Optimising general practice support for autistic adults: a realist review protocol

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Additional file 2: initial programme theory (IPT)

Our initial theory for this project is based around the patient pathway for obtaining support from general practice. This pathway contains several steps, outlined below. (Note: there are definitions for terms marked with an asterisk at the end of this document).

1) Identifying the problem

Interoceptive differences,* alexithymia* and monotropism* may mean that some autistic adults may not readily identify something is wrong and in need of medical attention, or that they need support for their physical or mental health. These differences may affect the ability to detect and attend to health. In addition, some physical or mental health symptoms may be heightened and could be more troubling due to sensory differences.

Some autistic people may not know what health or illness looks like for them; this might be atypical and they may not recognise it from how it is presented generally in the world. Public health initiatives might not provide information in accessible ways to help autistic people understand health issues or symptoms, which could mean autistic people are less able to identify when something is wrong.

Noticing when things have changed may be difficult, especially when dealing with overwhelm, burnout and/or needing longer to process information. Managing multiple conditions may also mean it is difficult to separate things out and notice if a particular aspect of health has changed and something is wrong.

Knowing how much pain people are 'supposed' to tolerate is difficult when autistic sensory differences have often been systematically dismissed and/or labelled as not real. Trauma and numbing can mask both physical and mental health problems.

For some autistic people, lower levels of education and health literacy may lead to symptoms not being recognised or being dismissed as not warranting medical attention. Not being able to access health information in accessible formats, or knowing how to check symptoms may mean people can't identify when something is wrong.

For some autistic people, communicating that something is wrong to carers may be difficult, or carers may not notice that something is wrong. Autistic people who use assisted communication may literally not have the words or concepts available to explain that something is wrong.

If an autistic person is used to be dismissed by family and/or healthcare professionals because of a lack of understanding of communication and/or interoceptive differences, they may not understand when

they should seek help or report something, because they may be used to being told their issues are nothing to be concerned about. If previous health concerns have been dismissed this could lead to an autistic person not trusting their own body and therefore not readily identifying when something is wrong.

2) Deciding to seek help

Seeking help may be delayed (or may not happen at all) due to not identifying physical or mental health symptoms (whether due to interoceptive differences, alexithymia, monotropism, or lack of knowledge etc). If autistic people mistrust healthcare providers, have had poor previous experiences, believe the service cannot meet their needs, or that the effort required to make or attend the appointment is too great, this could delay the decision to seek help. Existing medical trauma could make it difficult to decide whether to try to access further care.

The number of steps and decisions involved, coupled with uncertainty, may lead to cognitive overload which could result in decision paralysis or becoming non-speaking. This could delay a decision to seek help.

Continuity of care – being able to see the same practitioner – may influence the decision to seek help. Being able to see a known and trusted healthcare professional may positively influence the decision, but a previous poor experience with a particular individual could negatively influence the decision. Seeing a new healthcare professional and having to tell the same story (of health experiences and needs) again may be viewed as exhausting and could put people off from seeking help. Support (e.g. from friends, family, a paid support worker) and resources (e.g. financial, transport) to attend an appointment may also be a factor. Autistic people with learning disabilities and / or who are non-speaking may experience difficulties trying to communicate their symptoms to people who they need to support them to seek an appointment.

Putting off the decision to seek help could result in exacerbation of symptoms and push people into crisis. This may result in the need for emergency care, whether for a mental health crisis, or physical health, and needing to attend an Accident and Emergency (A&E) department.

3) Obtaining an appointment

If appointments can only be made by phone, or if general practice staff make follow-up contact by phone (e.g. to arrange an appointment) based on an online triage form, this could be a barrier for autistic people (speaking and non-speaking) obtaining an appointment. Waiting for the phone to be answered, being put on hold while on the phone, the sensory difficulty of being made to listen to certain music while on hold, or waiting for a phone call back, may cause additional anxiety or other difficulties for the autistic individual who is trying to obtain an appointment. This may be a particular issue if people need to phone at 8.00 a.m. on the dot to join a queue.

A certain level of literacy, the ability to use computers, mobile phones, standard phones, and remember passwords, may all be required to make an appointment. Not all autistic people (with and without learning disabilities) will possess these skills and abilities, and may thus face barriers to accessing care.

The practice needs to have available appointments and capacity, and clear information about the booking system. Autistic people may be less likely to obtain an appointment if they do not understand the booking system, if the practice is not responsive to their needs (including communication needs), and if appointments are not available at a convenient time.

There are power imbalances within healthcare systems and many autistic patients have to try to make themselves fit to what they think will get them the care they need. This requires cognitive and emotional labour and increases the burden on the autistic person, which can negatively impact health.

The effort required to make an appointment may exceed the capacity of the autistic individual on the day that they need to make the appointment, particularly if they are unwell. Written communication (whether by text, email, or an online form) may be easier for some autistic people but this is not always permitted or well received by a practice. Some autistic people may be concerned that an email may be perceived as making a complaint rather than just attempting to communicate their needs in the best way they know how. If practice staff do interpret email communication this way, this could create hostility between the practice and patient.

