

City and Hackney

Autism Feedback: Accessible Services



Summary



This document provides an overview of feedback gathered from autistic individuals, their families and carers as well as professionals supporting autistic residents.

This feedback has been used to shape the recommendations in the City and Hackney Autism Strategy but is also relevant in the implementation of the actions within so can be used as a reference point by services and departments.

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What does good look like....?

Primary Care

General tips

- **Ask** how you can best support someone - not all autistic people are the same
- GPs trained in autism and are knowledgeable and aware;
 - Awareness that depression may mask autism
 - Awareness of co-occurring difficulties (e.g. isolation)
 - Awareness of mature adults that have been undiagnosed or misdiagnosed
 - Awareness of the impact of a diagnosis and any follow up support that may be needed - sensitive communication
- Consistency of support - e.g. keeping the same GP where possible
- Having an autism register and flag
- Autism specialist in GP surgeries
- Access to advice easily for autistic residents
- Increase number of check ups for autistic people

Before an appointment

- Access of appointments including at quieter times
- Easy way of booking appointments - including without having to telephone
- Allow patients to send information ahead of appointment (e.g. via email) where they find it hard to explain

In the surgery

- Autistic friendly environment; lighting, quiet area away from the crowd
- Self check points can be useful
- Sticking to time or warning of delay
- Other practice staff (e.g. receptionists) trained and aware - able to dim lighting or direct to a quiet area or low arousal environment

At an appointment

- GPs need to clarify with patients they've understood them - ensure information is provided in different formats
- Active listening to ensure important information is heard (by both GPs and patients)
- Allowing for extra time (e.g. double appointments) and allow time for people to speak, clear information to be given and time to process rather than re-wording straight away
- Ask the right questions rather than too many questions or overloading someone; use clear and unambiguous language
- Awareness of different ways to assess pain (e.g. scale of 1-10 can be difficult for some)
- Understanding that an autistic person may not know or understand their normal or what may be a priority symptom
- Use of digital comms to follow up on information and appointments

Also see: [RCGP Resources](#)

Mental Health Services - adults



The following I-Statements were developed by autistic adults in the expert by experience group:

- I have my entire mental health history/record reassessed in the context of the autism diagnosis I have received as an adult
- I am confident the support I receive in mental health services is appropriate and delivered by professionals experienced and trained in autism including autistic user-led training
- I have been fully and clearly informed about what my treatment is intended to achieve and how, so that I can tell whether it is working and appropriate
- I have been fully and clearly informed about what to expect
- I have my treatment reviewed regularly with adequate notice so I have time and opportunity to express concerns
- I am confident that mental health professionals understand that my individual presentation may be different from neuro-typical people and other autistic people
- I can request to not have to participate in group therapy if I feel this will be particularly stressful for me and I am offered appropriate alternatives
- I have a peer/support network in place that helps me identify changes in my mental health
- I have any co-occurring mental health conditions explained to me in detail
- I am involved in decisions concerning my mental health
- I have a therapist who is skilled and experienced in working with autistic individuals

Mental Health Services - adults (cont)



The following I-Statements were developed by autistic adults in the expert by experience group:

- I am confident my particular needs as an autistic service user are recognised and professionals are able to differentiate therapy and support provided
- I am confident that autistic people's diverse mental health needs are recognised and accommodated and that professionals do not assume I will have the problems as the next autistic person (When you have met one autistic person...)
- I have support/ advocacy to help put in place reasonable adjustments
- I have access to an advocate who has experience of working with autistic people
- I get extra time to process documents and information about my mental health needs
- I have access to appropriate psychological therapies adapted for autistic people
- I have my current life problems and situation, as seen from my and my carers' perspective, considered along with my autistic needs and mental health diagnosis and treatment so that I and supervising clinicians have a common understanding
- I have any 'divergent' expression of positive mental health, such as stimming, obsessions or self-soothing behaviour, respected and not treated as a mental health problem, unless it causes distress that cannot be relieved by adaptation.
- Likewise my autistic expressions of distress including self-injury are understood and my underlying distress is addressed.

Mental Health Services for CYP



The following I-Statements were developed by parents/carers of autistic children and young people:

- I can regularly access an autism specific parent/carer support group to get helpful advice on supporting my child's mental health needs day to day
- I do not have wait more than 12 weeks access CAMHS autism specialists if I am concerned about my child or young person's mental health needs
- I can access crisis mental health support from an autism-experience mental health professional for my autistic child or young person if I feel that they need urgent help
- I can access support while we are waiting to be seen by a CAMHS psychologist
- Mental Health professionals listen to my child/young person and myself and take our views seriously
- Mental health professionals understand the complexity of the issues we face as a family and provide non-patronising, timely and sensitive support
- I am confident CAMHS will directly advise my child's school or college on how best to accommodate their mental health needs and that the school will follow their advice
- CAMHS professionals who know my child are present and contribute school meetings when decisions are being made about potential school exclusion

Mental Health Services for CYP (cont)



The following I-Statements were developed by parents/carers of autistic children and young people:

- I can access family therapy services confident that the therapists we are referred to have extensive experience of working with autistic children and their parents/carers
- I am referred to post-diagnostic autism courses including Early Bird, Early Bird Plus, Next Steps, Early Bird Healthy Minds and Pegasus and other support in a timely way and do not have to wait a long time to join a course
- I am confident that mental health professionals use autism-positive language when speaking to my me and my child/young person (autistic rather than ASD etc) and write reports
- I am confident mental health professionals working with my child or young person understand and can identify commonly co-occurring mental health conditions in my child (ODD, OCD, behaviour that challenges, anxiety and demand resistance) and know that these are separate from autism
- I am confident that if my child or young person is presenting with co-occurring mental health issues, professionals understand that these may be happening because of the way they are treated at school and other environments and are not an intrinsic feature of being autistic.

Communication Tips



The following tips have been shared by autistic people and/or their parents/carers:

- Important to have time to process information and not need to make decisions straight away
- Keep information clear and unambiguous
- Bright and fluorescent colours (such as on signs) can leave autistic people feeling distracted and unable to focus and some colours are painful to some people (red has often been given as an example)
- Greens and blues are given as examples of calming colours
- Some people prefer to use email or text messages as they find conversation difficult especially with people they don't know
- Ask for preferred method of communication
- Make information available in alternative formats (such as visual guides and social stories)

Services and Events in the Community



The following tips have been shared by autistic people and/or their parents/carers:

- Include maps/layouts with pictures and visual guides of facilities and what to expect so people can be prepared in advance
- Social stories are really helpful
- For an event, knowing what things are like (dark/bright, loud/quiet, formal/relaxed) will help people decide if they want to/are able to attend
- What is the 'map' of your service or event - where can I find the entrance, exit, toilets, an information point, is there a quiet space, is there food to buy, is there an itinerary, what is expected of people attending (e.g. to sit quietly or able to roam around), will it be loud, will there be a strong smell
- How can someone ask you to make an adjustment (such as turning music down in shops)
- For services it is helpful to know how it works; will I need to wait, what is the average wait, is there a waiting area and if so what is this like
- Make services accessible via email as well wherever possible - written information and advice can be easier to understand for some autistic people (rather than verbal phone or face to face communication)