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Project Summary

Background

Hospitals are busy places with multiple sounds, lights and smells which can add additional tensions and stress for children and young people with sensory needs when they visit for outpatient appointments or an inpatient stay. The North West Sensory Friendly Environments project worked with children, young people, families and staff to try and make Alder Hey Children's NHS Foundation Trust a better place for children and young people with sensory challenges. The project focussed on making changes to the physical environment, equipment and resources, and implementing training sessions to increase staff's understanding of children and young people's sensory needs.

An independent evaluation of the Sensory Friendly Environments project conducted by researchers at Edge Hill University, gathered information from families and staff within Alder Hey Children's NHS Foundation Trust.

Design and Methods

The methods used in the evaluation were guided by consultation with children and young people and parents/carers. Children and young peoples' views were collected through paper activity sheets, parents/carers experiences and opinions were gathered through short online surveys and the views of Alder Hey staff and the sensory project team were collected in short online surveys.



Findings

There were 189 participants who shared their views as part of the evaluation including 31 children and young people with sensory needs, 38 parents/carers, 110 Alder Hey staff and 10 sensory team project members.

Part 1 - Sensory environment training for Alder Hey Staff

74 staff from a broad range of departments took part in the training evaluation, with 42 completing both pre- and post-training surveys.

- After the training, staff reported improved knowledge and understanding of the lived experience of children and young people with sensory needs, and increased confidence to identify areas where support could be improved.
- After the training, staff left motivated to make a difference, with ideas for areas of practice which could be improved.
- Staff identified that the most useful information in the training was the opportunity to hear the lived experiences of children and young people with sensory needs, families and staff, with the video and animation being described as very powerful.
- Most staff reported the training met their expectations. One area identified as not covered was
 - techniques for working virtually with children and young people with sensory differences.
- Areas to be covered in future training sessions included barriers to offering sensory support and how to overcome them, how to support autistic parents/carers, strategies to support children and young people including the use of toys or equipment, and greater depth of learning to build on the original session.
- Staff identified areas within their practice to improve the experiences of children and young people with sensory needs staff. These included resources such as social stories or a video to support the family to prepare the child for the visit, flags in the in-touch system and use of buzzers when waiting; better signage, quiet areas, and sensitively decorated rooms; improved communication with families around needs and adaptations.
- Staff reported that further funding was needed to support further environmental changes and the provision of equipment, along with the development of a knowledgeable team to support continued improvements and roll out.
- Future training was reported as important alongside enabling all staff to exist this current training so the culture of the trust could change.



Part 2 - Reported impact of the sensory environment project

Children and Young people

A total of 31 children and young people (girls=19; boys=12) completed activity sheets from a range of inpatient and outpatient departments across the hospital.

- Children and young people wanted the hospital to feel more welcoming with rooms and walls decorated in a more child-friendly manner. Children identified many environmental issues that made visiting the hospital difficult, there was too much noise, the smell of the food and drink in the public waiting areas was nauseating, the lighting was too bright, the ambient temperature was too hot and the WIFI was unreliable.
- Children and young people wanted to be well-informed about why they had to go to hospital and not having enough information about their visit created difficulties for some children.
- Children and young people experienced long delays and wanted shorter waiting times. Whilst waiting children identified that comfortable age-specific areas would make them feel better about coming to hospital and decrease the likelihood that they would feel upset and/or worried.
- Children identified that seeing friendly, happy, smiling staff really helped their hospital experience. Children wanted staff to talk to them more often and to feel like staff were listening to them when they were talking.
- Not being able to have weekend appointments made some children worry about missing school.





Parents/carers

38 parents and/or carers shared their views in the online survey. The ages of their children ranged between 3–16 years. The parents/carers had visited a range of hospital departments with their child.

