

# Making health services better with people who are neurodiverse:

An action research project with  
**West Yorkshire & Harrogate  
Health and Care Partnership**

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Written by  
Martin Fischer  
(Fischer Associates)  
and  
Alyson McGregor  
(Altogether Better)  
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## 1. Introduction

The work outlined in this report can best be described as a small-scale action research project which set out to gain a deeper and richer understanding of how to support the development of kinder, more compassionate and more effective health services with people who are neurodiverse. We believe that we not only succeeded in this aim, but also gained deeper learning that could be valuable across the entire system which is highlighted in this report.

## 2. How this report was produced

The project involved data collection and analysis through interviews, workshops and surveys as well as drawing on the collective experience of the participants and the interpretive ability of the team who drew together this report and its recommendations. This project provides the foundation for an idea which is ambitious, and which seeks, with further research funding, to build an evidence base for delivering more compassionate and inclusive services.

Building blocks for the work included a brief scan of the literature and foundational work about the nature of the consultation and systems change that the writers had undertaken previously. This informed the design and approach to a series of workshops. (Appendix).

We started with two workshops. The first workshop was with a group of neurodiverse young people (YP) aged 16-25 who find themselves in one of the most difficult life changes: the transition between childhood and adult service provision. The second workshop was with neurodiverse adults and the parents, carers and supporters of neurodiverse children and young people. We also carried out an in-depth interview with a neurodiverse young person and her parent because their preference was to meet on a one-to-one basis rather than in a group setting.

We designed a short online survey for practice staff to help inform our thinking. The participating practices were asked to send it to the members of their practice teams.

Building on the learning from working with these groups and the survey data from practice staff we went on to design and run a joint workshop inviting the neurodiverse people who had contributed to the first round of workshops to work with the doctors, managers, nurses, and receptionists from two GP practices in Leeds: Oakwood Surgery in the north of Leeds and the Light Surgery in Leeds city centre. The two practices who came forward to participate were curious and keen to contribute and learn about delivering better services for people who are neurodiverse.

We explored the conditions for good services with a focus on navigating:

- Making the appointment
- Before the appointment
- Reception services and waiting for an appointment
- The consultation itself

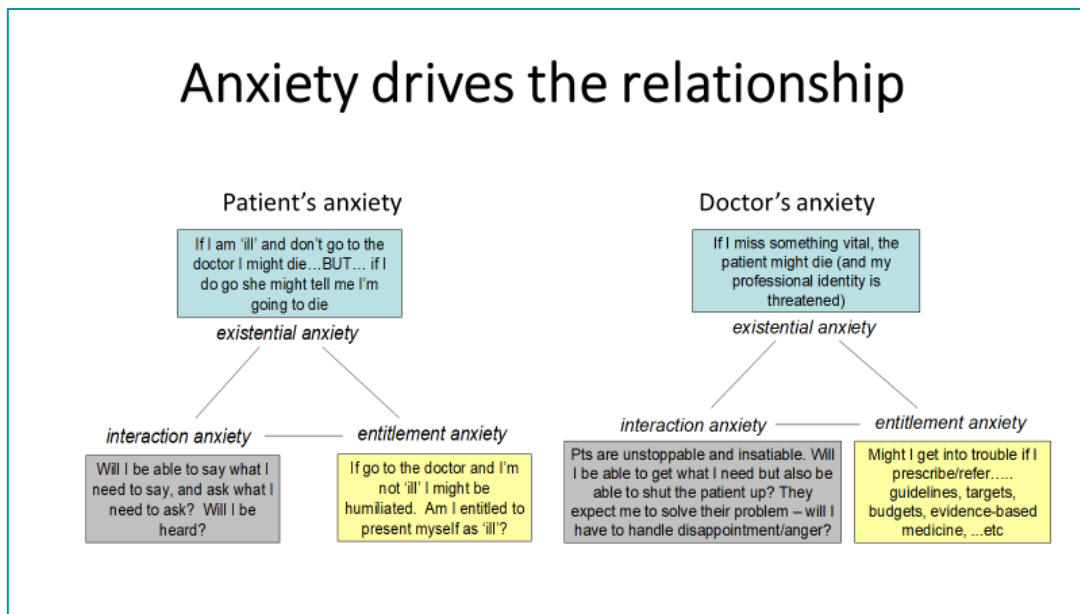
### 3. Context

#### 3.1 Anxiety drives the relationship

Not knowing and not being understood generate anxiety. When we are anxious, most of us are rarely at our best. In the face of illness, we are all anxious, both the patient and the caregiver.

Our earlier research (<https://www.health.org.uk/publications/when-doctors-and-patients-talk-making-sense-of-the-consultation>) has shown that the anxiety (which exists for both clinician and patients) is the fundamental dynamic and when not addressed it deeply affects the patient’s ability to both describe accurately what is wrong and to hear what the professional is saying.

