminds to say "thank you"





### Fastminds Adult ADHD Support Group Positive Impact



#### Organisation

- Help and support from Cherry has taken a lot of the pressure off Sheena
- More structure in place since Cherry became involved
- Pool of volunteers gradually increasing

#### Infrastructure

- Zoom meetings:
  - Don't have to stop/re-start every 40 minutes!
  - Less pressure on Sheena/Cherry to facilitate meetings
- Enquiries via website being responded to quicker
- New members being added to mailing list quicker

### Group

 Being invited to participate in more community projects – eg. contribute to Time To Change eZine





Kingston ADHD Service What's working?



#### Dan

- Confident about prescribing
- Listens to what you're saying, understands the difficulties we experience, very down to earth (possible ADHD?)
- He's the first person from the ADHD Service who has contacted Fastminds
- Has made an effort to develop a good relationship with Fastminds, and work with us to develop post-diagnosis courses
- Had great plans when he first joined Kingston ADHD Service
   Staff
- Fastminds Members invited to be involved with interviewing prospective clinical leads (July/Aug 2019 & 2021)





Kingston ADHD Service Positive Impact



#### Service

- Improved interaction between ADHD Service and Fastminds
- Able to give feedback to Fastminds members about ADHD Service's plans

#### **Fastminds & Patients**

 Involving Fastminds Service Users in interviews to replace Clinical Leads improves the chances of Yourhealthcare recruiting someone who we feel might be appropriate for the role, and Service Users will be able to trust and work with





#### Kingston Autism Service What's working?



- Fastminds can refer people to the service
- Patients can self-refer without having to go via GP
- New Speech & Language Therapist (Wendy Reed) has been a welcome addition to the service
  - She has an understanding of the broad presentation of symptoms for women
  - Very approachable and comforting demeanour
  - Great interviewing assessment techniques





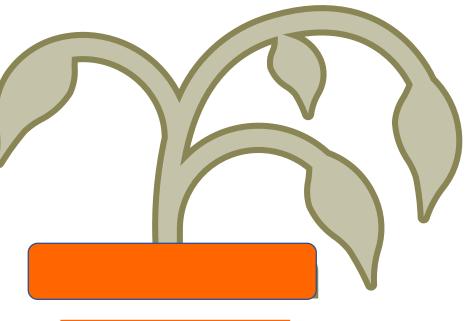
Kingston Autism Service Positive Impact



• More female patients receiving Autism diagnosis







# What's NOT working? & Impacts?







### Typical comments from Fastminds Members



..... On Monday I recieved a call from [my Psychologist] saying the service has recently changed and there are no longer any EMDR therapists in the service.....and that a specialist trauma therapist at Icope would like to reassess me (I was only assessed last April) and discuss alternative therapies on offer"





### Typical comments from Fastminds Members



"Many autistic and neurodiverse people are highly sensitive and experience social anxiety. It takes a lot to trust and open up to someone, only to be dismissed and have their difficulties ignored and disregarded.

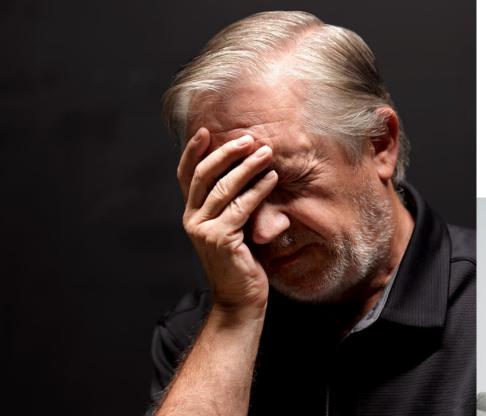
Going out, especially by themselves, is often a major struggle. I have missed numerous medical appointments, work and educational opportunities, as well as social engagements as a result. Being constantly late due to experiencing social anxiety that comes with having autism has caused many problems, misunderstanding, arguments and embarrassment.

Even some CMHT staff and other health and social services professionals have criticised, admonished or refused to see me because I was late."<sup>21</sup>



#### Impact on health if support is lacking





Fibromyalgia, Chronic Fatigue Syndrome/ME, self-neglect, attempted suicide..... Examples include: Anxiety, depression, substance abuse, Diabetes, self-harm, leg ulcers, migraines, heart condition





### Typical comments from Fastminds Members



"Several years ago, the CMHT told me that only clients who were "actively suicidal" were assigned a dedicated Care Co-ordinator. Not helpful for someone who struggles to deal with multiple people (I was diagnosed with autism several years later).

