NDTi Sensory Seminar

**Simon:** [00:00:00] So welcome everyone to this webinar on supporting autistic people to flourish at home and beyond, just to introduce myself, my name is Simon Williams and I'm the Director of Social Care and Improvements, and sort of head up the Care and Health Improvement programme. And the first task I have is I'm absolutely delighted to introduce Councillor Hensman to, you all know councillor Hensman has been a councillor for Braintree district council for Braintree Central and Beckers Green since 2015.

And. It's fair to say. He's a very active board councillor in his own rights and has been very active on local issues, such as accessible public toilets and making sure that the environment is clean and [00:01:00] it's a free so, absolutely great Andrew, to have you in your kind of role as a councillor, but we're particularly glad to have you with us because you've been a bit of a trailblazer in, being very open about, being someone with autism and being a very successful and valued councillor.

And in an addition of First, which is our local government association magazine. There was an article there about, how Andrew has been on that journey. Some of the challenges Andrew's faced, but what has been, I was particularly pleased to read about is how much Andrew is valued by his fellow councillors and his leader.

You're clearly valued by your constituents, Andrew. Cause I voted you in again in 2019, and an absolute kind of inspiration to people [00:02:00] that show. How it supports, people with all sorts of disabilities, including autism can be in public life and how all sorts of people can become councillors. So I'm absolutely delighted to introduce you, Andrew.

And I'm going to hand over to you now.

**Andrew:** Oh, thank you, Simon. I don't think I need to do my introductions because you pretty much done it all, but here it goes. So welcome everyone to this webinar on considering and meeting the sensory needs of autistic people in housing. This report has been produced by the national development team for inclusion.

The NDTi, one of the LGAs key partners in developing support for councils to improve their support for autistic people. And we are delighted that Jill Corbyn and Chris Memmott, who are associates from the NDTi have agreed to tell us more about this report today. I'm particularly pleased that this [00:03:00] report has been commissioned by the jointly managed LGA and ADASS Care and Health Improvement Programme CHIP because I'm autistic myself and recognize some of the sensory differences that Jill and Chris are going to tell you about while I'm praying to be a councillor as an autistic person, because I'm accepted for what I can contribute seeing beyond my autism.

And I've had some fantastic support in undertaking this role from Braintree district council. This has made it possible for me to have become exposed chair this year and just shows you what the right support can lead to for someone who is autistic like me, who knows where it goes from here, mentioned autism and many will think that it is limited to children.

These children with autism grow up to be adults with Autism. Recently high functioning adults have gained widespread publicity because the BBC has Chris Packham ITV has an Heggerty. Well, the LGA has me [00:04:00] and I'm immensely privileged to have been given this opportunity to be with you all today. Coming a long way since I did my article with First magazine three years ago.

Can you believe it? My thanks. Therefore, go to Rachel, Frankie and the team for working hard, supporting me behind the scenes, setting this up and then making this possible. No mean feat. I can tell you. Housing is one of my passions and I have done a lot of work with Essex county council on trying to help them understand the needs of autistic people locally.

During this time, as it's kind of canceled, changed how it works, and Nate takes an all age approach in both their commissioning and partnership working, perhaps something others could learn from. I'm sure this report will be in fantastic condition to the information councils can draw on when developing housing I'm really pleased.

The LGA is supporting this webinar just after the publication of the government's new national strategy for autism, autistic children, young people and [00:05:00] adults, which is the next five-year strategy to follow on from the autism act 2009, a groundbreaking piece of legislation in itself. I know council staff will be working through the strategy at the moment, thinking how they can respond and improve life for autistic people.

And this report I'm sure will help this work. As a mental health champion. It brings district council. I include all disabilities. Then she toilets and especially neurological conditions like autism as part of this. So I look at hidden disabilities, invisible disabilities, because as they say, not all disabilities are visible.

To go off on a slight tangent. It is encephalitus awareness week. The only reason I mentioned this is because it's survivors present strikingly similar to autism. I hope that what we gain from today can be applied as easily to other neurological conditions like this as they will for autism. Now [00:06:00] before I hand over to Simon Williams from chip, I need to let you know that we have had a great deal of interest in this webinar.

And so given the large numbers, we will be muting the audience with cameras off, please, whilst the presenters, Jill and Chris tell you about the reports. We'll have a question and answer session at the end of the webinar. So do please add your questions to the question and answer chat option as we go along.

We will circulate the presentation and the recording after the webinar. And we will also circulate a written up question and answer document. If there are more questions asked, then we can answer at the end of the webinar, we'll also have a short break before 3:00 PM and the webinar will last a maximum of two hours.

So best I get on with it. So anyway, housekeeping over with, you'll be pleased to know that that's it from me for now over to you Simon, to tell us more about how this [00:07:00] report came about and to introduce our amazing speakers.

**Simon:** Thank you very much, Andrew. So before I introduce Jill and Chris from and NDTI, I'm going to say this a little bit about why we in CHIP, commissioner's work.

What is CHIP first of all, it's a Care and Health Improvement Programme, which, is essentially managed by the LGA and ADASS, and is designed to support local authorities in improving the way in which they deliver and commission support for people who draw on social care. And clearly within that, support in the area of learning disabilities and autism, autism is a really, really important element.

Why don't we commission the work essentially because in recent years, a greater understanding of people with autism has emerged. One of the most important findings [00:08:00] is that most autistic people have sensory differences compared to most non autistic people. If you're autistic, you maybe over-sensitive or under sensitive to specific sights sounds, smells or textures.

This can be positive, but can also cause distress or comfort. So we listened to autistic people and other people around how environments can add to their distress and that when people moved into the community or lived in the community, not enough consideration was given to the impact of inappropriate environments on autistic people as they come out of the hospital.

So enabling autistic people to live well, it doesn't just mean improving environments in social care or hospital settings, but also considering a whole range of environments in everyday places. So one example would be from [00:09:00] busy supermarkets or the places where we would all normally go. Because councils are leaders in developing places and all kinds of settings in which people kind of live councils are really well placed to play a key role in making changes.

And if I'm thinking of some examples about how houses are kind of designed in the first place, or how common are living, maybe designs, all of these things, if with good design routes and right at the outsets can help to reduce or even eliminate distress that can be caused to people. So that's why we feel from CHIP from because we are based within the local government association, we felt it is particularly important to commission this work.

 It's also important to remember. There's autistic people working for councillors, and we're [00:10:00] really grateful to Andrew for agreeing to share this webinar. And just need to remember that there's a lot more to do. So that's why, our programme CHIP, decided to commission this work and I'm really looking forward to hearing the results of the work from Jill and Chris.

So I'm going to go on to introduce them now. From the national development team for inclusion or NDTi and has worked in involvement and advocacy for over 10 years. She's passionate about supporting people to know their rights and be involved in driving change. She's skilled in facilitating workshops and supporting participants to find solutions to barriers and try on new ways of working. Jill's most recent role was working as head of involvement at Brandon trust, a not for profit provider and here she co-produced and established an involvement framework and strategy to ensure that the voice of [00:11:00] people supported is heard in decisions throughout the organization.

Before that role in the Brandon trust Jill workedat Macmillan, cancer support, facilitating carer and patient involvement in service review and redesign. And she partnered with community organizations to design and develop these potent solutions to health equality, inequalities. That was great to have you with us Jill.

And then, Chris is also an associate of NDTI and and an expert by experience who works on the Care Education and Treatment Review Programme across the Southeast and Southwest. In this associate role, Chris uses his autistic lived experience to provide development support and the highly skilled training to staff teams.

He also undertakes environmental assessments of different health care settings. And since on a regional quality assurance board for two regions. Outside of his [00:12:00] work with NDTi, Chris is also a national advisor trainer and respite carer. He has an academic background in psychology and counseling, and has worked for many years with struggling autistic people, in both school and home.

So Jill and Chris without further ado. Absolutely great to have you with us. I'm going to hand over to you now.

**Jill:** Wonderful. Thanks so much for the introduction. I felt like, im on, this is your life or something like that. I don't usually get such a big intro. So I really appreciate it. And thanks so much to, the LJ, especially, Simon, thanks for the introduction.

Rachel Carter really, really need to mention for her coordinating and getting us this far and Andrew, it's been, yeah, it's been a real pleasure to work along scientists. I think. Thanks so much for joining and partnering with us on this, this webinar. , so I, I'm gonna, if I'll move us on to the next slide, please, Frankie.[00:13:00]

I'm just going to give a little bit of a background around, how this bit of work came about, while and NDTI were involved in what are our kind of relevant experiences. And then we're going to talk more about autism an essentially social processing difference, and link that specifically to housing.

It's some kind of key and clear recommendations that I hope will be, be useful. So I'm gonna start with kind of, some of the background and, and how the autism programme developed at NDTI. So as Simons introduction said I really have a background in working with people with a learning disability, and I was supporting the Care and Treatment Review Programme as part of transforming care.