- Many of the parents/carers reported not noticing a difference in the environment within Alder Hey Hospital for their child with sensory needs and continued to face high levels of challenge in attending the hospital with their child.
- The parents/carers identified many aspects within the environment which impacted on their child's visit, these included the loud noise, bright lights, strong smells, long waiting times, lack of toys and/or things to do in departments, and not having any quiet spaces for their child to remain calm and not become overwhelmed while waiting.
- Parents/carers reported that when sensory toys, systems to reduce the waiting time, a quiet place to wait, headphones and the ability to dim lights were available this was very helpful to their child and enabled them to remain calm.
- Parents/carers also identified challenges in the way that Alder Hey staff communicated with them and their child during visits. Some parents/carers reported feeling disregarded and dismissed when they tried to advocate for their child's needs and staff were reported as ignoring their child and not engaging with them.
- Parents/carers also shared examples of staff spending time, talking calmly and slowly, building trust and communicating directly with their child based on their individual needs. Some parents/carers specifically mentioned the learning disability team as an important support mechanism for their child to have a positive experience of appointments.

Alder Hey Hospital Staff

36 staff shared their views, representing inpatient wards, outpatient departments, community services and the Emergency Department and clinical and non-clinical staff.

- Staff identified that children and young people being 'welcomed' by staff who are aware of a child's needs is important. Staff reported feeling that they cannot spend the time they would like to (or need to) with children and young people with sensory needs.
- Most staff identified that environmental factors made visiting Alder Hey NHS Foundation Trust difficult for children and young people with sensory needs, these included bright lighting, busy waiting areas and loud noises.
- Staff identified that there was a need for dedicated quiet spaces, with dimmed lights to help children and young people stay calm and relax, particularly within busy departments.
- Reduced waiting times, quieter clinics and having the time to pre-plan a visit with families would help children and young people with sensory needs have a better experience.
- Most staff identified training in sensory needs as an important priority.
- Investment in resources (e.g. sensory equipment, fidget toys, Makaton training, more clinical time, quiet spaces, better waiting rooms) was identified by staff as a priority.

- Successful changes identified by staff included the provision of sensory boxes, distracting and stimulating décor on the walls and having tangible sensory aids (e.g. ear defenders, fidget toys, more signage) and televisions for children in waiting areas.
- The majority of staff who were aware of the sensory project reported feeling excited and positive about how the much-needed work will be beneficial to children and young people with sensory needs.

Part 3 - Reported barriers and facilitators of the sensory project team

Ten members of the project team took part in the survey, including one young person.

- The things that worked well included the collaborative approach which led to the project team engaging and listening to children, young people, parents/carers and representatives from across the NHS trust; there had been clear leadership to drive work internally; the team was reported as responsive and cohesive who are committed and enthusiastic; the online meetings had a clear structure and next step plans.
- The biggest achievement was the collaborative working with families and use of powerful lived experience stories in the training, video and animation. This was viewed as something that should be a continuing legacy for future activity.
- Other key achievements were: the impact of training on staff's knowledge and confidence to support this work, and working together as a team to create solutions and a better experience for children and families.
- The barriers identified included time for the work but also for change at an institutional and system wide level, including IT structures; the impact of COVID, and bigger changes taking longer than the project timeline.
- The challenges identified included, staff capacity, management of the communications, and becoming aware of problems within the current service. COVID restrictions made it challenging to create meaningful change in a short timeframe. For some there were challenges around following who was doing what due to the size of the team and slow communications at times.
- Things that could have been done differently or recommended for future work included engaging with families who may not be attending the hospital; having a dedicated lead/team to support fast implementation; a longer lead in time; greater use of parent/carer walk-throughs; involving more children and young people in developing resources.



Main report



Background

The hospital environment can be overwhelming for children and young people with sensory processing difficulties or sensory sensitivities (Gupta et al. 2019). Children and young people with sensory needs are most commonly autistic, have cerebral palsy or have attention-deficit hyperactivity disorder (Gupta et al. 2019).

Hospitals are busy places with multiple sounds, lights and smells and these can add additional tensions and stress for children and young people with sensory needs when they visit for outpatient appointments or an inpatient stay. Evidence shows that increased anxiety and feelings of being overwhelmed within a hospital environment can result in autistic children demonstrating behaviours that challenge resulting in child, parents/carers and staff stress and possible injury (Johnson & Rodriguez, 2013). Additionally young autistic patients can struggle to communicate their anxiety, needs and opinions and health-care providers and hospital organisations have been shown to be lacking in providing services which respond to these young peoples' needs (Muskat et al. 2015).