This is compounded when we don’t know or understand the correct etiquette of a situation.



Neurodiverse people like certainty more than most. Their response to uncertainty and ambiguity is anxiety. It is simply more heightened than most neurotypical people, not different. Addressing this will improve services for everyone.

There are some issues that might be specific to neurodiverse people. One is that waiting generates anxiety. Another is the need for certainty and that the unexpected generates increased anxiety. Other issues include the way pain is reported and specific communication needs.

Our conversations explored how general practice can be encouraged to operate in ways that uncover what is specific to any of their patients.

The relationship between the clinician and patient determines outcome. This can be extended to all caregivers. Both parties need to be at their best for a good service.

Whilst some anxiety is unavoidable, if left unmanaged or escalated it can be disabling and destructive.

Research the authors carried out for the Health Foundation in A&E (2010) showed that when patients had entitlement anxiety (about the legitimacy of them attending A&E), then until they were reassured they could neither describe their condition accurately nor hear what was said to them. Patients being at their best (relaxed in the environment) is critical to get effective care. General practice needs to organise in a way that enables patients to be at their best.

There is a reasonable amount of evidence in the literature and much anecdote (particularly in our work on Collaborative Practice) that shows how kindness is a particularly effective intervention for people in a state of anxiety. Whilst we fully support a value base that includes kindness (i.e. you choose to be a kind practice), our work demonstrates that it has an additional benefit of improving outcomes for everyone.

### 3.2 Role of kindness as an organising principle

We see kindness as having a key role as a 'substitute', to mitigate and dampen the impact of fear and anxiety (a 'balancing loop' in systems terms). Kindness should drive the clinician/patient dynamic, not fear and anxiety.

Equally, theorists (Varela/Maturana) emphasise that in social systems, 'unconditional regard' for others is the core interpersonal relationship. Systems need **functional relationships** to get the task done. Systems change by evolving/adapting. Diversity and inclusion are the fundamental processes that allows social systems to evolve. This is core relational practice. We see kindness as being central to this.

#### What kindness looks like in this work

Based on stories told by neurodiverse citizens and staff from the practices (GPs and managers, one who was neurodiverse). People shared stories of receiving acts of kindness and being kind to others. Their insights included:

- Kindness is when the person believes '*you didn't need to do it for me*'.
- Kindness is an action not an object (not a present you give). It's a behaviour.
- Kindness is an instinctive and innate behaviour for some. For others it is a deliberate (learned, encouraged) act of leadership. Both works equally effectively!
- Kindness starts by noticing.
- Kindness is simply asking. You do not need to understand what someone is going through to be kind to them. Although knowledge can be helpful and save time.
- Kindness is often preventative. It stops things escalating. Organisations tend to notice (and value) putting out fires, not preventing them (like health services spending a lot on interventions, and little on prevention).
- Acts of kindness often change the person's trajectory: "*words change lives*".
- Kindness is effective; better outcomes happen when the patient is relaxed.

## 4. Findings

### 4.1 Making the appointment

We are aware that most practices have given a lot of thought to making their appointments efficient and effective. Yet there is surprising variation across practices in both the patient experience and relative ease of navigating the system. There are no easy fixes.

In common with many people on the patient list, making an appointment can be problematic from the patient's perspective. It is not obvious what 'kindness' would look like in an appointment system (although in a workshop, someone wondered how different the appointment system would be if the per capita payment was linked to the ease of making an appointment!).

People said they wanted to be known and flagged on the record as neurodiverse so that all staff (reception team and doctors) know when they telephone or walk in that they may need some additional help.

Some YP found it helpful for their parent to make the phone call to arrange the appointment on their behalf although this was sometimes discouraged by the practice, creating more anxiety.

- Parents said, "it would be easier if we could get through to make the appointment."
- Face to face appointments were preferred to telephone appointments by many.

#### The challenge for services is to think:

What would a kind appointment system look like? (both online and a phone system)
How can practices flag neurodiverse people on the system so the practice knows they might need reasonable accommodation?
How can we offer appointments at quieter times (if they ever exist!)?

### What people said

*"Making an appointment is a nightmare – online system is hard and doesn't work if you have additional MH problems. End up having to ring anyway. Telephone system is long wait but better online"*

They worried about whether the appointment would be **on the phone** "I struggle to communicate in this way" and needed help from a parent to do this. On the phone "I am not able to see other people's reactions as its harder to tell emotions and know if you are explaining properly".

Other issues with telephone appointments included the uncertainty "not knowing what time the phone call from the doctors will be because you are given a time slot 9am-1pm rather than a time"

*"I like to know where I am going, who it will be. Telephone call is awful. Really struggle not knowing when the phone will ring. Can't prepare, prefer face to face."*



## 4.2 Before the appointment

People feel anxious and nervous about the unknown. The more certainty there was about what was going to happen, the less anxiety and discomfort was felt.