Everyone else (including myself) was told that their psychiatrist would be their Care Co-ordinator. However, this proved extremely problematic, as I never got to see my psychiatrist regularly (twice a year, if lucky) and she never co-ordinated anything."





#### Members

- Increase in enquiries & requests to join Fastminds
  - Fastminds resources supporting many users outside the Borough of Kingston
  - MANY new members have multiple neurodiverse conditions, complex needs (eg. in recovery from addictions), need support or are in crisis – with NOBODY ELSE TO TURN TO
- Increase in number of existing members:
  - Being diagnosed with additional neurodiverse conditions
  - With complex needs
  - Needing support preparing for or attending ADHD/Autism assessments/post-diagnosis report reviews
  - With complex needs who don't attend Fastminds meetings, and struggle without enough help/support





- Increase in number of existing members: (continued)
  - With physical & mental illnesses due to stress caused by overwhelm/lack of support from medical & other services – for example:
    - having been refused iCope mental health therapy due to complex needs
    - Inaccurate Care Needs Assessments (and offers of care don't meet their complex needs)
      - In September 2020 Fastminds referred a Member with complex needs to Adult Safeguarding – issues still unresolved
  - Needing peer advocacy help & support eg. filling in forms, liaising with DWP (PIP appeals, etc), moving home (liaising with Housing Support); medication issues
  - Finding Zoom meetings confusing, so rarely attend prefer to meet in-person





#### Increase in Members (continued)

- Using mobile phones to fill in forms, write emails, read documents, etc, because they don't have a laptop, because (for example):
  - they can't afford one
  - don't have the confidence to buy one
  - Are technology averse
  - Without Wi-Fi, so can't attend Zoom meetings

#### **Operations**

- Policies & procedures still work in progress
- No money coming in (other than occasional donations)
- No money for essential Marketing/Admin/Infrastructure support
- Volunteers unable to offer regular support





#### Organisation

- Too few doing too much & very intense Sheena & Cherry
  - Sheena hasn't had a break in at least two years
  - We're run by volunteers who put in MANY (too many!) unpaid hours per week
  - Sheena & Cherry won't be around for ever, and there's no succession plan....



# Fastminds Negative Impacts



#### **Fastminds Members**

- Deterioration in the mental and physical health of some Members with complex needs directly related to:
  - Being refused support from mental health services
  - Poor quality of medical support which resulted making complaints about (for example) medical malpractice, safeguarding, advocates, Social Workers, mental health service, medication reviews/being without medication due to not having had a medication review,
  - Not asking Fastminds for support, struggling by themselves
  - Fastminds not being able to support them enough
     Consequences? More complexity > worse physical/mental health > physical ill-health > suicide attempt(s) out of desperation
- Extreme risk to health & wellbeing of Members if Fastminds had to close



# Fastminds Negative Impacts



#### Infrastructure

- No statistics for funding/lack of availability > funding not yet applied for, bank balances dwindling – risk money could run out
- Risk of being non-compliant with GDPR, insurance....
- No file sharing system; major website overhaul required
- No time for Trustee/Volunteer recruitment/training

#### Organisation

- Who can we signpost Members to for free advocacy/support?
- Fastminds has virtually become full-time for Sheena & Cherry
  - what might have happened to Sheena last year if Cherry hadn't become involved?
- No sustainable future for the group if Sheena & Cherry are no longer involved in running the group



### Fastminds What do we NEED?



A collaborative, more holistic joined-up service – all medical and social care services working together – WITH FASTMINDS and Service Users

#### **Recognition for what we do at Fastminds**

 We help make it easier for local services to do their job – we want the services to make it easier to do ours





# Fastminds What do we NEED?



#### How?

- Give us the opportunity to share our knowledge and experiences with the community, by offering neurodiverse training to Kingston's agencies
- Increase funding & support for Fastminds, so we can build firmer foundations, and become more resilient and sustainable:
  - Improve organisational structure (eg. Recruit, train & support Trustees & Volunteers; develop strategies & policies; outsource admin, marketing & bookkeeping support; succession planning)
  - Develop website & contact management system
  - Improve self-funding options (eg. create a more effective way for selling arts/crafts created by Fastminds Members (to avoid cluttering up their homes)
- Specialist mental health support for people with neurodiverse conditions and complex needs



# Typical comments from Fastminds Members



#### <u>ADHD</u>

"If organisations like hairdressers, chiropractors, etc can provide text reminders about appointments, why can't the ADHD Service?!"