So, I'm sure many of you are familiar with it, but it's essentially, it's, it's a program. That reviews, the care and treatment of people who were in hospital or at risk of admission. So I've those people here have a [00:14:00] learning disability or are autistic. And the program really started out as a learning disability program.

And we were support an expert by experience across the Southeast and Southwest. And what we've saw in the program is a lot of people with learning disability are discharged from hospital. And we were seeing increasing numbers of autistic people, being admitted and being recognized. As, as needing additional support or as being in hospital or risk of admission.

So my team sought to recruit some autistic experts by experience, and we found that some of those, experts physically couldn't get into the hospital. Because the sensory environment in hospital was so challenging. And we started asking questions, like, why, why is that? I never understood autism as a sensory processing difference.

I always thought it was kind of behavioral. That's what I'd learn't. And we, we got commissioned to do some sensory environment reviews in hospitals. So we started walking around the hospitals and finding out what is the [00:15:00] environment like? What are the big challenges? are there any areas that work well, what practice can we share?

And, and that work really, really developed. So we've done a lot of in-patient sensory environment reviews. We've done some, a report with the CAMS mental health task force. I called it the rocket science to report that, that collates, that learning, and looks at inpatient services.

We've worked with the national autism team around sensory friendly wards and, pulling out some, some key principles and recommendations for improving the sensory environment in hospitals. But we're really conscious that so much of our work was, , inpatient based. We, we know from this work that hospitals are not a good, place for autistic people.

And often people seem to be ending up in hospital because, because we imagine their housing was problematic for them or that support wasnt right. So [00:16:00] we really wanted to support people to flourish at home. And we thought that we could bring some of the learning that we had from the sensory environments in hospitals, into, into the community and, and develop this to paper based, around the experience of a lot of autistic people.

So this is autistic land, so I'm autistic. Chris is autistic, the, we had some, yeah, a whole team of people who were involved in contributing to this paper. And a lot of people who participated and shared their experience and we've included some quotes in this presentation. We also had some really brilliant contributions and from some autistic artists, they're all credited at the end and we're including links to the report where you can go in and see all of the artwork and read the full report.

So that's, that's a little bit of background to how we got here. And this, this slide, I'm just [00:17:00] gonna, gonna read out the comment from Ruth. So Ruth was one of the people who participated and they said, being out in the world is frequently exhausting. So being able to come home to a space that's relaxing and reviving is essential to me.

So we met like for all of us, I think. home is really, really important. and in the next slides, Chris is going to talk to us more about, how for autistic people. We literally have a different sensory processing, style, like our, our experience of the world is literally different, than, than for neurotypical people.

So it's really, really important that we were aware of that difference and that we considered the sensory needs of autistic people, and really hope that this paper and this webinar will give you some hints and tips about how you can start to do that. How you can consider that in support, in planning, in [00:18:00] design, in decor, and yeah, in daily life.

So if we move on to the next slide and I'll hand over to Chris

**Chris:** thanks. Joanne had it everyone. So you might be wondering why, if some of you have worked in autism for a long time, these ideas about sensory evaluations, about sensory being such a large thing is, is kind of new. And the answer for that is because honestly, we only just realized how dramatically large, a portion of autism it is.

And that's because we put people into brain scanners. Here is one of the classic example where brain left his lady who to Temple Grandin pretty famous and the brain on the right it's a neuro-typical lady whose name, I don't know, I'm afraid, but their task was very simple. They were shown a picture and asked to describe what they see.

Now we can see just how different the response here is. And this is where we started to realize that autistic brains aren't broken in some way. It's not the some portion doesn't work. It's, there's an actual difference in brain design the [00:19:00] neuro-typical brain on the right has a very clear motorway. for social chitchat, for engaging in conversation.

And that means the rest of the brain is operating utterly smoothly. It means that traffic is going down that motorway for conversation very easily, Temple Grandin's brain. On the other hand, clearly doesn't have that motorway what's happening with heris she's getting the same input she needs to put through that road, but it might be a little country road.

It might be a foot path for all we know Temple Grandin herself, really struggles to speak. She has a very robotic voice and she can engage for only a few minutes at a time. What you can see happening there is overflow and that the traffic can't get down her communication road well enough. So what's happening?

Is this going to just to about every other portion of the brain and overloading it. She is somehow managing to process a process that she says is amazing that she can actually speak looking at this, but her brain is just overloaded. It's exhausted. It's using channels it shouldn't be using for communication.

What that means is that she's on a timer. Her brain will quite literally [00:20:00] overheat brain will shut down and we've realized that the autistic brain has this problem. A lot of the things neuro-typical brain can do, our brain is simply not set up to do. Our motorways are in different places. They're for different things.

Anyone ever heard of special interests with autistic folk? The things we hyper-focus on. I mean, the classic one is trains is maths. And so on like that, I mean, that's a stereotype. Don't get me wrong. It's not the case for everyone. But having a hyper-focus is a very autistic thing because those are our motorways.

They're not necessarily the same as neuro-typical. In fact, for those who have a similar brain set up to to a neurotypical, they usually don't get diagnosed because why on earth would they, they can engage in conversation. They can mimic behavior. They can do absolutely fine. And so if we move on to the next slide please, I've had to try and explain this brain difference to so many people over the years.

And I come up with many different visual metaphors. I'm a very visual person. The one that's really stuck is roundabout theory. The idea of thinking of the brain is a series [00:21:00] of roads and information being traffic. And the idea is, as I've just explained to you at the motorway, the autistic person has a brain that sets up very much as a specialist brain.

It has a few motorways and lots of country roads. The neuro-typical brain, the non-autistic brain tends to have more of a generalist set up. It has kind of equal size roads going everywhere, apart from maybe communication, which tends to be an important part of daily life. And what that means is they don't really specialize in things, but you put them into most jobs.

You can train them up, you put them into most situations they can do. All right. If they've got the base skills, an autistic person won't be able to do that because they might be being forced to utilize little country roads, little footpaths, something that physically cannot handle the traffic. If you don't utilize an autistic persons, motorways, their brain gets overloaded.

And what happens then is they can't process. And when they're then pushed into a corner, asked to do something, they can't handled or put in a situation they can't handle, they lash [00:22:00] out, they shut down, they enter fight or flight response. And just so everyone's aware, it's fight flight, freeze faune and flop.

The last two are often overlooked very, very relevant for autism faune as in fauning how to explain. Faune as in sucking up to people trying to, this is what I actually do myself. I'd go hyper social and talk my way out of a situation. I explained that I've got, say a headache that I've got. I've not slept very well.

I need to go somewhere. That is fauning. Flopping is when you just hit the ground you're done. You'll actually, you've turned off basically. And that often gets noticed because obviously it's an issue, but things like fauning things like just freezing, they don't get noticed as much. We've moved on to sensory processing.

I think Jills is actually going to take over here, but thinking about the roundabout, imagine what happens if you've only got small country roads for an important sense, like sounds, like touch, like tastes, like sight. What happens is you're absorbing so much from the [00:23:00] environment that you've actually shut down portions of the brain.

And this is very much what we're gonna talk about today, especially in regards to the home.

**Jill:** Thanks Chris. So as Chris says, autistic people literally have a sensory processing difference, and now our five external sensors, which are, noted on the slide here. Commonly known, are three internal sensors are less well known..

So they are vestibular, proprioception, and interoception. Proprioception and vestibular is like our, our balance and knowing where our bodies in space, interoception is like the thing that tells us, like, what am I feeling? Am I hot am I cold? Do I need the toilet? That am I thirsty? Am I hungry? And what happened?

This, this is a real generalization but, but for a lot of autistic people happens is our external sensors are hypersensitive. So we get, some additional information or additional input from our external senses. So for [00:24:00] me, it's, it's really sound. I'm very, I'm very sensitive to sound. I can't filter it out. I don't habituate.

So if there's a sound in the background, like a lawn mower, for example, if my neighbors were cutting a hedge, something like that, cutting the lawn, whatever. I wouldn't be able to, block that sound out. I wouldn't be able to filter out and I would continue to hear it. It would continue using Chris' analogy.

It would continue to add cars to my road. What happens is that those external senses seem very, very noisy. Like they had a lot of traffic and it kind of drowns out my internal senses. So, I find it really hard to, to know what I'm, what I'm feeling. I find it hard to know if I'm thirsty or if I'm hungry, if I'm overloaded or if I'm getting a lot of sensory input, then I find it really, really hard to, to eat.

 So, yeah, so generally autistic people have heightened [00:25:00] sensitivity to their external sensors and struggle to hear our internal sensor. So you might notice, for example, some people might, become, quite wobbly on their feet. They might hold a wall. Chris is going to talk more about proprioception and kind of building layout a little bit later, but, no we might also kind of like cross our legs or, or, yeah, like lean against things or want weighted clothes or a weighted blanket.

And that gives us additional feedback because we don't, you know, we we don't always know where our bodies in space. And so we're really seeking, that feedback about, about where we're all bodies and, And you know to support our, our, our placement in space and in the room. And Chris, I'm sure Chris would probably give this example later, so sorry for stealing your thunder.