Two significant but simple things a **kind practice** can do to reduce the anxiety are:

### a) Reduce the uncertainty as to what will happen when they arrive

Videos / visual aids that describe the appointment experience – from the car park on – explicitly explaining “we have a team of receptionists, doctors etc.,” Many examples of this emerged during the pandemic to prepare people for what they will see/experience when they attend the Covid-19 Vaccination Clinics.

### b) Help patients prepare so they can make the most of the appointment

Helping people prepare might include preparation so that they can say what they need to say. Practices might also create a video/handout of how the consultation process works including why questions might be asked that do not seem obviously relevant.

We suggest that Practices could adopt the Right Conversation Right Time (RCRT) Guide - [Right conversation at the right time appointment guide — Altogether Better](#). This is an existing tool based on research funded by the Health Foundation. The guide has been designed to



support the consultation process. Most practices who use it, to good effect, offer it to all their patients.

Parents thought the RCRT guide would be very helpful. Many made a list in advance of their appointments as they knew it was hard to remember everything under pressure and the list created a sense of certainty.

Preparation might also help to reduce the worry about the pressure on time and the length of explanations in real time. The doctor can look at the guide and ask if they have anything to add? Talking it through with another person beforehand can help people to think through and plan what they want to say.

## What people said

*“a video would be heaven that showed what happens in what order and says that the people you see may not be the same “*

*“before the appointment there’s anxiety going through my head because you’ve no idea what the doctors going to say”*

*“worries me which doctor I am going to see, have I seen them before- the unpredictability of it makes it hard for me”*

*“are they going to touch me? Am I going to be weighed?”*

*“at a recent appointment I had not been prewarned that they intended to remove the brace, created a lot of anxiety- a meltdown”.*



### 4.3 At reception

Every GP we have met talks about trying to enable the patient to 'be at their best'.

The research we did in A&E showed conclusively that until a patient feels they are 'welcomed' (it's right to be there), they both cannot describe what is wrong with them accurately or hear what is said to them. Everyone has entitlement anxiety; kindness involves ensuring they feel welcome.

***The essence of the receptionist's role is to put patients at ease, show care, understanding and kindness. In some practices, receptionists struggle, not because they don't wish to be actively kind but because they are under terrific competing pressures.*** There was strong agreement that reception is a busy, stressful place to work. Receptionists are continually multi-tasking, they are the first port of call for unhappy patients, often not able to give people what they need. The practice needs to find ways of organising reception in ways that are kind to the staff so that they, in turn, can be kind to the patients.

GPs need to value their receptionists' role in ensuring that everyone enters the consulting room at their best. For some practices this requires changes to the way they organise. This work's scope did not include how to bring this about, but there are suggestions on how to approach embedding kindness as an internal organising principle on page 5.

This is important work which is ***fundamental to good clinical care and is far deeper than being nice to people.***

#### What would kindness look like at reception?

Organise around the principle that the receptionist has a critical role in making patients relaxed. Train them to 'defuse' anxious patients (and value their skill and the time they spend doing so).

- At the start of a session, look at who is booked in that morning/afternoon and anticipate any appropriate accommodation that might be needed at times. Thinking ahead about what might make it easier for receptionists and patients can prevent difficulties for both.
- Many young people expressed fear that the reception staff might not know that they may need some additional help from staff or from a parent/ supporter, even though they have filled in the forms which explain that they may require some additional help, and some wore the hidden disability lanyard.

### What you said

Receptionists were anxious too.

"saying wrong thing can trigger them"

"there is a need for calm, trained staff"

Receptionists were anxious that patients "will feel we are not helping them enough"

Receptionists questioned whether they were organised in the right way

"can we accommodate their needs?"

Neurodiverse people wanted to be understood by the receptionists

"I often headbutt (as a tic) the desk at reception which seems to annoy the receptionists. I worry about doing this which makes me do it more".

- It was suggested that their neurodiversity could be flagged on their notes and the receptionists could be aware that they were coming in and be able to prepare for them/understand they might arrive early/understand their need to be accompanied in the appointment etc.
- It was suggested that they could wear a meaningful identifier such as a neurodiversity pin or a lanyard that meant something to the receptionist. We understand that identifiers exist but have lost their value during the pandemic having been taken to be an identifier that they are mask exempt.
- There were many stories of receptionists being dismissive of teenagers/YP being accompanied. Aside from being rude (and none of their business), having an advocate is not only a right but increases effectiveness. Covid was given as the reason to 'not allow' people to be accompanied. Given that the young person was likely to live with the person accompanying them it was experienced as unkind and unnecessary application of the rules.
- A very frequently expressed worry was whether the receptionist would be friendly and understanding. The need for eye contact and patience came up frequently.
- Strong agreement for the need for consistency in service and a request for things not to change so much. It would be helpful if receptionists said the same things each time by way of introduction.
- Being told by the receptionist who they are going to see, and photographs of the staff is helpful
- Many prefer automated check-in, but not all patients will; some like the human interaction.

