

HTP Learning Disability & Autism Focus Group

Held on Tuesday 14th November 2023
 18:30 – 20:30hrs via MS Teams

QUESTIONS/ANSWERS

PART 1	<p style="text-align: center;"><u>HTP Learning Disability & Autism Focus Group</u></p> <p>SATH members of staff responding to public questions</p> <p>Gareth Banks - (GB) Regional Director at AHR Julia Clarke – (JC) Director of Public Participation Kerry Davies – (KD) Youth Worker on the Childrens Ward at PRH Adam Ellis Mogan – (AEM) Technical Lead for the HTP Kirsty France – (KF) Acute Liaison Nurse for L&D Marilyn Jones – (MJ) Independent Autism Advocate Martin Jones – (MJ) Art Insight Tom Jones – (TJ) Implementation Lead for HTP Hannah Morris – (HM) Head of Public Participation Matthew Neal – (MN) Director of HTP Chloe North – (CN) Art Insight Julia Plant – (JP) Divisional Director for Women & Children Ed Rysdale – (ER) Emergency Medicine Consultant and Clinical Lead for HTP David Sandbach - (DS) Joint Health Overview & Scrutiny Committee (Observer) Ruth Smith – (RS) Lead for Patient Experience Elaine Thomas – (ET) Clinical Lead for Acute Liaisons Rachel Webster - (RW) HTP Nursing, Midwifery and AHP Lead</p> <p><u>Q&A's FOLLOWING PRESENTATION</u></p> <p><i>Q: What will the lighting be like in high traffic areas – wherever possible it should be low level</i></p> <p>A: (GB) – There's not one solution that fits all. Generally, the lighting levels will probably be bright, but then there'll be quieter pockets for individuals who prefer lower levels of light. This is not a solution that is fully formulated yet, but these are options that we can include in the design. We can consider the acoustic environment, reverberation times and the key elements of “retreat” spaces to make them work for everybody. This will be a key focus of how we treat those spaces.</p>

A: (MJ) – We are looking out for opportunities to bring in spaces where the lighting can be more comfortable. In some areas within the hospital there is a clinical requirement that lighting has to be bright. However, we are also looking into ways of making it as quiet as possible because that was raised in some of our consultations that noise can be one of the most anxiety causing and or confusion causing things in hospitals.

Q: *Will there be specific retreat areas from bright lights, busyness? and accessible for wheelchair users- some of the pods and smaller spaces we've seen would not be easily accessible (those who have learning difficulties, disabled and autistic needs may also be wheelchair users). What available spaces specifically for them will there be?*

A: (GB) – We will make sure those spaces are fully accessible. There will be some fixed seating and also spaces so that if you're in a wheelchair, you'll be able to pull your wheelchair in and utilise the space in the same way.

Q: *There's nothing on the ceiling when you're lying down, what will you see on the ceiling and what fabric will be used for the chairs? Will there be chairs that move (such as safety rocks) for vestibular movement.*

A: (GB) – Absolutely agree that ceilings are a critical part of the design. There are areas where you're going to spend a lot of time on your back that we need to think about how we include some features. We can use different coloured ceiling tiles, and there are other illustrations that we have where ceilings feature more heavily. It's not that we're not doing anything we just haven't included that element within this presentation. Regarding the fabrics used, we need to be mindful of durability and of infection control requirements as well as comfort etc. All those things will factor in as part of that as we get into the detailed design at that level, which will be much later in the process.

Q: *Will the floors be shiny?*

A: (GB) - We're proposing using vinyl generally.

A: (RS) - We don't use shiny floors within the Trust, the recommended standard is matt.

A: (JC) - We will be having other focus group sessions like this. Again, in due course we will start to look at materials, fabrics and flooring as we develop the design plans.

Q: *Have you considered floor noise levels from traffic, noise levels from reception areas, telephone areas etc. Any sort of safe retreat needs to be away from reception areas wherever possible.*

A: (GB) - There are different things we can do. There are general things we can do to dampen background noise, for instance, in the main entrance area, we've got the concrete on one side which is going to reflect sound, although it is quite heavily modelled which will break the sound up. On the other side, we can use sound absorbing fabrics behind wooden baffles at high level to take that reverberation time down in those areas. Where we've got vinyl, this can be cushioned vinyl subject to durability etc to reduce noise. There are definitely things that we intend to do to modify that acoustic environment and also localised things that can be done to further acoustic separation, including the use of booths. We are not just focusing on the visual environment, but also the acoustic environment.