But he, you know, we'll, we'll always kind of hold the doorway as he goes through. He doesn't, he struggles to know what, where he is compared to his space around him. [00:26:00] So we'll always come and touch a wall or a doorway. So we've got this quote from Marianne and she said, if I'm fighting sensory input, I don't have processing space to deal with anything else.

I'll filter out. Sensory input really matters. Not being able to adapt and environment means that I have sensory input that increases my stress levels. So, so again, neuro-typical people generally can habituate, they can turn off, they can block out, they can filter. So that means like, you know, if there was a lawnmower next door, you might be able to stop listening to it.

Whereas for autistic people, we don't habituate. We don't get used to it. And so we continue to hear or to notice that sensory input. And so it will really add to our stress levels. It will really add cars to the road and what that. And then that delays other things. So for example, if I have a lot of cars on my road and my roundabout was blocked, somebody asked me a question.

It's going to be tiny, fast but. I'm [00:27:00] not necessarily going to be able to engage or to know the answer. So the sensory environment will really, really impact, our engagement with other people, our ability to work, our ability to have relationships, our ability to, have social time, our ability to be able to engage verbally.

All of those things can be really significantly impacted by the sensory environment and being able to like decompress and have that space at home to regulate can be so, so important to us when the outside world is unpredictable. and noisy in so many ways, there's a couple of quotes here that I, that I'll read out.

 The timer on the cooker is triggering. It's not just annoying. It climbs into your soul and pulls it out. And that's remember Ruth said the most important element for me and perhaps the hardest to get right is for my home to be a quiet [00:28:00] space. So I think that the quote from Emma I included, because I think it, it really, it really demonstrates like the, the impact that noise can have, like, it's not that it's an inconvenience. It's not that it's a kind of, it'd be nice if. It really has a very significant emotional impact. And Ruth, I think is another good quote because she's, she's saying, you know, this is so important and it's also so hard to get, right.

Particularly thinking about autistic people, having a different sensing system, we will, we'll, we'll pick up and we will experience different things than neurotypical people. So often when Chris and I are doing sensory environment reviews, we will walk around the building with people who have worked there or have used the space for a long time.

And we will we'll notice. [00:29:00] That people who use the space have never noticed before, or they won't have heard it, you know, they'll have filtered it out, they'll have blocked out. And so they, they don't hear it anymore. But often it's, it's like background humming noises, its you know, it might be from, from lighting or it might be the water in the pipes, or it might be, from the heating or the forced air or the air conditioning.

It's stuff that, you know, there's a lot of neurotypical, people might not notice. So what, one of our recommendations in this report is to work with autistic people, because they literally have a different sensing system and will notice different things.

**Chris:** As Jill's just said, I've had an experience in my life where we had a young child who for 80% of the year was an absolute angel and to school and no problems at all that come Christmas time, every single year turned into kind of a, Hellian just uncomplete, non-controllable nearly going into care because parents couldn't handle harming everyone. It's just going horrifically . And [00:30:00] it's only for that 20% of the year. And they brought in psychologists, they brought, they thought everything they could possibly think of.

And what they came up with in the end is to bring in an autistic person, just as kind of a last ditch, what the hell is going on. And I went in and just pointed at the wall and immediately, and went, do you understand how loud your heating pipes are? And then what do you mean? And I said, well, seriously, the heating pipes are, are insanely loud.

It's like a shouting at me. And it turned out. It was just that the heating pipes came on, the child couldn't handle the noise. The child broke. That home environment had been ruined by a thing. The parents didn't even notice that they completely ignored. for me it's baffling. I can't imagine how they ignored that cause I couldn't focus during it. It's just different in perception is why it's so useful.

**Jill:** Thanks Chris always welcomed. We love, we love these little stories. So what we sometimes hear is that autistic people have, for example, pulled the pipes off the walls. Become very distressed when alarms go off, are upset [00:31:00] by slamming doors.

I was, I was chatting to someone, when we, when we were developing this report and they shared, that they'd been, they'd been chopping, chopping some vegetables for dinner and that someone that they were with had come and grabbed the knife. And he said, you know, if, if that had been a residential or a hospital environment that could have really been misunderstood as this person trying to cause harm, actually they were really distressed by the noise of the knife from the board and, and I recognize that and I was able to stop.

So it's really about, identifying what, what those auditory inputs are and thinking about how we can do different things. So, with the heating, I, you know, Chris has often talked about his, family negotiations around whether or not heating's on, so being aware of it, acknowledging the impact that it can have on people, [00:32:00] supporting choice and control, under floor heating, if you do new builds under floor heating tends to be a lot quieter in the, some comments from an autistic architect in the paper, relating to that.

Some of it is about changing practice. So, you know, doors slamming, for example, can be really, really distressing. You know, my colleague Richard describes it as being like a shotgun going off. And when we, when we pull the doors to quietly, you know, it's actually hasn't been any cost without that. Hasn't, it hasn't required any changes. Sometimes like adjusting the hinges or putting a door arm on can help, but often it's noticing and those change practice, or, you know, putting felt on the bottom of a, of heavy furniture and that kind of thing can really reduce the noise.

The other thing that we, we see causing a lot of problems is where there's a lot of hard surface. So again, this is particularly prevalent in inpatient services, but I think also in some kind [00:33:00] of residential or other services where, you know, there's kind of infection control issues or, you know, places want to be easy to clean, but a lack of soft furnishings and carpet and heavy curtains means that the sound really bounces around a lot in a way that can be really, really distressing for people. So keeping that in mind. Yeah. Acoustic vinyl flooring can be good if it doesn't need to be wiped, clean, sound absorbing panels can help. But additional soft furnishings can really make a difference and absorb some of the sound.

So other things to think about is outside noise, including at different times of day. So thinking about the location of schools and shops and, busy roads, you know, again, that background noise that can be really, really difficult to tune out or impossible actually to, to tune out. So the other thing, that, that people who contributed to this report told us was that everyday noise [00:34:00] from neighbors was incredibly distracted into them.

And again, thinking about if people might be living in shared accommodation or in, in housing that isn't, the, this is something that's really important to be mindful of. particularly because people weren't talking about, like, antisocial behavior, they were just talking about everyday noise. Yeah, the washing machine going on the toilet, flushing the door, closing a phone, call an alarm, an electric toothbrush charging in the next room.

You know, I think 20% of people who participated in this report could hear electricity. So yeah, all of the, all of the people who contributed to this report said that they would really find it difficult to live with people that weren't family members or partners. So noise from other people, including staff, you know, if the staff overnight, where are those staff based?

What are they doing? You know, and again, this I'm not imagining that [00:35:00] they're doing anything they shouldn't be doing, but if somebody is very, very sensitive to noise, then thinking about, you know, tapping on a phone or a tablet or a laptop or watching TV or listening to music, it could be incredibly disruptive to somebody with auditory sensitivity.

Cool. Okay. So vision and lighting. The two, the two sensors that people talk to us most about was, hearing and vision, and lighting in particular, can be incredibly challenging to autistic people. I'm just going to read this quote from, from Carly. A home with variable lighting is a major factor for me being so light sensitive, I can go into shut down if exposed to too much artificial light.

This renders me almost catatonic and unable to speak in a great deal of pain. I use a lot of small yellow lights and light bulbs. I also have in the past huddle room painted block to help with sensory overload. I need to have a neutral paint skin with most [00:36:00] things now, beige or white. So that was from Carly.

So yeah, so many of us are incredibly sensitive to lighting. I work with colleagues that are Chris being one of them. Fluorescent can be a really, really challenging for a lot of autistic people. So many people can, can see the flicker. They also make noise sometimes. We are developing some, some guidance on led lighting. What we've found is that, actually that there isn't any clear guidance around, how to get led lighting, right. So some of the standards are not very clear. Often the component parts, are a lot of very good quality. They seem to be often put on to dimmer switches, and the electrical signals, cause it to make a noise and flicker and deteriorate over time.

So it is possible to get it right, and the things that I would encourage to get it as right, as possible is user control. So avoiding automatic lights where [00:37:00] possible, or where they're needed. Also, I think the switch that they can be turned off, making sure that lights aren't connected on the same circuit, as the extractor fans . So this is something, that's really, really common in bathrooms. So the building regulations say that bathrooms do have to have an extract fan, but they don't have to be on the same circuit as light. So it can be really, really helpful if it's possible to switch those off separately.

The other thing to think about is, is shadows. So changing light levels can be very, very difficult for some people to process and can lead to, real, real challenges with transitions and, you know, even avoidance of certain spaces. So trying to get clearer and stay consistent light levels can be really, really helpful. And you know, using natural light where possible. The other thing for those you who've seen the report. A lot of people talk about is having smaller lights, [00:38:00] sidelights, fairy lights, candle lights. And so being able to have much lower lighting levels, and again, the user choice and control there that can be really beneficial.