### A radical and simple act of kindness at reception

A radical version of kindness, given the detrimental impact of the anxiety generated by waiting, could simply be that neurodiverse people are given the next session with their GP, letting them jump the queue in the same way as people with specific health needs arriving at A&E are prioritised.

## What you said

A repeating comment was not to be challenged, questioned, or denied by the receptionist about being accompanied by a parent/supporter

*"mum is a willing advocate but not always welcomed by the service"*

Worry about the receptionist being unfriendly

*"the receptionist was typing and wearing a headset, she didn't look up and so I didn't know when to speak because she kept on working- increased my anxiety – mum had to speak up for me even though I had prepared"*

*"I worry about the receptionist being dismissive and not giving eye contact"*

Fear of being met by a non-communicative receptionist was a trigger for the worry that

*"I have done something wrong" "feel like I am a bad person. "*

Some expressed a need for more understanding of what it means to be neurodiverse

*"would be better if I was not laughed at for giving one-word answers to questions that require one-word answers "*

Valuing the role of the receptionist

*"I think the thing that's hit*

## 4.4 In the waiting area

The waiting area is an inherent generator of anxiety, in large part because patients have no control over it. To improve care, two approaches can be taken:

1. Make the environment as anxiety-reducing as possible.
2. Simply take away the waiting time and see them next. (This is 'queue-jumping to do no harm' and to increase the possibilities of a consultation by enabling the person to be at their best for it).

### 1) Making the environment as anxiety reducing as possible

Waiting is never going to be eliminated and there is great deal that can be done to mitigate the negative impact of waiting by creating the right environment.

Neurodiverse people tend to be more aware of their environment than neurotypical people. They can feel overwhelmed because they are more sensitive to external stimuli, often unable to filter noise and distractions. They can find this exhausting and confusing, not enabling them to be at their best for the consultation.

Whilst a separate quiet room is not always possible, quiet, less busy spaces within the waiting area are more easily creatable.

Many things they talked about as stressful and anxiety creating apply to all patients e.g. Is it kind to make someone ask for a key to toilet? You wouldn't do it in your home, and these are publicly funded premises.

### What would make it better when waiting?

**Queuing was a cause of anxiety** – Suggestions for reducing anxiety at check in included:

- ❖ a ticketing system so people understand exactly what is happening and where they are in the queue
- ❖ Electronic check-in was liked by many and big touch screens helpful
- ❖ Electronic call pads (used in restaurants) were used in one practice which meant the person could go outside, use the toilet etc. This reduced much of the queuing anxiety.

**Running late was a cause of anxiety** – suggestions included:

- ❖ a real time information system with a screen to let you know how late appointments are running
- ❖ guidance about how long to wait before asking if you have been forgotten
- ❖ Would help to have an early/first appointment to reduce waiting time and the numbers of people waiting.

**Visuals help:** Pictures in the waiting area of the staff team, a video that shows what happens, a simple map of where all the rooms are.

## What you said

### Interaction Anxiety

*"will I be heard?"*

*"will I remember everything I want to say?"*

*"I give up if they don't listen" (YP)*

### Anxiety about being believed

*"don't think they believe me"(YP)*

*"they won't believe me because my child doesn't look like they are ill – high pain threshold" (Parent)*

**All liked distraction while waiting** – whether it was their own music, stress toys to take into appointment, books available. Suggestions included:

- ❖ Having fidget toys/ something to stroke that they could take into the appointment/ and their need for sensory support to be understood
- ❖ People found it helpful to listen to their own music or watch YouTube on their phones on accessible Wi-Fi

### The environment can help or hinder

Suggestions included:

- ❖ **Keep the waiting room simple** avoiding rows of chairs, with seating close together and that create the feeling that people were staring. Prefer to have chairs with tables next to a wall so don't have to look at everyone. (not unlike the way cafes and restaurants seat paying customers).
- ❖ **Creating calm** Too much going on can be unhelpful. Suggestions to improve the waiting areas included providing a quiet room or a quiet corner with seats that were non screen facing. People suggested somewhere more private to wait to help with the embarrassment of being different (sweating profusely / tics).
- ❖ **Continuity matters** Continuity is important, and anxiety increases when things change. Signs or maps to help to find rooms help *"my memory doesn't work- they tell me where to go and I get lost because I can't remember, and reception staff are rude"*
- ❖ **Reducing uncertainties and need for more interaction** Need easy access to toilet facilities. Worries were expressed about having to ask for the key, losing the key and being buzzed into the toilet.
- ❖ **Privacy** - A frequently expressed worry was about being judged by other people in the waiting room. This reinforced many's desire for a quiet room/quiet corner/somewhere more private to wait.