"If ADHD Service personnel don't understand why some people get exhausted, even when we're medicated, what hope is there for us when we're dealing with other services?!"





### Typical comments from Fastminds Members



#### **ADHD Medication**

...As well our difficult experiences with Icope myself and my daughter have had difficult experiences with our GP surgery who have rejected both mine and my daughter's prescription for ADHD meds (on more than 2 occasions) without informing us they had done it or why they had done it.

So that when I went to pick up the prescription from the local pharmacy it has not been there.....we have had to miss a few doses of meds each time.

...My prescription was rejected due to the fact I hadn't gone for a blood pressure etc check but no one informed me of this".





Kingston ADHD Service What's NOT working?



#### Assessments

- Assessments waiting list too long
- ADHD Service only assesses for ADHD, can't fast-track for Autism assessment - patients join the bottom of the Autism queue
- There's currently only one Clinician to carry out assessments position is currently held by a man, which is no good if patient has (for example) PTSD and issues with a man
- No fast-track process for patients who have received private diagnosis, to speed up Shared Care
- Questionnaires not written for people who fill them in **Staff**
- Dan hasn't told clients that he's leaving they're finding out through word-of-mouth
- In 2019, only two candidates applied for the position only one (Dan) turned up for the interview



Kingston ADHD Service What's NOT working?



#### **Operations**

- Service struggles to cope with patients with complex needs (eg. multiple issues - neurodiverse, medical, psychological, relationship, employment, law, etc)
- Systems not updated by therapists, so Sheena has to repeat herself several times when talking to people on the phone
- Mishandled phone calls, dismissive and unhelpful attitudes of Admin staff who lack knowledge about ADHD (medication review is different to titration)
- Sheena's had difficulties referring people eg. misleading instructions, problems with email attachments, referral email address changed without notice;
- No nurses to do titration check-ups
- Patients penalised for forgetting appointments
- Changes made to NHS secure email service without informing users 35



### Kingston ADHD Service What's NOT working?



#### **Operations** (continued)

- Not enough interaction with other services ADHD Support Groups
- Not enough support for teenagers transitioning from children's to adult services

### Post-diagnosis support

- Don't know what happened about post ADHD-diagnosis groups which were set up
- Service not knowing where to refer patients to eg. someone was referred to iCope for Bereavement support, which isn't listed on their website as being one of the problems they can help with
- Discretionary post-diagnosis support given for certain patients with complex needs
- **Pre-18 -** ADHD Richmond say:
- Sensory processing support (therapies) are very hard to access for families





## Referrals

- Sheena was asked to email referrals as "single sided and full page.... To save us time in processing the referral"
- GPs don't always know about "<u>Right to Choose</u>" which gives patients the choice of where they receive treatment (incl. ADHD assessment)
- Kingston's residents don't know:
  - about the ADHD and Autism Services
  - they can bypass their GP and directly request a referral for an ADHD or Autism diagnosis – it's not something that's promoted
     Medication
  - Member had medication issues new cheap version of medication prescribed without understanding consequences



Kingston ADHD Service What's NOT working?



**Referrals** (continued)

- <u>Your Healthcare website</u> Referrals page
  - Doesn't explain that the Neurodevelopmental form should be used for ADHD & Autism
- <u>Neuro-developmental service</u> page of the Yourhealthcare website
  - Says they accept referrals to their services from anybody and has a link to their referral form, but:
    - It's not easy to find there, even if you knew it was there somewhere and were deliberately looking for it
    - Not listed as an option on the ADHD Service or Autism Service pages of their website
- <u>Neurodevelopmental (NdS) Referral Form</u>
  - The form is very un-user-friendly (minute font near the top which explains the different conditions, tiny spaces to fill in personal details and relevant information)



Kingston ADHD Service Negative Impacts



#### Services

- Increased risk of high staff-turnover/burn-out (clinician & others)
- Increased pressure on mental health services
- Patients more likely to visit GPs to request referral for ADHD assessment (because they think that's what they're supposed to do) than self-refer – because they don't know it's an option, and it's not highlighted on the Neuro-developmental page of the Yourhealthcare website
  - Significant cost savings for GPs if the option to self-refer were promoted – which would free-up appointments for other patients
- If the ADHD (and Autism) services were promoted more (and people knew they could self-refer) it's likely there would be more people contacting them, and the waiting lists would be longer if there's not enough staff to cope with the increased demand