Okay. So connected to, to vision enlightened, is decor . Again, this is something that a lot of people had very clear and definite views about. And this, this really lovely image, from Tommy Yates. He's one of the artists in contributed. So Rachel said clashing wallpaper can induce nausea and headaches, conversely pleasing colors do wonders..

So, I've, I've worked with some colleagues before who really struggled to access space where there's, where theres patterns and particularly patterns on floors. Excuse me, anything there's one building that I'm thinking of that has a squirly pattern on the floor in the reception and, you know, some, some of my colleagues physically can't get into the building because they're worried that they're going to be drawn into a Whirlpool or something like that. So plain and neutral [00:39:00] colors and carpets and flooring decor can be really, really helpful.

The other thing that we really encourage is, is, is storage. So. A lot of places have a lot of visual clutter. My office actually is quite prime example of this at the moment. So where there's a lot of visual clustered, there's, there's a lot to process and often it needs to be processed every time that the space is accessed. And if one thing moves, it's like everything has to be processed. And then. Some of us also get quite drawn into patterns and absorbed in patterns and counting and that kind of thing. Particularly if we're having a challenging time, so neutral furnishings, neutral furniture and a plain and calm environment can make it a lot more accessible.

 There were a few people who, who contributed to the report who said, actually they really like a busy wall or a busy environment, and we'd really encourage that personalization. But in, in private, you know, [00:40:00] private space rather than in kind of hallways or access areas that a lot of people are going to pass. So we, we tend to say go neutral and calm and, and start from like neutral palette and then build them personalized from them.

So I think we have got almost slide from Chris and then can have a break. So Chris, if I can pass over to for this slide.

**Chris:** Certainly thanks, Jill. So as Jill mentioned earlier, I struggled with proprioception myself and I need to make sure that everyone understands it doesn't mean things like hand-eye coordination.

I was a national rugby player. I played tennis at reasonably high level. I have good foot control for football and stuff. That's fine. It's about what happens when you're not paying a lot of attention. What happens when the brain is overloaded or you're just not focusing on walking through somewhere.

Cause that's where I lose track of my body entirely. For me, it's like, I'm just a head floating along. I have no input on where my body is in [00:41:00] that situation. So as Jill said, when I walk through a door, I have to touch the door frame otherwise I walk into it, there's a certain bit of wall in my house that I swear moves.

It's broken my toe, like six times it's malicious. And yet I can't avoid it for some reason. I kick it like every other day because it sticks out a little bit more than I expect. So. A big part of building a good autistic environments, making sure you have things like a clear line of travel. You don't have things that stick out.

We've in our house. Again, we don't have surfaces with sharp corners otherwise we will walk into them and damage ourselves. It's just, that's the thing it happens. So we have likecurved surfaces, things like that. It's also having very delineated edges of things. You don't want. There needs to be no worry that you're about to walk into something and it needs to be no worrying that you're about to touch something unexpectedly. The first CTR case I ever worked on, I worked with a young chap who was in a wheelchair most of the time. And he really just couldn't process the [00:42:00] world outside of his wheelchair. To him it was almost as if he was blind and the rest of the world was a white mess, apart from his wheelchair. That's the only thing he could, he could like see, feel, touch, taste, everything else was outside. So he needed people to pass things in a very specific height because it's the only way he could process it's coming in towards him. And if something fell off, it say he's eating the food and it fell off his lap onto the floor it's gone now. He can't process it anymore. It's an extreme exampleof proprioception but at the same time it was missed by the care team. They thought it was about control, about rituals, about things like that. And they were really against it. And in reality, he just couldn't process the world outside that point. So building a room that makes sense to the individual is as important as it is to a blind person.

We need to know where everything is. We need to be able to process it. Some people might like clutter. We have our hoarders or just people that have clutter everywhere. We have some people that have entire rooms built up 10 foot high somehow. It is about the individual. I would say in general, you want an open space [00:43:00] that people can then fill. So you go for a neutral, open space. People can feel and make sure people are comfortable walking through it. It has good lines of sight and things like that.

So much the same on this slide as the previous ones, to be honest, thinking about the roads, thinking about traffic, coming in, thinking about input, important to note with smell it truly doesn't matter if it's a good smell or bad. If you walk into my presence and you're wearing the world's most amazing perfume, or you could really do have a shower, both of them are going to be a lot of cars coming onto my road. If you consider just how many smells are actually around you, it'll be on you at this time. You start to wonder just where people with a very sensitive sense of smell, actually pick up from the world around them.

 We've got quote here from Carly again, certain smells can really help to calm and soothe. Me on the contrary. Other smells can make me feel quite unwell. There's some autistic people the sense of smell can be so strong and it feels like you're being force fed. Now I myself have nearly, no sense of smell, unless it's extremely strong in one or two areas.

So for [00:44:00] me, I can't deal with citrus, which is an issue for nearly every cleaning product and quite a lot of the, detergents and it basically means I can't enter public toilets or a lot of people's houses after they've been cleaned. If I was in hospital and they had to clean my room and I came back to that, I would no longer be able to enter that room.

I know my colleague, Jill has, sent when she's had to cleaners round to the house before they've used something like a, a rhubarb scented cleaner, which meant she physically couldn't get into her own house until that smell went, which was, I think days is I think I'm right in saying it's days later almost.

So smell is incredibly important to think about it's again, it's, it's a flood of information for those roads. Its when one sense is overloaded.The first portion of the brain that tends to catch the traffic, that catches, the overload of traffic. Is this a communication portion of the brain. I forget the correct term, but the communication portion of the brains, social communication, you can't talk anymore.

I will [00:45:00] go non-verbal if I can't process my sensory information, I said sensory information like 12 times in a row. Ignore that.

Wonderful. Okay. Tah. Much like with, proprioception. It depends on the situation now. Again, I played national rugby and I was a prop. So anyone that knows rugby knows I'm used to being groped just about all over the entire time.

But I was ready for that. I accepted it as part of being part of the team, part of the sport. I could deal with that. Touching. If someone comes up to me in a corridor, in a workplace, and even just placed a hand on my back to get my attention. It's like ice cubes down my spine. Everything else stops. It's the only impact that met the matters.

I remember going into London once for a conference and I sat down and on the train and I sat down and a very pretty young woman came and sat down next to me. We should be a great thing. Hell, maybe I talk to her and get lucky. Who knows if I'll get her number, but no, because she, when she sat down, her knee [00:46:00] touched mine and I froze for the next hour and a half journey into London.

Because my body had just utterly shut down. I had no input at that point because I had an unexpected touch. So be very, very careful with what is touching anyone. And that is just people. Consider at this moment, what you have touched in you, your body at this moment, like I'm assuming clothes, I'm hoping clothes personally.

I'm assuming you're sitting on something or maybe lying down or something. Imagine if those fabrics that are touching, you are unpleasant. Imagine if those are adding extra cars to your roads, how much processing you will lose just from having the wrong clothes on. Just from having the wrong seat texture. How many places of a care environment, home environment offer things like different bedding and they've pushed for it.

What if someone doesn't like the bedding they're using? What if it, it moves traffic onto the brain? So their brain never really starts off cause it's always processing. If people [00:47:00] can't sleep, they can't process. They can't progress. They can't become better. Better versions of themselves.

Touch is incredibly important. I remember we went around hospitals, Jill and myself for a sensory assessment and as we're going up the stairs, we both reached out for the bannister and it was what we thought was wood, but it turned out to be freezing cold metal. They'd been painted to look like, like wood. And both of us just stopped on that stair.

It was an unpleasant moment. Like it was very close to sending me out of the building. I was nearly done with that assessment because I had an unexpected clammy cold sensation on my hands where I wasn't expecting it. The flood of cars came very close to shutting down my entire brain. And I would have had to leave that for somewhere a lot quieter.

So be very aware of what fabrics you're asking people to live with. For example, my parents bought a sofa that is absolutely wonderful for them. Only the issue is it's built for someone their size, which is half my size so I can barely fit on it. And the second [00:48:00] one is I can't deal with the texture. The fabrics wrong for me.

So I've never touched. I used to vegetate in front of the TV the entire time. Maybe it's a good thing. I don't now, but like I don't watch TV anymore because I can't sit on the sofa. I can't actually use that room basically now. So be very aware of what you need to do as you need to give choices. It's unique to each individual. There is no universal best fabric. There's no universal best texture. It is individual. And so you just need to offer choices. We're not very subtle. We'll go through what doesn't hurt. So if you offer us choices, we'll go to the textures that don't have hurt. Be aware of things like tags in clothing seams in clothing.

I personally love bamboo stocks, which is rare. Cause I think socks are the devils invention. I absolutely hate them. When I was younger, used to have to fight to get me into socks. I can't stand them at all, but bamboo socks are pretty wonderful. Especially ones that are loose enough that they're not constricting in any way, shape or form.

I've had to have stick on shoes. I could go on this subject for literally a day or two in a row. It's a [00:49:00] major thing for me. Just be very aware, like give the choices, please. I beg you choices are good, we like choices.