## What you said

### Need calm environment

*"I am afraid that I will go into sensory overload as often the lights are very bright. A different waiting room for those with problems with my tics or a sensory friendly"*

### Noise is distressing

*"The noise on the speaker is awful – a sign saying your name may help"*

### Fear of being judged

*"am thinking and will they judge me for engaging in my OCD behaviours or think I'm attention seeking if I start having a panic attack."*

*"conscious about sweating"*

### Continuity matters- change increases anxiety

*"I thought with the phone calls the receptionists would have something standard to follow",*

*it's very difficult if things change, helps to have certainty about what is going to happen, e.g., know the place, know where will sit, how you will be called, everything"*

## 4.5 During the consultation

For a consultation to work well both the clinician and the patient need to be at their best.

**Questions can generate anxiety** - Neurodiverse people tend to think carefully before they speak to give precise answers. Do not rush for a response, it only generates more anxiety (and slows them down). If the question was unexpected, people will need processing time (not saving time by repeating). If you repeat a question, use the identical words or they might think it's a different question.

If you don't get the reply you expect, start by assuming it was not a well-phrased question (if you want detail, don't ask a yes/no question).

**Shared decision making** - Some people shared that they had opinions about their diagnosis/treatment and that the GP didn't listen and dismissed them. There were examples of GPs assuming and not asking. YP expressed a need for the clinicians to be honest and logical.

**Take time** – It is helpful to give people the time to process what you are saying/asking and don't take silence as yes or no. When anxiety is high some people are unable to respond at all *"I go mute – usually nothing comes out"*.

**Existential anxiety** - People also expressed existential anxiety which is present in all patients but is so much greater in people who are neurodiverse. People found it unhelpful when the GP told them the things they were ruling out because it gets interpreted as *"you have it"*.

**Being believed** - anxiety about being believed is particularly high for neurodiverse people. Think about how you could evidence that you believe them. Encourage them to be honest, not say what they think you want to hear. It is worth noting, a few neurodiverse people find pain comforting and significantly under-report it and some may find it difficult to communicate their pain and how they experience it.

**Uncertainty** - Explain two steps ahead everything you are going to do, and why. Be clear. It's analogous to being given directions whilst you are driving; it's not helpful to be told to turn left just at the moment you need to turn. It is much more helpful to understand what is going to happen ahead of it happening.

**Unexpected, unplanned offers** - Offers that might be generous to neurotypical people e.g., *"why don't you pop next door for blood tests now so that you don't need another appointment"* can throw the neurodiverse person into extreme distress. Make it as an offer (in other words, shared decision making). Many people may prefer the anxiety of a second appointment so that they can prepare rather than the extreme stress of the unexpected.

**The 3-person dynamic** - Having parents/ supporters in the consultation and communicating well is very important and was often a cause of

## What you said

### Reducing the unexpected

*"I thought I was going to have my BP checked but then they said they wanted to weigh me – made me anxious and uncomfortable"*.

### Shared decision making

*"I am struggling but perhaps not stating that obviously enough –they don't seem to react or do anything about it. "(YP)*

*"I wish the doctor hadn't talked over me and would have let me say what I think is wrong"(YP)*

*"I didn't say what I wanted to because it was rushed, and I had to repeat myself"*

### Existential anxiety

*"I am stressed, I hope they understand – what happens if they don't "(YP)*

*"not knowing what to do or say, how serious it is "*



concern. Good practice requires clinicians to offer young people the opportunity to speak with them without the parent/carer being present. This can be more complicated for neurodiverse YP. As with other accompanied people, it is important to keep them at the centre of the consultation and not talk about them in their presence.

Suggestions about how to make the 3-person dynamic work better included:

- ❖ Don't challenge what is normal at that age (e.g., challenging why a parent might be there supporting (this came up repeatedly)).
- ❖ Doctors could simply say, "I just need to speak to your parent" if they need to address them separately.
- ❖ Do ask if they are comfortable to see you for part of the consultation without their supporter in the room and explain this is simply standard good practice.
- ❖ Don't speak 'about' the YP in their earshot.
- ❖ Don't talk about the poor services the YP might be receiving from other services in front of them (this increases anxiety).

### Other issues raised

- ❖ Some reported finding it more uncomfortable to be seen by locums. Examples of difficult behaviours included reading notes while the patient was in the room, which made them feel the doctor wasn't good.
- ❖ Pain isn't always shown or described in the same way as for neurotypical people (some find it a comfort). People may experience more pain more often than they are saying.
- ❖ Helpful to ask people what they need: "is there anything else you want to ask us?"
- ❖ Helpful to consider what the patient can see on the screen, which "can be both degrading and inappropriate".
- ❖ Previous medical history can feel like a burden to the patient and discretion is needed about bringing information in inappropriately to every appointment.