Kingston ADHD Service Negative Impacts



### Fastminds & Patients

- Delays to referrals via Fastminds being accepted by the ADHD Service > extra time/stress on Sheena > more time on referrals, less time for other things
- Clients with ADHD <u>and</u> Autism (diagnosed or undiagnosed) likely to find it difficult changing to a different Clinician once Dan has left – especially if they haven't been warned in advance that he's being replaced and know a bit about his replacement - so they may find it difficult to develop a rapport of trust with them
- Complex needs patients not referred to The Maudsley
- Patients get removed from the waiting list for missing appointments
- Health & wellbeing of patients deteriorates as the ADHD service can't fast-track patients for Autism assessment
- Delays to Shared Care for ADHD medication mean patients pay for prescription, or go without if they can't afford it



# Kingston ADHD Service Negative Impacts



- Patients attempting to complete the un-user-friendly Neurodevelopmental Services Referral form could easily give up, and not bother to refer at all
- Issues with titration check-ups & medication reviews
  - Patients with health issues or medication mis-use during titration goes unnoticed - they may have so much going on in their lives that they forget to contact the service
  - Patients ask Fastminds about titration/medication issues instead of ADHD Service
- Delays to assessment/diagnosis increases risk of person having issues with health, relationship, employment, safety, accidents
- Extra pressure on Sheena, Cherry & Fastminds Members to provide support for members waiting for assessment
- ADHD Richmond (& Kingston)
  - Would like more support for teenagers & families





# Staff

- Courtesy call/email/text to let patients know that Dan's leaving, so it doesn't come as a surprise and upset people with Autism
- Lower staff-turnover
  - Increase grade for Dan's replacement (Level 7 or 8) or employ 2 at lower grade?
  - Provide Dan/his replacement with more support
  - Recruit/train more staff able to cope with clients with multiple neurodiverse conditions and complex needs
    - More nurses required
    - Make it clear that Yourhealthcare CIC is NHS, not a social enterprise
- Hire male and female Clinicians so that patients have a choice
- Appoint Fastminds to provide practical ADHD and Executive Dysfunction training to phone/admin staff, to improve call handling<sub>42</sub>





#### **Operations**

- Increased interaction with other services (AND FASTMINDS) to provide a more holistic service
- Merge service with another Borough? Eg. Richmond?
- Shorten waiting times for assessments
- Ensure process for updating systems is followed
- Send text messages to remind patients about appointments if hairdressers can do it, why not the ADHD Service?
- Arrange for an ADHD nurse to make regular pro-active contact with patients, to find out:
  - What's going on in your life? How's your medication going? etc
- Give newly diagnosed patients an **ADHD Passport** explaining:
  - Difficulties they might experience
  - Signposting to appropriate support services that could help eg Employment (Access to Work, reasonable adjustments





### Referrals

- Suitable referral service as high percentage of adults with ADHD and Autism have complex mental health needs
  - ADHD coaching
  - ADHD tailored CBT
  - ADHD therapy
  - Autism therapy
  - Learning how to understand/accept your diagnosis
  - Psycho-educational services
  - ADHD/Autism-tailored occupational therapy
- Be able to refer directly to a suitable service and avoid long waiting times when referrals have to go through GP services
  - We know that the services currently available are wholly inadequate
- Make the online referral process and form more user-friendly





#### **Operations**

- Fast-track:
  - Patients for Autism assessment if the ADHD Service suspect they may have Autism
  - Privately diagnosed patients so they can get Shared Care
- Refer patients with complex needs to The Maudsley
- Post-diagnosis groups
- **Pre-18 -** ADHD Richmond say they would appreciate:
- Healthwatch going to talk with them too
- More support for transitioning teenagers with:
  - Training Life-skills; Sensory processing (therapies) for families; Executive Functioning; Risks - substance mis-use and the vulnerability of women to sexually inappropriate behaviour (to win friends, naivety)



# Typical comments from Fastminds Members



#### <u>AUTISM</u>

"There is a serious lack of awareness and specialist ASC and neurodiversity training of various professionals in Kingston, including RBK Social Services, CMHT, iCope, GPs, CCG etc, which is very evident when trying to request services and support, undergoing Care Needs Assessments, applying for Personal Budgets and Personal Health Budgets etc."

"My ex CMHT Link Worker admitted that none of her colleagues at Kingston CMHT have had official training in Autism, apart from research or reading they have done by themselves!"





# Typical comments from Fastminds Members



"Once diagnosed, there is no-one to turn to for ongoing advice and support afterwards.