**Jill:** Okay. One for me. So, taste and eating. So we're really conscious that this, this presentation in this paper is really about the built environment.

 Taste and eating. So obviously taste is, is one of our external sites. And we tend to spend a lot of time in the work that we do talking about, food and eating, particularly the dining environment. So often dining rooms are the most challenging sensory environments, perhaps second to bathrooms, which tend to be absolutely the worst.

 But dining rooms often, there's a lot of hard surfaces. Usually usually the chairs and tables don't have felt on the bottom and they, they make a noise as they pull across the, across the hard floor. Usually there is solid walls without very much soft furnishing. Usually there is, a [00:50:00] solid ceiling with some very bright overhead lights.

Often thats not very good or much natural light. Sometimes the dining area is connected to the kitchen. Either canteen style or part of a kind of kitchen dining area, which seems to be all the rage these days. Often there's a kind of a social expectation around food and eating. Yeah. And so there's, there's so much, so much input and like eating literally affects all of our senses, like it's our taste, as we've put the food into our mouth. It's our proprioceptionas we lift a fork to our mouth, assuming we're using cutlery which I usually don't, but assuming we are using cutlery it's like this proprioception as we bring the food to our mouth and then there's the taste as it enters our mouth. There's the sensation of, of the food inside. And, you know, the, the kind of the way that it moves down through our bodies and sits inside us.

There's usually a social demand. There's usually kind of [00:51:00] pressure from the chair or the furniture. There's often a smell. There's the visuals. Yeah, there's often kind of background noise from fridges. You know, they're really a big challenge in my life, the nose of fridges, you know, some people have them in dining rooms, which baffles me because I can't, I cannot switch off from, from the noise and for a lot of theres additional challenges with eating. So some, some people that affects more extremely or less extremely. So I think Chris and I probably both identify in. Myself in kind of quite in minor way. Like if I'm stressed or if I have a lot going on, then I find it. I find it difficult to eat. Like I can get quite anxious. I can get quite uptight. And it can be really difficult for me to process food if I have other, other things going on. But for some people, it's, it's a really significant factor. You know, for people who have the [00:52:00] sensitivity to taste and texture, they might have very definite preferences around what they want to eat or how they want to eat it or how it, how it should be cooked or how it should be set out on a plate.

Now adds to that additional sensory, demands. So bright lighting, smells, other people, noise from other people eating, social demands, either from other people that we're supposed to eat with, or you know, for those of us who need support from staff being around. Often, in communal settings, there's often, like a radio on or additional background noise and it can be really, really overwhelming. And this is something that we're expected to do at least at least three times a day and often, and kind of social demands, often following another busy activity. And before we do something else, so it's really worth considering how we can neutralize the sensory environment in dining rooms and also how [00:53:00] we can support people to have more choice and control.

So, there was a Brazilian research paper, published. That engaged a lot of autistic adults and the, the very strong preference from most people was that they eat on their own. And they said, this is something that Cos echoes. So Cos said, I need to be able to eat away from other people. This isn't all the time, but if they're eating smelly food or making loud noises or eating with their mouth open, it makes me feel quite ill.

Cos identifies as an autistic elder and a lot of Cos' like focused and interest is on, kind of care and support for older people and been supporting choice and control for autistic people as we get older. So, you know, one of, one of the things I hope I'm representing her fairly, but one of the things that I have from Cos is you know, as we get older, we, so a lot of people have, missed a diagnosis, because diagnosis wasn't very [00:54:00] common and is, you know, until the 90's if you didn't have a learning disability, you couldn't be identified as being autistic. A lot of people didn't meet the narrow stereotype. And so we're not recognized as being autistic. And so they, they perhaps missed a diagnosis, perhaps in invisible in older age, and then moving into older people services are often identified again as a generic group of being an older person, rather than having an additional identity such as being autistic.

And so, Cos you know, her, the, the thing that Cos really brought to that is how are we considering the needs along the people. How are we considering this when we're thinking about support for all the people and also thinking about, kind of, long-term home and support needs and, and adjustments that we might need to the home and the environment to make sure that it's right for people as they get older.

 So yeah, dining rooms really challenging. There are really [00:55:00] like straightforward, cheap, practical adjustments that we can make that make a really significant difference. Turning the lights off, felt on the bottom of seats choice can control about when and where we need. Choice and control about what and how we eat, being able to eat alone and also being able to predict. So knowing what I'm having on one and being able to prepare and plan for that can be really helpful to us.

Okay. So, other people, so a quote from Carly. Sensory wise, shared accommodation made a huge negative impact on my mental and physical health. I think I mentioned this earlier, nobody in this paper, who contributed to this paper, wanted to live with other people aside from their partners or immediate family.

So there was a real aversion to shared accomodation. And not because, not because the participants didn't like other people, but because it had such social demands and had such, such a lot of sensory input living with other people, even, even if people are behaving just in a normal human way, you notice stuff.

I [00:56:00] mentioned the flushing toilets, their washing machine, the music, the phone ringing, the doorbell. Moving around. All of those kinds of very normal household noises can actually be really, really distressing. So what people said to us was it really limits my choice and control for my sensory environment. If I was needing to share with other people or what I've had shared with other people it's really dramatically negatively affected by mental health. And I would avoid it as far as possible. So in the report, people also commented on the challenge of having shared spaces. So perhaps not feeling safe in the shared spaces, not knowing what the social, or cultural expectations are in that space. So again, this speaks a little bit to, autistic people often have a different culture and communication system. So, you know, we really need the implicits to be made explicit. So I talk about, in the job I worked in, it's there was rules around [00:57:00] when you brought your own tea and coffee, and one year used the, the office team coffee.

And if there was a biscuit on one side, it made it, you could eat it. But if food was on a different side, it meant you belonged to somebody, but that wasn't written anywhere. So it's like, there's all of this implied knowledge that people somehow know or pick up, but isn't always made explicit. And so what we find sometimes then in shared environment is that there is implicit expectations and social norms that can be really difficult for autistic people to be able with that, to know like, you know, we don't always get to the subtleties of neuro-typical communication and really prefer it to be direct and clear. So we know where we stand.

Okay. So this is an image that, Alexis Quinn shared with us as part of the report. So Alexis, contributed their kind of personal story or case study to the report. And some of you will be familiar with Alexis from, from their work, with [00:58:00] the, restraint reduction network.

And of course, she's the author of the book, Unbroken. And Alexis talked to us about, about her experience of, of being in hospital and then being discharged and how important the sensory environment has been to Alexis. And I included this image because we really wanted to mention shut down and meltdown.

And Chris in preparing for this, Chris and I were, we were talking about our own experiences of shut down yesterday. So when we talking about shut down, what we're really talking about is a sensory angle, social overload, And not that presents differently for different people, but essentially it, I tend to, I tend to get shut down and so, so shut down when it happens for me, I, I will, I'll go quiet.

I will withdraw. I will probably be staring into space. I, I often like my head gets really, really hot and I [00:59:00] probably like the touch. I feel really hot, but I also feel really cold. So if I if I can I'd be like under a duvet or like wrapped up in a jumper and, you know, with the fire on and, I'll probably be crying. But I might be able to hold that back. And I can't talk. So I go and I go non verbal. I usually can't move or I might be able to move like after about an hour and a half. So it's like my whole system just shuts down. I get overloaded and I shut down. And what happens for other people sometimes is that they, they go into meltdown.

So I go into a kind of a freeze response, but other people might go into a fight or flight response. And that's why you might see people trying to run away or leave a building, or, you know, perhaps if, if, if they're touched or come into contact with people, then you know, they might, they might, kind of bite or punch or kick or scream to try and get away from this overload.

 So Chris and I were discussing this yesterday [01:00:00] and Chris will share his experience of, of sensory overload by saying that my overload really tends to be social. So I definitely, can get overloaded, from overwhelming sensory input, but, but I'm much more sensitive to, to social overload. So, I, I can do pretty well in a professional role.

Like I know what's expected and I know how to deliver it, but if you put me in a social environment where I don't know what the rules are, or I don't know what's expected, or I don't know how I'm supposed to behave or what I'm supposed to talk about or what's acceptable, or I get really awkward and I sometimes start to stammer. And I try and plan everything that I'm going to say and try and work out if I've said the right things. And like, it just creates so much input and so much, so much anxiety and it's so exhausting, you know, thinking about those brain scans earlier. Like no wonder my, my brain is overheating. It's [01:01:00] working so hard to try and, communicate and connect and maintain these social norms. And when I get tipped into overload, like it's really physically painful, right. It's, it's very, very uncomfortable. It really hurts. And I will, I will go out of my way to avoid it. And I think what we see sometimes when people are struggling in their homes, particularly in shared environment, particularly where their sensory needs haven't been. That particularly where there are a lot of social demands.