Q: *Can you give information on toilet facilities?*

A: (GB) – There are toilet facilities throughout the public spaces. We do have a Changing Places facility which will be just off the main entrance. We don't propose to replicate this on other floors, but there will be fully accessible and assisted toilets on each floor, both in communal areas and within the wards.

Q: *Will there be side entrances and where will they be located?*

A: (GB) - If you're visiting the hospital for the first time there needs to be very clear points when you park your car or get off the bus so that you know where to head. I think for users of the hospital at the moment it can be a little bit confusing as to where to enter. So, in the new design all types of areas will be fully signed at the main entrance. However, we know there may be patients where the main entrance environment does not suit them. Potentially, if you were a patient attending an appointment you could pre-arrange to use that entrance and would be able to press a button and speak to somebody who would then let you in. This side entrance however, would not be geared up to receiving large numbers of people directly.

Q: *How will the lift be designed to be softened; a lift can be a scary place for some as it's a small, confined space?*

A: (GB) - The lifts are split into two different types. There will be standard passenger lifts and there are certain requirements for accessibility that go with those in terms of whether a user is wheelchair bound or semi-able. There will also be larger lifts which are designed as bed lifts, but to improve the service level they will be available to the public. So, we will have one dedicated lift which will be used for clinical transfers – which is important from a patient dignity perspective. There is also a second large lift, which is provided in the bank of public lifts which in effect acts as our standby lift if the main bed lift is unavailable, which covers the opportunity to get patients in beds moved throughout the building. Obviously, the finishes of those lifts have got to be

durable if they're taking beds. There will be an opportunity to look at the detailed design of those lifts to accommodate some of those issues.

Comment: (JS from Parent Care in T&W who represent families with children aged between 0-25years) – With regard to the disability signs on toilet doors, not every disability involves a wheelchair. Also, we've just done some work with leisure services locally in Telford and Wrekin around hidden disabilities and we'd like to talk to you about that and the use of interactive notice boards. We've had conversations with families over the last few months around USB charging points around the hospital seating areas and it would be useful to be able charge up devices and communication devices.

Arts projects – we will be doing some work with short breaks locally and wonder if there was any opportunity to incorporate some of that into the artwork going up into the hospital. Local parents and carers have been fundraising for community communication boards which have been created for leisure centres, local parks, and schools in Telford and it would also be fantastic if we could get these into the hospital as well.

Q: *Will inpatients be able to control their lighting?*

A: (GB) - When we focus on the bedrooms, there will be a lot of discussion around the degree of control, colour palette and materials, etc, for those individual spaces. I don't know about lighting control options at the moment but certainly we can put that on our list of things to consider.

Q: *Will there be handrails in the corridors?*

A: (GB) - I think we're all familiar with the grey protective heavy wall bumpers that go down hospital corridors which give a very institutional feel and I find it quite unwelcoming. So, I think we need to look at how we treat handrails and areas where patients do need support. So that's a piece of work that we're going to be looking at over the next couple of weeks and will look at possible solutions.

Q: *When a child gets dysregulated, they might want a certain space to enable them to go to retreat to. So, it might even be a small tent or a small little pod, and it's somewhere where they've got their own space that is personal to them. So maybe somewhere in the hospital, perhaps the corner of a room or somewhere where they can go, and they can escape that environment.*

A: (GB) - I think that's something we could highlight on a sensory map by highlighting safe spaces. So, a visitor with a child with those needs could refer to a sensory map in the main entrance and identify retreats which would support need.

A: (CN) - I think the sensory map is also something that could be potentially uploaded onto a website or portal so that people have access before they've even got to the hospital as another way of reassuring and helping people know the direction that they want to travel in.

A: (TJ) - The clinical team came up with the design team to include a sensory room within the paediatric floor. That would be a space that could possibly be accessed, discussions are ongoing.

Q: *Will hospital staff receive training around supporting adults with learning disabilities and autism, particularly communication and relaying information?*

A: (ET) - The acute liaison nurses do workshops within the hospital on each site, these are open for all staff and will cover learning disability awareness training, communications, and some of the barriers to accessing health. That is provided at Shrewsbury and Telford Trust and is ongoing so that the Oliver McGowan training is available to all.

A: (MJ) - I deliver autism education sessions with Midlands Partnership University NHS Foundation Trust (MPUFT) which I have done for about five years now, so that offer is available for interested staff.