### Some factors to consider when using the kindness lens

- ❖ A smile makes you feel you belong (entitlement anxiety).
- ❖ Telling patients that they have the time they need, reduces interaction anxiety.
- ❖ Ask about their communication preferences.
- ❖ Shared decision-making works well (power sharing).
- ❖ Capturing what needs to happen afterwards in a way that works for the patient (record consultation on their phone so they can re-listen later, write down etc).

**Using the Right Conversation Right Time** approach reduces clinicians' anxiety, allows the clinician to understand the real agenda/issues (patient saying what they want) and ensures the patient covers all aspects of their understanding of the issue (not leave things out) as well as focussing the conversation (reducing the time needed). They also have the responsibility to create the conditions for the patient to be at their best.

### During the consultation clinicians worried about:

- ❖ Do I speak to the patient or the carer?
- ❖ Worry that the GP and carer talk more than the patient.
- ❖ Am I phrasing it so they understand?
- ❖ Am I using phrases that can be taken literally?
- ❖ It's difficult making sense of what I am hearing. How can I help them articulate?
- ❖ What would be most helpful for them?

**Clinicians thought the following would help:**

- ❖ The kind of things that are in RCRT guide.
- ❖ Asking people's preferences.
- ❖ Showing they understood the condition.
- ❖ Time (how long it takes depends on the quality of the communication).
- ❖ Checking understanding.
- ❖ Ensuring the advocate didn't get in the way of understanding the patient themselves.



## 4.6 Miscellaneous findings

In this section we address two issues that came up but were beyond the scope of this small piece of research.

### 1) Kindness within the Practice

During this work we heard stories from staff working in practices about the exceptionally positive impact being treated with kindness had on them and their ability to do good work with joy. Developing guiding principles for how to do this and prototyping with some practices was beyond the scope of this piece of work (and we will seek funding to do). We would encourage any practice that was interested in trying to simply bring together mixed groups of staff and share stories of being kind and receiving kindness at work, looking at the patterns and uncover the underlying principles. Then, weekly, ask staff to reflect and share times they saw these being practiced or opportunities to apply them that were missed.

### 2) Building on citizen's expertise

Parents/Carers and YP themselves had lots of expertise about both how to prepare for appointments and then act upon what came up in the consultation. It would benefit everyone if a group could pull together and share some 'tips' of what neurodiverse people and parents/carers have learnt works. For example, tips to reduce the anxiety included: only telling children and YP the day before the appointment and talking through exactly what the process is. This could be a living document - open to anyone to add to - to help prepare what to say, encourage people to do the things that make them feel most at ease. This might include listening to music, bringing fidget toys and using ear defenders to block or cancel noise. Other tips include suggestions that carers and supporters can sometimes add to the discomfort if the YP perceives their actions as fussing.

A library of resources and/or navigation to respected websites where YP can find clear and simple descriptions of common conditions, likely treatment, and outcomes. If such a resource list was being drawn up/adapted, we would of course, strongly encourage you to bring together a group of neurodiverse people of all ages and parents/carers to do this.

## 5. What we learned

### 5.1 Unanticipated outcomes - The Tyranny of the Majority

We approach most of our work from a system's perspective. In systems, the relationship determines the outcome. Our initial hypothesis (based on the literature and our experience of working in the NHS for over 30 years) was that if organisations and services were designed with kindness as an organising principle, the outcome would be better for everyone. It has overlaps/resonances with the contemporary theme of 'Compassionate leadership' but is very different as an organising principle. We are not looking at being kind to patients (a version of Victorian charity to the deserving), but as a relationship between everyone: internally within a practice as well as a mutual relationship between staff and citizens.

Kindness is good for all staff and all patients all the time. It is not something to be brought out when all else fails or in times of stress and overload. It is, as many important, systemic phenomena are, an emergent outcome (of noticing and valuing people for who they are). Thus, if a patient does not experience kindness at reception (or seeing a clinician), the intervention is not to hold the receptionist to account (or send them for training), but to explore how the reception service is organised that means people don't have the time/approach to be kind. Unkind receptionists or clinicians are a symptom of how the service is organised. They are victim, and we don't start by blaming them. It is only once the system is right do we explore whether individuals are unsuited for the role.

We recognised, as the work progressed, that whilst kindness is probably a necessary condition for better outcomes, it is not sufficient. We (both neurotypical) recognised that there was an ideology that shaped how services were designed. It was as if the 'norm' was right and everything outside the norm was a bit of a hassle. Some of these had (slightly grudgingly) to be accommodated, so there was a policy language of 'reasonable adjustment' (Equality Act) – which inherently privileges the 'norm' which further deepens inequality and takes attention away from equity and transformation.