 It's that people get overload and they, they go into fight or flight. And what happens for some of us and actually I think for a lot of this is once we've hit that threshold that takes us into shut down or, or meltdown actually we become much more sensitive. So unless we get time to really decompress and regulate, and for things to be okay for a little while that it doesn't take much to take us back into that. And we kind of get into this quite difficult [01:02:00] cycle of being constantly overloaded, not able to regulate. And some of those will go to quite extreme lengths to try and regulate. So, you know, we might, have, have things like favorite hobbies or, stimming or moving or verbal tics or, or, you know, a favorite thing that we might use to normally try and regulate us and if that doesn't work, then. You know, when I, when I get overwhelmed, I think, you know, what I would, it feels like would help me is to hurt myself. Like, it feels like a really effective way to regulate myself or have enough of the things now that I don't need to do that anymore. But, but that's why we really see people having a difficult time. And it's often in this overload that we see people being, being admitted to hospital

Chris if I can pass over to you to talk a little bit, about sensory overload.

**Chris:** Thanks. As Jill said, I kind of experienced the opposite side of this. I can be overloaded by sensory, [01:03:00] but it's more common that it's going to be. Can be overloaded by social sorry, but it's more likely that I'm going to be overloaded by sensory. For me it genuinely feels like my brain starts slowing down. It feels like I start dropping IQ points and by the time I'm in fight or flight mode, I feel like I've lost 50 IQ. Like, I don't feel like I can engage in conversation at that point. I'm embarrassed by how I engage in conversations. It's very simplistic.

And it can be, it can just be rough to try and converse with people because I just feel like an idiot and it's a really painful feeling. It's also frustration based for me. I'm frustrated that I can't engage. I'm frustrated that this noise won't stop. I'm frustrated that I can't get away from it. And so if someone pressures me in that moment, that is why the fight or flight comes in.

Personally, I'm a bit like Jill I shut down, which is why both of us got away without being diagnosed when we were young most likely because who cares if someone just goes quiet. It's when they lash out or runaway that you get a real issue and you get the diagnosis quite often. We're getting better [01:04:00] at noticing people who shut down now. But yeah.

When it comes to social situations, I actually faune my way out. I talk my way out, as I mentioned earlier, and it's a really peculiar cause as I say, I go basically non-verbal apart from, I have what I call panic talking. So I've almost prepared this beforehand and I give a spiel about how I need to go and do something and then I can leave.

When I am in a sensory overload it's yeah. Pain, anxiety, frustration. It presents for me like a migraine. But there's nothing I can take to stop it. So that there's no possible way I can do anything to it. I can't focus on anything. I can't explain it to anyone very well. I I'm basically left just waiting it out as I occasionally go and throw up. And unfortunately for me with how extreme my sensory, you can't see me at the moment, but I'm sitting here in a pitch black room with noise canceling headphones on underneath a cover that is especially chosen Egyptian cotton and so on. Just to try and limit my sensory input as much as possible. So I can engage in this kind of work.

if it goes badly enough for me, when I'm out in public, I I'd [01:05:00] say 30% chance, like at a migraine, every time I leave the house, sometimes it's delayed. I often will. If it's especially for work, I will fight through it.in the moment. But that can actually exasperate what happens when I get home afterwards and I can be out for a day or two after maybe even longer, a full week is not outside of the realm of possibility.

The brain needs time to recover. Downtime is how an autistic person copes with the world. We need our down time and we need the chance to download to someone. Possibly. We need a chance to focus on our special interest. We need the chance to clear out roads in whatever way possible that is. It's as important as well organised uptime is well organized down time. Working out how you can recover and clear those roads. Because if you don't, when uptime comes along and you don't have the room to deal with it, I've had days where I've had to say no to work, because I just don't have the room to it. On that day. I've had to disappoint my colleagues and so on because I've had to say, I can't do this to them. Sorry, because I haven't prepared myself well enough. I haven't taken into account the journey or something like that. It's a lifelong experience of learning and you can learn to deal with it and you can [01:06:00] manage to cope with it to a certain extent. But those triggers are always there. So much of autism is about learning how to clear the roads, and as we've seen today, sensory pretty gigantic part of it.

So home, the important thing to realize, like, I show you already picking this up today. It doesn't matter how nice the home is. It doesn't matter if everything's new or in fashion, or even like, I guess, like, I guess it doesn't matter if it's clean and cleans good, we like clean. But. It's what works for the individual. We're looking for downtime. We're looking for somebody so comfortable they can recover from the world. And that's the word I want to use as recovery. We're looking for a space they can recover, that doesn't have input randomly coming in. Jill mentioned earlier, my constant fight against evil in the world is heating and washing machines. I absolutely hate them. I hate the fact that my family likes having clean clothes. It's unreasonable. I don't like it. Because what happens is that when that machine is on, it's like it's invading my space. I can't focus on anything else. I [01:07:00] can't do anything else. I'm just aware of that noise. And so we have like, obviously I sometimes allow them to clean their clothes and wash their clothes. So, we kind of let each other know in advance when that's going to happen. So I can prepare to say, be doing something else. I'll be out of the house or something like that. It's something you've really need to think about. And again, we have quote here from Cos again, which is, people, design homes are like a posh clinic.

They think that autistic people need a home that you can clean with a J cloth. I don't want that. I want a home that is calm and comfortable. Again, she's looking for somewhere. She can be comfortable, that she can recover. It's not simple. So again, it's offering choices to people until they build the environment they're most comfortable with.

Don't never assume that you can build something for someone that's perfect for them. It doesn't matter how amazing you are. Their the one that's gonna know best. You need to be able to give them the opportunity when they're processing to actually manage, to build that. What you can build is a very good neutral environment they can then customize. It's what we recommend on nearly all of us sensory visits. It's basically [01:08:00] impossible to build a perfect house for an autistic person. What you can do is build one that's neutral. It doesn't add anything to their roads, and then they can add the stuff thats good and helps.

So, yeah, as I say, outdoor spaces, one of the worst contributors to overload I see it's actually roads. And especially because for some reason, people like building houses directly on main roads and care homes on a main roads, easy access, I guess, things like that, but that noise, you can't get away from it. The older I've gotten, the more I've realized I can't ever sleep with my window open. I like cold air coming into my room at night, it refreshes me. I like sleeping with that, but I just can't handle the noise. I can't handle the cars going past. I can't handle the occasional drunk person walking home singing to kylie Mynogue, singing to whatever they're singing to at night. Like whatever that is, it's just, it ruins my, my safe environment.

So the location is important. It's again, probably unlikely to find the perfect location, but the more remote, the more isolated, the more. I guess [01:09:00] the less input you can get from the outdoors. Wonderful. And if someone, some people really enjoy an outdoor space, a garden. I know for example, Jill, if she lived in a world where she wasn't allowed to go for walks with her dog, I don't know if we'd be seeing Jill here today.

Like it's utterly integral to her. I, myself, I'm a homebody. I think the outside world is evil and out to get me, but some people really do love it. And so garden space very important. Got a quote here from Ruth about this exact subject.

The garden recharges me. I can sit there. We'll do some weeding or planting, listen to the birds, read under the trees, the curves and softness of the plants are soothing. Having space to escape to in-house means again, the ability to decompress as well as places to recharge. So I low arousal environment is key for both. Once again, she's not designing her garden. She's not re designing a house for interest for looks for anything like that. She's designing it for low impact, a low arousal environment. And that is the key. Once again, it's just about the roads and it all comes back to roads. When I've worked even an autism training session, I ended up saying the [01:10:00] word roads 50 million times in reference to the brain simply because it's, it just all comes back to how many cars are people dealing with. What's going on? Like how many IQ points are they dropped because there's a fan on because the , the heating pipes are going, do they have room to process because they've been dealing with the washing machine. It all comes down to that. So thinking about an outdoor space as again, very important. Again yeah, let them design it, let them have some input into it if they really want that, let them be a part of this decision. It really, really helps.

**Jill:** For sure. So this is, kind of a bit of a summing up slide, really. We're coming to the end of the presentation. So Emma says If my sensory environment is right, its blissful. If it's not right, I feel stressed and it can provoke meltdown, anxiety, and depression.

Ruth says sensory overload to me, it's exhausting. So living in a lower arousal environment, isn't an essential part of maintaining good mental health and emotional regulation, for me. Part of the solution is feeling safe. So, you know, w [01:11:00] w we've talked a lot about the different sensors and, the way that housing can be, adapted, all sensory needs can be considered in housing. We absolutely believe that this is vital for autistic people, but the thing that has become clear in the course of our work is that actually it's also really beneficial to other people. A calm, neutral sensory environment is likely to be beneficial for anyone that's accessing the space.

I'm just going to pick up on one of the questions that that's come into the chat at this point. So, the questions that, and there's been a couple of them, a similar theme, but around. How, how do we design an, a house or a living environment that's suitable for an autistic person? One individual need varies so much. I think it's, it's a really good question. And there is one that comes up quite a lot in our conversations.