A: (RS) - As the building designs are finished, we can then look at developing patient videos for wayfinding which should help reduce some of that anxiety. Next year we are bringing an autism awareness bus on-site, which is for our staff to give them an increased awareness around what it's like to experience and live with autism.

ACTION 1

ACTION: Ruth Smith to contact Thomas V (attendee) re autism bus

A: (KF) – From the Learning Disability Nurses perspective and Liaison Nurses, we are planning to set up ward champions and department champions for patients with learning disabilities. It will work very much in the same way as a Link Nurse might currently do for tissue viability, oncology, or any of these specialist areas. We're also going to be having those link workers within departments so they can champion the disability care provided. We're also looking at setting up some very bespoke training for departments. We have some training planned with the theatre departments around learning disability service users' accessing operations, day surgery, emergencies so that we can be better prepared in terms of maintaining safety and reducing trauma.

Comment: There are currently several young people with learning disabilities who are not able to access the hospital because of anxiety around the way things are set up. They are not able to access things as simple as blood taking or having scans and that is a significant concern for our community at the moment. I do think that there is an opportunity when this transformation is being done to think about and maybe to talk to those families to think about how the hospital environment could be potentially arranged that might help those young

	<p>people or those families to be able to access basic healthcare that the rest of us take for granted.</p> <p>The other thing is we talk about training and it's really great that all that training is happening, but actually, particularly for those with learning disabilities and for those who are autistic, one of the most important things is familiarity with the environment and to make that environment available to people to come and engage with on a regular basis, particularly if we know that they're young people who are going to have lifelong needs. It isn't just about training the staff; it's about building the experience and confidence of the community within that environment and within the staff as well. It is important that that's acknowledged and discussed at some point.</p> <p>A: (ER) – It's important that we bring this up from a HTP point of view, but this isn't particular to HTP, but HTP may be a lever to generate change, but we need to have conversations going on which will see wider changes happen over the next couple of years.</p> <p>ACTION 2 Action: Ruth Smith to develop a Learning Disabilities and Autism Patient Experience Group through the Patient Experience team to develop processes and support for people with LD and autism, including wayfinding videos</p> <p><i>Q: How do you communicate with staff without words, that you need support - maybe a sunflower lanyard or an autism card? This is important because someone who is autistic may find it difficult to communicate that they need support.</i></p> <p>ACTION 3 ACTION: Ruth Smith to take this work forward through the Learning Disabilities and Autism Patient Experience Group as part of the Trust's patient experience work (not as part of HTP).</p> <p><i>Q: In learning disability and autism many people will present with behaviours which are challenging when they are anxious, including self-injury, e.g., hitting head with force against walls, floors, and doors. Will the spaces you discuss with the service users to retreat to take this into account with alterations to the space furniture to reduce risk of injury, e.g., using rounded edges and walls with bounce backs?</i></p> <p>A: (GB) - Yes, I think it's important that we recognise that there won't be one shelter space that would meet all needs. So, I think again it's important that we identify exactly where those retreat spaces are and that we've got appropriate furniture etc.. We're not at the end of this process, we're at the start and this is all valuable input that we can take account of and feed back to you over the next few months to demonstrate how we're incorporating feedback received.</p>
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Q: With regards to sensory rooms capable and robust environments, have occupational therapists with sensory awareness training been involved at this point?

A: (GB) - At present we have identified spaces, but we've not commenced the detailed briefing of them. We will have all relevant professionals involved in that design process to make sure that they work for the benefit of everybody.

Q: What about the users who are vision impaired?

A: (GB) - Vision impaired is a wide spectrum. I need to make sure that people can read suitable information. Certainly, I'd expect us to be taking on board that cohort of users and making sure that the building is navigable.

Comment: (MJ) - What really helps is to do mock ups of the things that you're proposing and see how they work in the space. That would be something that we'd like to do, and this would be monitored so that we can work on how people are responding to them in the space.

Comment: (KB) - We already have links with Visually Impaired Groups in Shropshire and Telford & Wrekin So again, if anybody has any connections in the community that you think would be helpful for us, in advance of any future meetings, please just reach out and let the engagement team know at sath.engagement@nhs.net and we'd be happy to do that.

Q: Have the speech and language colleagues been spoken to, to advise the design team on suitable information symbols?

A: (GB) -There will probably be a dedicated workshop where we explore a range of symbols and options to find a solution that works for as many people as possible. I'm not sure whether there is one single solution that will work for absolutely everybody and we will need to consider whether we need to do some dual iconography, but it's certainly a key part of the work that we're going to be doing as we develop the scheme.