The NHS is deeply engaged in exploring how unearned privilege leads to poor outcomes for many. This holds for women (NHS wage differential is 37%) and BME staff (differential in promotions, referrals to GMC) and patients (differential access to hip replacements for socio-economic groups). Thus, many people "live in a world that isn't built for me". Most organisational protocols/procedures are designed by and for the majority.

Medicine is adapting. Now physicians know if their patient is a woman, they should anticipate different symptoms as indicators of a heart attack than if a man. This is moving to equity; one size does not fit all. It is not 'reasonable adjustment'. An exemplar is Intermountain Healthcare in the US (widely seen as one of the best healthcare systems in the world):

*When they introduce new ways of working, new protocols, new ways of treating people they do not spend ages working it out. They spend a couple of weeks with a small group of experts working it out and the medical director says this is our new way of treating someone and I will fire anyone of you who follows this for every patient.*

*He says what happens is that every week we look at the records of patients who needed that treatment and we will review with you whether you followed the protocol. There are three options:*

- 1) You didn't follow the rules because you improved on the protocol. You will be praised, and we will change the protocol, and all follow the new one.*
- 2) You didn't follow the protocol because the patient was unique i.e. there may be additional health conditions or something else that was going on for them. The best way of treating them wasn't the*

*protocol way for this person. There was something else going on and you not following the protocol is what we pay you lots of money for. This is what we regard as being a good doctor.*

3) *And the third option is you should have followed the protocol but didn't for your own convenience...and we will slap your wrists*

Each time they check it out they show that they know that patients are unique, and one protocol is rarely ever right for absolutely everyone.

We realised the need for a similar process for organisational processes. Instead of a single process, **we need conditional pathways** e.g. If the person is neurodiverse (or some other differential characteristic) we do y, not x. This is not favouritism or 'reasonable adjustment' (implying the norm is still 'orthodox') but a genuine recognition of legitimate diversity.

Once we became aware of it, unsurprisingly, we could see it in many other situations. At its heart, the NHS privileges physical conditions and fixable conditions (i.e., those things that can be diagnosed and treated - preferably in a one-off). For long term conditions (where the citizen needs to come to terms with it and change their behaviour) the primary intervention is still seeing a clinician for a bespoke time slot (despite it not being able to address the patients core needs). Similarly, Mental Health (MH) is approached through a primarily physical model (e.g. no of places where an annual check-up with the GP is seen as the solution to the 20-year disparity in lifespan for people with Serious Mental Illness (SMI).

We need multiple protocols, not single pathways.

## 5.2 Unanticipated outcomes – learning from the process

**All participants who gave their time to take part in the inquiry were personally invited by people they were in relationship with.**

Neurodiverse YP, adults, carers, parents, and supporters were invited by Shelley Russell the Autism Project Manager (West Yorkshire and Harrogate Health and Care Partnership). Likewise, although several practices were invited using a communications and marketing approach the practice that came forward was a practice who had existing relationships with the Altogether Better team.

- **Engaging people takes time and care**

The importance of spending time engaging and involving both neurodiverse young people and staff in the practices should not be underestimated. This is not an admin exercise – it is an example of host leadership. Time was invested in personally speaking to people in the practice and with the neurodiverse young people, adults, and carers.

- **Creating the conditions for people to be at their best**

Actively creating the conditions for people to be able to be at their best in the workshops and interviews was a large part of the success of this work. This started with the invitations, making sure invitations were clear, welcoming, and reassuring and asked the question what would help you to contribute.

- **Applying the if/then rule**

When we found out that one neurodiverse young person was uncomfortable with joining a group workshop, we applied the if/then rule and asked what would work for that person. The request was for a

telephone call with the young person and her parent. The richness of the information was beyond our expectations.

- **Finding the people who care**

We discovered that the practices who came forward came forward not only because it was the right thing to do but because they had personal reasons. Within the small staff community within a practice one GP was neurodiverse, one of the managers children had been recently diagnosed, and other staff had family members who were neurodiverse. Finding people who had a personal stake in making things better added richness to the work.

- **The insights of 'boundroids'**

Boundroid is a term used to describe people whose working lives are spent working at the boundaries between parts of the system. They understand what happens in systems but are not a part of them, having a foot in more than one camp. Neither of the Altogether Better facilitators brought experience of neurodiversity and a consequence was being able to see things with fresh eyes because they saw the world differently. This reinforces our view of the importance of diverse perspectives.