 Absolutely. Everybody is different. I think that's true across the board, but particularly, it's true for autistic people where we all [01:12:00] have individual sensory profiles and individual needs and wishes. The thing that we would really encourage is a neutral, low stimulus environment with as much choice and control within that as possible. So we'd go calm, neutral colors. We'd go quiet. We we'd, we'd make it kind of pretty plain. So no, no kind of quirks or flourishes, you know, which architects tend to love, but that can be really confused and, And cannot a lot of, lots of stimulus. And so we'd go calm, calm, neutral environment, choice and control.

So for example, with lighting, a lot of places just have a bright, overhead light, but if we can have the side lights or a good quality dimmer switch that doesn't hum, then it gives maximum user control. It tends to be easier to add in additional things than to remove it. So we'd start really, [01:13:00] really simple, really calm, kind of pastal, neutral colours, not a lot of visual inpu t. So not a lot of paintings on the walls or that kind of thing. And then we would add from there and like tailor it to meet the individual need. I think that if we can do that, we will be getting it right for most people. So the key, sensors that I'd really consider is, sound so trying to make sure that it's quiet or that noise is predictable.

 But the other one is lighting. So really avoiding harassments is key having good quality, only the installations and would use a control. So not automatic. And there's also kind of slightly general questions, but there was a question around, smell and someone, someone wanting a little bit more information on that.

So the, the really key thing I would say around smell is, like if it's not possible for people to have choice and control, for example, You know, maybe around what detergent to use and that kind of [01:14:00] thing, what washing liquid to use and, you know, what cleaning products to you use, choice and control can be really helpful. But when that isn't possible, the stuff that can really help is making it predictable. So, Chris mentioned my, in my previous house, I had some cleaners that came in once a fortnight and I knew when they were coming and I had an agreement with them that they didn't always stick to around what cleaning stuff they were going to use.

And so make it predictable. So I know on that day, actually, my house is going to smell a bit strange. I'm probably not going to want to be there. I'll probably want to, kind of have the doors open, make it possible for people to move away. So I would always go out with the dog, but that time when they were there, when it was at the strongest, but also a masking smell can be really helpful. So. And the smell of my choice on a, on a tissue or something like that, that I can use. So it's adding cars to the road, but at least it's cars of my choice rather than something that's, either unexpected or led by, by someone else.

Yeah, so sensory needs are so, [01:15:00] so important. And if we can, if, if we can keep these in mind and consider them, then we will help people to flourish and to, to lead good lives.

So if we can just go onto the, I think it's kind of our last slide. So some suggested next steps. Please, like if it's been interesting, please have a look at the report. There's a lot more kind of recommendations and suggestions and more background information about what we've spoken about today. At the back of the report is a checklist. So have a look at that if you're reviewing a sensory environment and ideally work with someone autistic in that we literally have a different sensory experience. So it's really, really unlikely that neurotypical peopleweill get this right for us, because you're working on a different operating system.

Ask questions about sensory needs. They're often not recognized, autism, you know, our understanding is still developing and sensory needs, only just part of the diagnostic criteria. So if you're working with someone who's autistic and try and get [01:16:00] housing, right, for them ask what are their sensory needs? Have they had a sensory assessment done? What are the things we really need to think about in terms of the sensory environment, for this person. And plan for a calm, neutral environment and support. People are often the most unpredictable thing in any environment. And so getting the right team with the right approach is so important to getting that the environment right.

Thank you. Okay. So when these come out, there's some, some links there, that you can access to the checklist, the LGA, executive summary, the NDTi full report, and a CQC report that compliments the work that we've done.

And then the next slide, I think, is a shout out to the artists and the contributors. So we've had a ton of artists and other contributors who, whose images we've used in this presentation. And, yeah. Do you have a look at the rest of their work. I don't know. I think we are onto question and answers. So.

Ah. Okay. So who would you approach for a sensory needs assessment? So I would approach an occupational [01:17:00] therapist. He was qualified, to do that work. That's, that's the official answer. It can also be really, can be really good to, to involve other autistic people. So, you know, perhaps along, alongside, alongside the OT to have someone who, who shares, those, those sensory needs and that sensory experience can be really beneficial for people.

So I don't know a lot about stroke, but I, I guess that it, a stroke might alter someone's, brain function and, neurology. I guess a stroke potentially might also make somebody differently sensitive to that sensory environment. And or might, mean that people need clearer, or more explicit communication.

So I, I'm generally not aware of similarities, but I think that the approach that we're advocating for calm, clear, neutral environment can actually be beneficial to, to a lot of people regardless of, of their need.

**Chris:** When it comes to the behaviors. And so on that, occur due [01:18:00] to overload, is very similar realizing to epilepsy and so on, which I think is another brain, a well-known brain condition slash thing that happens. Our brains is already working with important words now. So forgive me, but I think, we were realizing that a lot of things are interlinked on just basically being overloaded by the road system, shutting down or firing off in a place where it shouldn't be firing off or shut, or like things like that. I think.

 There's one. I noticed that earlier I'd like to ask, which is, can autism be diagnosed at brain scan? And in all cases was asked, asked that is a complicated one. Simply because what is autism? As far as we can tell autism is now basically having a bit of a specialized brain quite simply, because there's no way to tell based on ability or even just affinity for things. So we've got some people are amazing socialists and people are amazing at maths. And so on there, it's really difficult to tell. It's become a bit of an umbrella term for anyone that's not neuro-typical and can't be diagnosed with anything else.

**Jill:** I think, one of the really interesting things at the moment is there is a mix of diagnostic [01:19:00] criteria. So there isn't a single criteria for diagnosing autism. And I think, I think that says a lot about our current understanding of autism and their diagnostic criteria. And I think autistic people, are increasingly being seen and heard. Yeah, but it's, it's, it's evolving. And I think it lacks clarity

**Chris:** A good question we had was, which is I'm going back to noise. How can we support when it comes to hair clippers and dryers, answer to that is again preparation. I think, doing all you can to prepare the person for it and making it as low impact as possible. So if you, as a supporter, are quite hyped up and worried about it going in, obviously that might raise anxiety. If you're going in with a plan you've worked on the plan, they've agreed on the plan and you go in and just casually and being, and give them a time limit. Like it's no matter what this is going to be taking five minutes, something like that. Like we know it's going to only take that long. It gives us something to strive for. It's like cope for 5, cope for 5, cope for 5. [01:20:00] Just be aware if you do that and it go to six all hell is going to break loose.

**Jill:** Yeah. The other thing I'd add is, is it needed. You know, would something else, do the job, you know, could the person grow the hair a bit longer? Could scissors be used instead? Is it dryer necessary? So I think we often can sit through something if we know how long, but it also it's like, it'sat what cost. So if I'm sitting through something for a certain amount of time, then it's going to take an enormous amount of energy and will for me to do that. And I'm going to need a break afterwards.

So, you know, if I'm really set on wanting my iPhone personally, I find my hair cut socially a very demanding thing. And it's pretty much my one activity for the day when it happens. But I do it because it, it feels important and the benefit pays off for me. I felt good about that. So I think it's about like, thinking like, you know, is it worth it for this person? How can we make it tolerable if it is, or there were other adjustments that would help and having the downtime afterwards, I think that [01:21:00] the opportunity to relax and have a break can be really helpful.

We had a question around mental health, inpatient services. So I I'd point you to the Not Rocket Science report. That's something on the NDTi website. And that was a report that is specifically around, things that inpatient services need to consider that is, like targeted around CAMS. But actually that was just because he was commissioned by CAMS and involved children and young people. In that participatory way. But I would say that the learning can be applied all age and yeah. So that's, that's the report. I'd look to for that. And then there's a free online sessions, one in the NDTi website on that.

**Chris:** Yeah. Yeah. We've got one. I don't know if it's a question such, but, from Stella, which is, son is autistic and speaks very loud and doesn't realize this, conversely, he cannot cope with loud noises that are unpredictable, unless they had to do things like get off public transport, in a risky area because he can't stay on there any longer.

He wears noise canceling headphones, but I can disconnect him socially. I think you've just described or I've maybe I've just [01:22:00] described my life, reading out your question. I've had to do that exact thing and leave a situation many a time. I'm always in noise, canceling headphones. What I will say is it's rather than looking at just the noise you want to look at, what else is going on. If you've already taken every step you can to reduce noise, it's worth looking at, is there a, is there a lesser issue you can also remove? So for example, if out of a hundred, he's getting a 70% of it is noise. That's overloading him. What about that last 30%? Is there anything can do with closes that you can do a preparation is there anything you can do with, smell or something like that, and then try and reduce in different ways to give them a bit more room to process.

 Focusing hyper-focusing on one sense as a bit of an issue, like when I first got diagnosed and realized sensory issues were a thing, my first focus was actually on light. So I wore sunglasses everywhere, but I didn't even think for about three or four years about wearing headphones, which is a huge mistakes, because it turns out noise is worse for me than light. So I kind of scuppered myself that cause it's, didn't think about it. I've been considered the for [01:23:00] options. So yeah. Think about all the different things, even if it's a small thing, if you can receive light by 5%, 2%, 1% it's still worth it. Basically.