If a practice has triage criteria based on 'typical' presentations, and autistic people present 'atypically', e.g. being able to talk coherently when in severe pain or suicidal, they may not be allocated an appropriate or timely appointment. Practice staff may assume that people are exaggerating, however autistic people are usually factual which may be different from what staff expect, as well as having atypical presentations. It can take a lot of social skill and confidence to know when to stand your ground and insist, if you being told there are no appointments available. Sometimes when autistic people do stand their ground, persistence and/or expressions of frustration may be mistaken for aggression and the practice may refuse the individual an appointment until they have calmed down.

If a practice insists on same day appointments, this may present problems for some autistic people who may not be able to attend on that particular day, for a range of reasons.

4) Getting to the appointment

Some autistic people may experience time blindness (e.g. due to monotropism) and could struggle to attend appointments on time.

Access to transport and access to support from friends, family, or a paid support worker may impact getting to the practice for the appointment. Some practices have merged and being asked to attend an unfamiliar practice may cause difficulties. This could also increase the cost of attending when using public transport and taxis.

Autistic people may experience stress and anxiety due to a lack of information about what to expect (e.g. what the rooms look like, the sensory environment, what types of questions they might be asked). This could be particularly relevant where practices have merged and there are several locations a patient could be sent to, which could increase the uncertainty, stress and anxiety about the facilities and environment.

Once in the practice, the practice environment (e.g. sensory stimulation: light, sound, smells) could affect an individual's ability to stay and wait for their appointment, or hear their name being called. Reception areas that don't have clear signage can be problematic. People may not see where they are meant to go and may be put off and leave. Receptionists should expect and accept that people accessing services may be in distress and this may influence how they communicate. The person accessing services may not communicate as well, articulately/clearly or politely as they might in other circumstances. It could be helpful for staff to be trained in de-escalation techniques.

Some things that may appear 'incidental' can interrupt processing and cause anxiety. Being sent to different parts of a building, with staff you haven't met before and with no information beforehand about what will happen is unhelpful. Having clear information about what to expect and the patient pathway, is helpful. Peer support for an autistic person attending a healthcare appointment could be helpful, as they can provide support around navigating the environment and communication.

Social interaction with potentially unknown people (e.g. the receptionist) may be required, as well as dealing with other patients in the waiting room (the energy and distress of others, potential discrimination). This could increase social anxiety and trigger past interpersonal trauma.

5) General practice interaction

Existing medical trauma could mean that new instances of care are harmful because of the stress of being in a healthcare environment again. For appointments at the practice, sensory overload from being in the waiting room could impact the ability of an autistic person to think clearly and communicate their needs in the appointment. Video and phone appointments may be helpful alternatives, however they may present difficulties for some autistic people, due to technological aspects or not being able to see the person, or be with the member of staff in person. There is often no choice about the type of appointment patients can have – this is typically decided by the practice.

General practices may not easily accommodate alternative methods of communication such as Makaton or AAC (Augmentative and Alternative Communication). This can present barriers for some autistic people (with and without learning disabilities) who may be non-speaking some or all of the time.

Autistic people may over-prepare for appointments and ask lots of questions, which may be perceived as trying to undermine the GP. It may also be perceived as being rude, or a 'difficult' patient, which can impact the care provided. A greater understanding of autistic people, including that some people may not yet be diagnosed as autistic (or may not declare their diagnosis), could help healthcare staff to better support autistic patients with their needs (whether they are diagnosed as autistic or not).

Some autistic people may be reluctant to tell the healthcare professional they see that they are autistic due to fear of being treated negatively. E.g. being undermined, treated like a child, not taken seriously, having concerns dismissed, and having some services withheld. Such bad experiences can lead to mistrust of professionals and services.

The way individuals express their distress can be discounted as behavioural problems, but this may be the only way people can express their distress. This can lead to people being criminalised or sectioned.

Autistic patients may present differently to the 'typical' clinical picture, or explain their symptoms in a way that is different to what general practitioners (GPs) are used to or can understand. The lack of research into differences in autistic experience of natural processes (e.g. pregnancy, menopause), ill-health and response to treatments (medication and therapy) could mean clinical staff lack knowledge about how to support autistic people. This can lead to a poor healthcare experience or exclusion from care as GPs may hold implicit biases about how patients with particular health conditions should present and communicate.

Appointments are often short and don't allow sufficient time for autistic people to explain their concerns. Some practices offer 'double appointments' that allow more time, but this is not standard across all practices. Autistic patients may want more detailed explanations of a diagnosis, treatment, and next steps, and GPs may not always have the time or inclination to explain things.

GPs may have a lack of understanding of minority groups in society, and intersectionality within the autistic population, due to a lack of studies on intersectionality of race, gender, and sexuality within autism research. For autistic people of colour, there may be additional masking due to culture and living in a predominantly white, heterosexual and patriarchal society, which could impact their presentation and how they are perceived during a healthcare appointment.