A: (KF) – Makaton are the symbols most frequently used in special education schools, and it's something that young people will be recognising more and more. So, I think that Makaton should be considered, particularly in paediatric settings, because these are the symbols that are going to be used every day at school and in the Picture Exchange Communication System (PECS). Also, within school environments they'll use Makaton symbols to direct students around schools, it would give that consistency of approach to people, particularly children and young people who need that consistency and predictability.

Q: What about smells and aromatherapy in the hospital?

A: (KF) - My concern around aromatherapy is that some aromatherapy oils can interact with medications and with people's sensory systems in a negative way.

Also, things like respiratory conditions can be triggered by aromatherapy oils. I can understand that the smells of the hospital can be upsetting for people with sensory regulation difficulties, so having those highlighted areas of areas to avoid would be useful.

Q: I struggle with taking my son, who has ASD, severe learning difficulties and epilepsy to outpatient appointments. He does not understand the need to wait, etc and it can often cause considerable stress for him and me, a sensory room for ASD around children's outpatients or wards would be so beneficial.

A: (GB) - I think there's a whole range of things we can look at, at this stage we can identify opportunities and then I think as a group we can agree how we allocate those types of spaces as there's still time to influence that.

A: (JP) - The paediatricians obviously highlight any special needs in their referral letter, so the GP needs to ensure that they make any special needs very clear on the referral. Also, children and young people may be under a community paediatrician, and they can do the same. We work closely with our community colleagues.

A: (JC) - If there is something that provides a particularly stressful situation, please get the GP to mention it in the referral letter because if they do, then we may be able to do something about it, but if they don't then we won't be aware and will not be able to make any advance accommodations.

A: (KF) - From an adult perspective, we recommend hospital passports are utilised and shared with the hospital prior to the appointment whether they are an e-mail or through ourselves as liaison nurses, we would then advocate for reasonable adjustments such as longer appointment times or reducing wait times. It's about those reasonable adjustments being put into place.

Q: I know many autistic adults who would struggle with a room full of children. If there's going to be a sensory required space, there perhaps needs to be somewhere that is for adults only and child free also.

A: (GB) - There's a dedicated sensory room within the paediatric children's ward, which has just been included. With the sensory map we can identify areas which are more adult-orientated and there can still be quiet spaces within those adult oriented spaces. We can also provide more children-orientated spaces. Across the building there are opportunities for us to include those spaces in different directions. We don't just have one waiting area, we've obviously also got the cafe area which gives us further opportunities, spaces in the atrium and space that we can use. I think there's opportunities, the challenge is identifying those and then allocating them appropriately.

One of the key improvements that we're making as part of the ED works is we've got split adult and child waiting areas now and we need to balance the need for space against the need for clinical observation on those spaces. I think the spaces are sufficiently large that we can create areas within those spaces using slightly different approaches to materials and textures.

Q: I think the difficulty that we've had is not just about the person when they are really dysregulated and anxious in an environment, it's also the effect that their anxious behaviour has on the other poorly people in that environment as well. So, in the cases where we've supported most recently, it served the purpose of keeping other people safe.

A: (ER) - Having a separate room for a dysregulated patient in a waiting area is tricky because generally the patient will need to be in an area that's observable by clinical staff. There are safety and security issues that have to be paramount. There will be a children's mental health crisis room in the ED, which hasn't been designed yet. There will be a single room at PRH and at RSH there will be 3 rooms, 2 for adults and 1 children's room for patients with mental health issues. The rooms can be dual purpose, but there's still got to be some work around that. The children's area will be separated from the adult area and will be designed differently.

A: (JC) - We recognise that we need to try to meet the needs of the patients that are presenting in ED, but that has to be against a balance of giving them safe clinical care. We are trying to find some possible solutions that meet both of those requirements, but clinical safety will always take priority.

Q: There is a big difference between mental health and disability, if the rooms are going to be labelled "mental health" rooms from the outset, that takes away usability for other vulnerable groups of people. I think that it needs to be identified that they're multipurpose rooms rather than specifically for mental health.

A: (ER) - We haven't said there multi use yet and this is what the focus group may be able do. At the moment they are designed as mental health rooms, but one of the possibilities from today is, could it be? I'm not saying it will be, but your points are well made, and it will be something we look at as part of the process.

ACTION 4

ACTION: Design team to consider safe rooms that could be multi-purpose i.e., for patients with mental health issues and dysregulated patients who need calm environment