Some boroughs have various groups for adults with autism to meet up, socialise and get support and advice.

Kingston has nothing "officially" organised by the ASC Service etc, apart from a 6 session "post-diagnostic group", which is run sporadically. After that then people are on their own.

There definitely needs more resources and funding to set up an ongoing dedicated ASC support service and/or enable groups like Fastminds to increase the services and support they can offer adults with ASC etc."



# Typical comments from Fastminds Members



"Kingston iCope and CMHT use Autism as an excuse to not treat and/or discharge someone who has other mental health problems.

They say that the ASC Service should support them (thus leaving them with no services or support for chronic severe depression etc), despite the fact that the ASC Service is purely diagnostic".

"Unless a person wants to start work or is already in a job, unfortunately, there is no organisation in Kingston that offers ongoing support for adults with moderate/high-functioning ASC who are not well enough to work"





# Kingston Autism Service What's NOT working?



## **Operations**

- Assessment waiting list too long for people with complex needs
- Service struggles to cope with patients with complex needs (eg. multiple issues - neurodiverse, medical, psychological, relationship, employment, law, etc)
- Some Clinicians don't understand ADHD and the differences between Autism and ADHD – seem to think all symptoms are ADHD
  - Autism Service not referring patients for ADHD assessment because they don't think it's necessary

# Post diagnosis support

- Main post-diagnosis support is with group sessions which don't really work for people who have difficulty socialising with strangers
- Discretionary post-diagnosis support given for certain patients with complex needs



Kingston Autism Service What's NOT working?



### Communications

- Fastminds hasn't heard what the results were from the <u>research</u>
   <u>project</u> that Yourhealthcare's Neurodevelopmental team was due to
   carry out after being awarded £51k by <u>Health Education England</u>
   (HEE) in 2018
  - HEE is responsible for the training and education of both clinical and non-clinical NHS staff
  - What we knew about the research project
    - Aimed to address the gap in knowledge surrounding young adults' experiences of transitioning
    - 30 participants diagnosed with attention deficit hyperactivity disorder (ADHD), learning disabilities and autistic spectrum disorder (ASD) respectively.
    - Aged between 18 and 25 just gone through transition



Kingston Autism Service Negative Impacts



## Services

 Lack of support increases the pressure on mental health services which can't cope with/reject/discharge people with complex needs

## **Fastminds & Patients**

- Patients with Autism diagnosis not being referred for ADHD assessment by the Autism service – possible negative impact on patient:
  - Missing out on receiving treatment (eg. medication) that could transform their life
  - Continue being unable to focus or manage their lives
  - Continue being at the mercy of Adult Social Care & other services that are not ADHD/Neurodiverse aware
  - Continued anxiety > deterioration in physical and mental health > suicidal ideations



# Kingston Autism Service Negative Impacts



#### **Fastminds & Patients**

- Existing patients with Autism (diagnosed or going through the assessment process) likely to find it difficult changing to a different Clinician once Dan has left the ADHD service, so they may find it difficult to develop a rapport of trust with them
- Extra pressure on Sheena, Cherry & Fastminds Members to provide support for Members
- Can't help wondering how Service Users with ADHD & Autism have benefited from the 2018 £51,000 research project



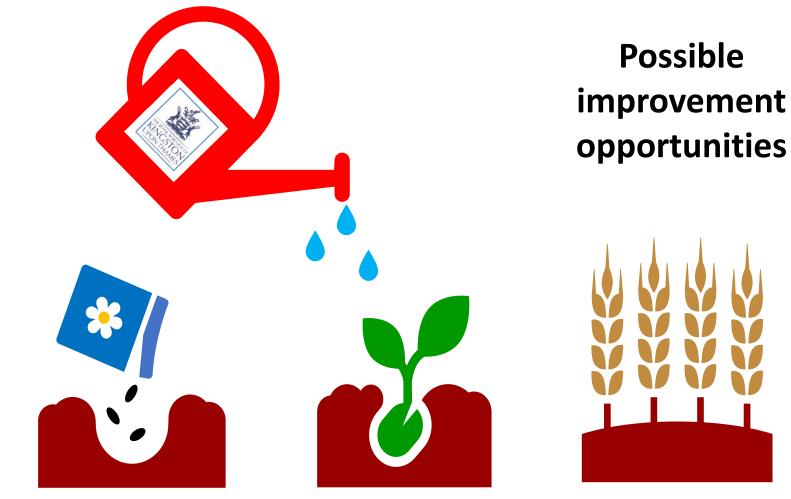
Kingston Autism Service What do we NEED?