The interaction may go better if autistic individuals know their access needs, what adjustments are reasonable and feel able to self-advocate. This can be easier when there is a tick list that people can select from that has been endorsed as 'reasonable' by a respected third party. E.g. the Autism Healthcare Accommodations Tool from AASPIRE Healthcare Toolkit for Autistic Adults (autismandhealth.org). However, such preparedness and self-advocacy may not always lead to better outcomes if there is a perception that patients are trying to undermine GPs.

Biases based on gender, ethnicity, and socioeconomic status, as well as diagnostic overshadowing* can further impact the healthcare interaction. Longer consultation times may be needed to allow for differences in communication styles, as well as information processing differences. Information needs to be provided in a format that works for the individual, with time to process this (outside the consultation) and the opportunity to come back with questions. Interpreters may be required for patients whose first language is not English.

Practice staff beliefs, skills, and knowledge about autism and autistic people's experiences are important, as is empathy, and accounting for the double empathy problem*. There is a lack of knowledge about individual differences within the autistic population, and how experiences can vary. In addition, GP's lack of knowledge about commonly co-occurring conditions experienced by autistic people (e.g. gastrointestinal conditions, hypermobility) could mean diagnosis and treatment can be missed or delayed. Staff training may be helpful, however general practice staff may not have time to undertake additional training when services are already overstretched. There may also be financial implications regarding the backfill of staff on training. In addition, training may need to be repeated at certain timepoints like other NHS mandatory training, to keep up with growing research and ensure skills and knowledge are up to date.

Autistic patients may not feel empowered to negotiate care, and continuity of care (seeing the same practitioner) may help to build trust and improve the healthcare interaction. Seeing the same healthcare professional could also lessen the burden of having to tell the same story again, which can be exhausting. Cultural humility on the part of healthcare staff, and being genuinely curious about an individual's experiences may help in trying to meet the needs of autistic patients. Lack of clarity about what to expect, the limits of the role of general practice and changes as demand increases can make it even more difficult for patients to feel empowered.

Autistic people may spend a lot of time and effort thinking about and trying to understand how others (e.g. general practice staff) may interpret their behaviour and what they have said. This can be exhausting for the autistic person. Some autistic people may also experience emotional overwhelm when they are not understood by others at times when this really matters, such as when they are trying to communicate their health experiences and needs.

Tools and supports such as healthcare passports or records of adjustments that are needed, may have the potential to be supportive. However, if they are not implemented properly or adhered to, they could be the cause of another communication breakdown and thus worsen the healthcare experience. Being able to take a carer or other support person to an appointment could be helpful, however there is a risk that staff then speak to the carer rather than the person themselves.

Autistic people may have trouble understanding how to navigate general practice and healthcare generally, and understanding their rights. For example, knowing when to ask for a referral to a specialist or when to ask for a second opinion. These skills (accessing and navigating healthcare) are not routinely taught, and could be something that autistic patients would benefit from. Access to healthcare can be competitive and people who shout the loudest tend to get the support, which can put some autistic people at a disadvantage.

6) Post-appointment, and supporting long-term outcomes

During the appointment there may be uncertainty about what was decided, what the GP (or other member of staff) said, and some autistic people may be concerned about forgetting what has been said. A debriefing document, leaflets, or the option to record the consultation, could be useful. Some autistic people may want to take someone with them to the appointment, to help remind them of things to say

in the appointment, and to remind them afterwards of what was said. This can help autistic patients to adhere to any agreed treatment plans.

Autistic patients need clear information about who to contact to follow-up on referrals or test results, what the timeframes are for different aspects of care, and when it would be reasonable for them to follow-up if they haven't heard anything. Following secondary care procedures, autistic people may need greater support and predictability from general practice.

If care coordination is left to autistic people this can be an additional barrier. For example, if a GP recommends blood tests, but the autistic patient needs to book these themselves, it becomes even harder.

***interoceptive differences:** the ability to feel internal body sensations may be lessened or heightened.
***alexithymia:** difficulty identifying, recognising, and describing emotions.
***diagnostic overshadowing:** symptoms may be attributed to autism rather than a health condition.
***monotropism:** a theory of autism and a trait. Monotropism explains attentional differences where there is a tendency for monotropic minds to have "few interests highly aroused, … An aroused interest is an interest charged with feeling." (p.140, Murray at al., 2005; and https://monotropism.org).
***double empathy problem:** autistic and non-autistic people (and professionals and non-professionals) have different experiences, knowledge, and communicate in different ways. This misalignment can lead to difficulties and misunderstandings, and has been termed the 'double empathy problem'.

References

Murray D, Lesser M, Lawson W. Attention, monotropism and the diagnostic criteria for autism. Autism. 2005 May; 9(2):139-56. doi: 10.1177/1362361305051398. PMID: 15857859.