## 6. Conclusion

We believe that this work could be a significant first step in a research programme proposal which seeks to reframe service delivery towards providing more caring, compassionate and inclusive services which will help to reduce health inequalities and **make services better for everyone.**

## Annex 7.1 Building blocks

We have drawn on several building blocks to support this work:

### **When doctors and patients talk**

[https://www.health.org.uk/publications/when-doctors-and-patients-talk-making-sense-of-the-consultation?gclid=Cj0KQCQiA0fr\\_BRDaARIsAABw4EvrVjf04zSCyLmwsVx3nMuJlBFDoqtLEfteW8waVUIt4g0-uX\\_VOvMaAlAnEALw\\_wcB](https://www.health.org.uk/publications/when-doctors-and-patients-talk-making-sense-of-the-consultation?gclid=Cj0KQCQiA0fr_BRDaARIsAABw4EvrVjf04zSCyLmwsVx3nMuJlBFDoqtLEfteW8waVUIt4g0-uX_VOvMaAlAnEALw_wcB)

Original research done for The Health Foundation showed that the dynamic between doctors and patients determines the outcome, there are unspoken etiquettes that get in the way and when driven by fear (on both sides), this leads to poor outcomes (Martin Fischer and Gill Ereaut (June 2012).

### **The Right Conversation Right Time**

<https://www.altogetherbetter.org.uk/allresources/2018/9/7/right-conversation-at-the-right-time-appointment-guide>

Applied research and PDSA cycles resulted in the coproduction of simple devices which allow the invisible to become visible and improve both the quality of the consultation and the associated outcomes.

### **Delivering Appropriate Services for All (Authors: Dr Julian Pratt and Martin Fischer for DoH)**

Work for the Department of Health on improving services for BAME people brought together mixed groups of clinicians and BAME citizens across the country and developed a set of beliefs and guiding principles that when applied in GP practices, improved outcomes for everyone.

### **Paediatrics: consult with the patient, not just the parent**

Work done with Young People, Parents and Paediatricians and specialist nurses on 3 party consultations led to the development of online training resources and interventions in paediatric departments in London.

### **Collaborative Practice Evidence**

<https://www.altogetherbetter.org.uk/collaborative-practice>

Work with organisations to become more inclusive and compassionate systemically (i.e., building care, kindness, and compassion into the way the organisation thinks and acts and not the property of having/training the 'right' individuals).

## 8. More about our team

**Altogether Better** has been part of the NHS family since 2008. Our staff and associates bring experience and diverse perspectives from a broad range of backgrounds. Our team has worked in general practice and primary care, social care, the voluntary sector and with people in communities over the last 30 years.

**Fischer Associates** - After 17 years at the Kings Fund where he set up and led the systems leadership group, Martin set up as an independent organisational/management development consultant. His work includes leadership development, organisational development, and whole system change. His work brings people together in conversations about what matters and what makes a difference. They begin seeing the world together, creating solutions that neither could achieve alone.

**Working together we** have designed and led leadership development at all levels within the NHS (from Experienced CEOs and medical directors to junior doctors and new management trainees) and have expertise in delivering bespoke programmes (e.g., for trusts, STP CEOs, and practice managers in a CCG). Much of our work is supporting real time change (organisational development) in both primary and secondary care. We have facilitated the leadership of STPs and aspirant ICSs and have an extensive track record in organising networks to add value. We bring expertise in systems approaches and use this to support organisations to adapt and evolve.

Using a systems model of organisation development and an evidenced-base health champion approach to citizen involvement, Altogether Better has prototyped and scaled a radical system intervention which slowly, gently, and subversively allows the system and the population it serves to co-evolve. This award-winning approach, which we call Collaborative Practice, has brought us national and international recognition. With funding from the Canadian Government, Collaborative Practice is being tested across several sites in Ontario as their approach to social prescribing.

We are well connected to developments around the world. We not only work internationally, we also have led study tours (for presidents of Royal Colleges, for CEOs or aspiring leaders) to places like South Africa, India, Vietnam, Holland, and the USA where we can see both new approaches and emerging trends.

### Creating and sharing best practice

We are Faculty members of the NHS Leadership Academy, sit on the National Social Prescribing Steering Group and our work has been featured as a model of innovation and good practice in publications by The Kings Fund, the Health Foundation, HSJ, Innovation Hub, RSA, and others. Our work was highlighted as best practice in NHS England's GP Five Year Forward View.

Working nationally, we've not only created best practice, but we've seen it and can bring this to the work. We recognise that time is short and so we bring together evidence about what's needed and the tools to reduce appointments and improve outcomes.

We're very good at engaging those working in general practice (not just GPs). We understand that teams can feel pushed around, reluctant, and jaded. We bring experience, stories and a compelling vision that gets them engaged and energised. [Find out more at www.altogetherbetter.org.uk](http://www.altogetherbetter.org.uk).

Report authors: Martin Fischer(Fischer Associates) & Alyson McGregor (Altogether Better) October 2021