## Staff

- Fastminds to be commissioned to provide ADHD training for Clinicians, so they have a better understanding of the differences between Autism and ADHD (and refer patients for ADHD assessment as a result)
- Recruit/train more staff able to cope with clients with multiple neurodiverse conditions and complex needs
- Refer patients with complex needs to The Maudsley?
   Operations
- Increase interaction with other services (AND FASTMINDS) to provide a more holistic service
- Shorten waiting times for assessments
- Pro-active post-diagnosis calls to patients to check how they are
- Fast-track patients for ADHD assessment if the Autism Service suspect they may have ADHD

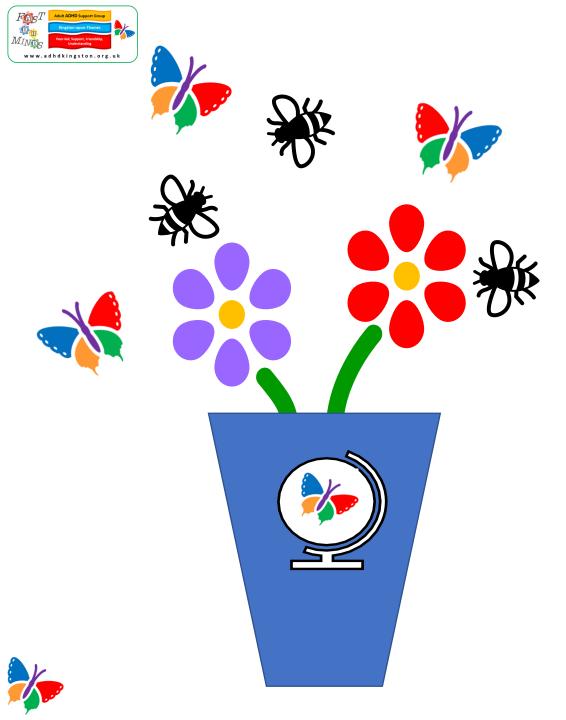








- Borough of Wandsworth
  - Have done a deal to refer ADHD patients to the specialist ADHD service at <u>The Maudsley Hospital</u> (open to all UK)
  - Assessment, diagnostic & follow-up service
- The Croydon, Lambeth and Lewisham Adult Attention Deficit Hyperactivity Disorder (ADHD) and Autism Spectrum Disorder (ASD) Service (also known as the 3-borough service)
  - Combined ADHD/ASC service launched in August 2020
  - Referrals can be made by GPs or NHS secondary mental health teams
  - ADHD diagnosed patients offered coaching
  - Brief post-diagnostic psychological support
  - Down-side = Mental health therapists are all trainees so have insufficient knowledge or experience of ADHD, etc



# SUMMARY What do we need so we can bloom and grow?



56



# What do we need? SUMMARY OF PRIORITIES

- **1. More funding for ADHD Service & Fastminds**
- 2. ADHD Service to be able to refer directly to suitable service providers, should a user need it
- 3. Better cohesion between the ADHD and Autism Service understanding of each other's conditions/cross-over
- 4. Develop & maintain good relationship with Fastminds
- 5. More training and education for any professionals involved with neurodiverse people (eg. social workers, GPs, anyone in mental health)

Fastminds helps make it easier for local services to do their job – we need the services to make it easier for us to do ours (which done by **unpaid neurodiverse volunteers**)





# What do we NEED?



# A collaborative, more holistic joined-up service –

all medical and social care services working together

with Fastminds and Service Users

#### **Recognition for what we do at Fastminds**





# What do ALL Neurodiverse people need?



More professionals capable of supporting Neurodiverse individuals – especially those with complex needs



Training about Executive Functioning & Neurodiverse conditions for ALL Government departments (especially healthcare, social care, emergency services, education, legal)



so that everyone views life in the context of Neurodiversity

Create Neurodiverse Champions, instead of Neuro-Sceptics

Introduce it into the school curriculum

so that FUTURE GENERATIONS learn to be empathetic to the symptoms of and challenges faced by people with neuro-diversities & the importance of detecting early and treating it correctly 59





#### Less stigma, more STABILISERS



## More EQUALITY for people with Neuro-disabilities Discrimination arising from disability is unlawful unless the organisation or employer is able to show that there is a good reason for the treatment and it is proportionate The Equality Act 2010



# For more information

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