**Jill:** Thanks, Chris. We've had a question from, from Tracy around, he was, he was involved in this paper. So we, yeah, it's a really interesting question. We had a range of, of people involved. And we, we went out to people and we, we invited people to take part in life the way they wanted. So we invited people to take part like verbally.

So to, it was, it was in COVID. But to meet with us online and to have a conversation or to have a phone conversation, or to send us their views written format or to send us artwork or to contribute in whatever way they wanted. So we, we really tried to, to, Approach this being mindful of the fact that, that not everybody uses verbal communication and not everybody feels [01:24:00] comfortable or confident, in conversation with another person.

And we tried to set up the questions and the intent, and also to provide support afterwards. We've had a range of contributors, so we didn't hear from anyone who is in hospital at the moment because, the focus was very much on housing. Therefore in the report. We only heard from people who've been in a hospital setting.

 And we had, contributors from, we didn't have anyone who was in residential support, but we get have people who are in supported accommodation. And, living independently, but also from people who'd live, who'd lived in a mix of environment. So bothshared accommodation, supported living, in, in their own homes, either as tenants or are, or owners.

So yeah, we really tried to hear from a mix of people. I think this kind of links a little bit to a question around, working with people, who have learning disability and, or who don't use verbal communication. Of course, we want to involve people and we want to [01:25:00] consider people's communication and, you know, I'm sure you're all aware, like people tend to communicate, even if they can't use verbal communication. So, you know, we'll, we'll kind of just, over 90% of communications through body language and that kind of thing anyway. So it's like, how do we hear what people are showing us and telling us? Even if they're not telling us verbally. And I also think there's tremendous value in working with autistic people who can do use verbal communication.

And a lot of the work that my team does is kind of as a translation service. And, you know, Chris is, you know, one of the team who, who, who, who leads a lot of this work, and that's really about us spending time with people and working alongside people to understand what their sensory and social needs are, so that we can actually translate that from the team and the people working with them. Because often it's really, really clear to the autistic people, because we identify with that person's experience and communication, and actually it's that it [01:26:00] hasn't really been seen or heard by the, like the neuro-typical team who, who might be working with them, you know, and not because they're not trying or that, that it's not well intended, but they haven't got those skills or their working from a different operating system. So I think it it's really about, like bringing in the expertise and working with autistic people to, to kind of provide that translation support so that we can. We can hear and learn about autistic communication.

**Chris:** I've got a nice thing here from Sharon, which is saying basically it's about a lot of the sensory work is about personalizing it, making it personalized care. And also that Jill's voice is very soothing. And I agree.

There's one question, which is, from a housing point of view, how can we help anyone who is autistic? Cause that seems to be a varied aspects to it. And one property can not meet the needs of all the service users with shortfall of appropriate housing it's almost impossible to meet the needs. How do we address this? And I think the answer to that, at least for me, is do you do the best you can? [01:27:00] Obviously there's going to be restrictions. There's going to be some ways that you can't do things. You do everything you can to prepare and you do your best to let them at least have a personal space that they, that is as perfect for them as they can make it. You might not be able to put, you obviously can't change where the house is located or you, and you probably can't change the fact sometimes that they're going to have different housemates inside, but you can put in things such as noise canceling panels, different doors that can cancel out more noise.

And you can, break up the space. You could try and have certain rules in the house where behavior and noise and so on things like that, you work within the limitations you're given as long as there's not going to be enough. And people are going to really struggle, but often just the awareness that there are, those issues makes a pretty huge difference, in adapting to the individual, basically as long as you're not expecting them to adapt to the environment, which is a very common thing, and it just never really works.

As long as you can hope, hopefully adapt the environment enough for them to survive. They will build it up into something they can cope with hopefully. While you search for something more appropriate. And if Jill's got anything else on that, [01:28:00]

**Jill:** Ah, yeah. So the other thing I'd add to that, and we haven't touched on it a lot in this presentation, but there is, more on it in the report.

 So we we've really focused around changes that can be made to the built environment in this presentation. But, you know, there is a lot of things that we can do to support people, to manage themselves. So Chris has spoken about noise, canceling headphones, and sunglasses can really help, caps can really help, like they cut out a lot of glare, but also minimize the visual intrusion. So that kind of, they can act kind of like blinkers, which can be really helpful. So. So, yeah, so there's, there's adjustments that can be made that can support the person to manage that input even when we can't control or change the environment. You know, the thing that I think can be really, really helpful is to make it predictable.

So if I know, for example, if my neighbors were going to do building work and they told me what the bell, what was happening when it was happening, how long it was [01:29:00] going to last, I'd find it a lot easier to tolerate if I have full information and knew what to expect. So I think it's also about making it really explicit and clear and supporting people to have a choice.

So for example, if my neighbours are doing building work, then I'm like a plan. That I can be somewhere else. So if it, if it becomes too much, I've got a choice to move and, and in having that choice, it makes it more likely that I'll be able to tolerate sitting through it. So I think, you know, a lot of it is about how we approach it more, what information and support we give to people as well.

Has there been any research done on products in new built homes, which are good for people who experienced sensory overload, but also meet sustainability criteria, et cetera. Rachel, I'm not aware that there has been any research. I think there's a real lack of research. So what we're seeing at the moment, which kind of is a good thing. Is a real focus on sustainability and carbon emissions and that kind of thing. And, you know, particularly in lighting we're seeing this,[01:30:00] but also, you know, across the sector with, heat pumps and that kind of thing. I think what we're seeing is a focus on sustainability and emissions, cost of other impacts. I'm not aware of any research, but this says being looked at as part of the, I think the PAS touches on this.

So this is something that British standards Institute we've got out at the moment. And it's something that we're talking to, those who, the team here, right in the health building notes, around in-patient services. Yeah, but I'm, I'm so delighted that you're asking this question and, you know, I wonder if, you know, how, how we kind of bring the learning together. So we're talking with quite a few different, kind of architects, teams and environments teams and the estates team. Yeah, so I'm sure there's kind of an interested group that we might be able to bring together and kind of share some learning. Yeah. So maybe if you would be happy to, to email me and we might be able to think about how, how we joined up and, and share what we're learning and what works and what [01:31:00] doesn't work.

So a question from someone about how, how to engage and co-produce. So my, my best suggestion on this is employing an autistic person as an advisor. So that that's, that's how, how we work when we're coproducing this. From the beginning, we get an autistic advisor and they work with us to advise on what are we asking the right questions? How do we get our approach, right? How do we get our payments right? What information and support do we need to provide to people? What format do we need to do it in. How do we do it in an autism informed way, in a way that's really accessible and will help us to reach the right people in the right way. So yeah, there's a lot of kind of hints and tips around, kind of, how to make it accessible and engaging, but I'd really, advocate getting, getting an autistic person as an advisor and working alongside you on that.

**Chris:** Can family do more to support their loved ones? As when dealing with some cases, tosupport their loved ones, [01:32:00] when dealing with some cases. It's more of a housing issue than anything else. I think that goes down to that personal side of things jill was mentioning a few moments ago, working on everything that they can do for the individual rather than the environment. So headphones, even things like, chewies like chew toys, that's fiddle stuff. Like I've just ordered a few more tangles, the fiddly finger stuff. So like having my fingers, doing something, there's also things like that. And also also just supporting, understanding, research, looking into things so they can engage.

One of the best coping mechanisms in the world for an autistic person. I firmly believe this is having someone download to. Having someone you can talk to about your special interest about your day, about anything. It's the way to clear the roads. My family lives, but downloading each other in the evening. So like it's the only way we cope with our lives half the time is so we go downstairs and whoever has had the worst day tends to download at the other ones. And then we kind of move it back and forth after that point. Like, it's just a thing that happens. It's so it's our equivalent of going to the pub and having a drink with friends. So that [01:33:00] family can offer that family can actually care about that. And that's a huge way of doing things.

**Jill:** Very good. Thanks so much, Chris. So I think, I think we're at time. So thanks again to, to Andrew for starting us off and, for working with us on this. Thanks again to the LGA for hosting. Chris, thanks so much for your time and expertise and storytelling. Do have a look at the links and, yeah, we'll, share, share the presentation with all of that information and links to the references that we've made.

 There's also going to be a feedback survey, some app. So if you're willing to complete that, we'd really be very grateful. All right. Very good. Rachel, any more from you?

**Rachel:** Well, just to say a massive, massive thank you to Chris, Andrew, and to Jill for a really, really fantastic presentation and to everybody who helped organize it.

I think it's a really great presentation, great report. There were lots in there for everybody. And we will circulate a link to the [01:34:00] report, a link to give you the PowerPoint. We'll be putting it up on the website as well. Cause we've got a recording of this and we will answer all the questions fully.

So, but thank you to everybody for their time. And I hope you have a really good afternoon.