Alder Hey Children's NHS Foundation Trust received funding from NHS England to implement changes throughout the trust to improve the sensory environment for the many children and young people with sensory needs which are seen within inpatient, outpatient and community services every year. The North West Sensory Friendly Environments project asked children, young people, families and staff to work together to help make Alder Hey Children's NHS Foundation Trust a better place for children and young people with sensory processing challenges and sensory impairment to visit. The Equality Act 2010 places a duty on service providers to make reasonable adjustments to ensure people with a learning disability and/or autistic people are not disadvantaged by the hospital environment.

The North West Sensory Friendly Environments project is led by Lisa Cooper, Director of Community and Mental Health Services at Alder Hey Hospital and hospital colleagues, working alongside two charities, <u>Contact – for families of disabled children</u>, and the <u>National Team for Development and</u> <u>Inclusion (NDTi)</u>. The sensory friendly environment project is focussing on:

- Making changes to the physical environment to improve children, young people and their family's experiences when they visit the trust including lights, sounds, seating and spaces;
- Making changes to some equipment and resources provided to children and young people with sensory needs including fidget toys and sensory rooms;
- Staff training to increase their understanding of children and young people's sensory needs including non-clinical staff, so everyone involved in the child or young person's visit has awareness of sensory needs.

Patient and Public Involvement and Engagement

In the process of designing this service evaluation, we consulted with six young people who mostly had additional sensory needs. This consultation occurred online via Teams through dialling into an established youth forum (school-aged children and young people). We also spoke individually with one young adult via online video link. The consultation focussed on asking children and young people for input into the recruitment and data collection methods. This aimed to make sure that the methods proposed did not add any additional anxiety or burden to children and young people coming to the hospital and that the methods used enabled the widest group of children and young people possible to share their views and experiences, being particularly mindful of individual sensory preferences.

We also held an online meeting with two parents of children and young people with additional needs to gain their insight into the best approaches to use to gather information from parents/carers and also to use with children and young people. The suggestions and preferences from the consultations fed into the evaluation design and the materials which were developed for parents/carers and children and young people to ensure that they were appropriate for the clinical settings and placed minimum burden on participants.

Design

This project used a mixed method design drawing upon structured information from online surveys whilst also enabling participants to share their views and experiences in open text qualitative responses. The evaluation consisted of three main parts;

- 1. **Part one** focussed on the reported impact of sensory environment training within Alder Hey Children's NHS Foundation Trust which was delivered for clinical and non-clinical staff by NDTi;
- 2. **Part two** focussed on the self-reported impact of changes made as part of the North West Sensory Friendly Environments project on autistic and/or learning disabled children and young people, their parents/carers, and clinical and non-clinical staff working within a range of environments across the hospital and identified areas for future improvement;
- 3. **Part three** explored the reported barriers and facilitators to the North West Sensory Friendly Environments project and its implementation from the perceptions of the project team and those involved in delivering the sensory environmental alterations and staff training.





Ethical considerations

The project gained ethical approval through the Health Research Ethics Committee within Edge Hill University (ETH2122–0236) on 28/04/2022 and subsequent approval with Alder Hey Hospital through the Audit/Service Evaluation Panel (REF: 6612) on 04/05/2022.

Parents/carers and children and young people with sensory needs were identified by staff and/or the research assistant and were handed a one page poster/flyer which briefly explained what the project was about and outlined the different ways they could join in. If a child or young person was too anxious to agree to take part, or did not want to take part, then the parents/carers could complete the online survey on their own. The research materials were designed, with help from children, young people and parents/carers to be accessible, short and simple.

Verbal consent from parents/carers and assent from children and young people was obtained and continued agreement to take part was viewed as an ongoing process, with several points along the journey where parents/carers and/or children and young people could change their mind about participation. Consent was assumed from staff by the submission of the online survey, with a box to tick to confirm participation.

A short debrief/support sheet was handed to all children and young people and parents/carers before they left the department, this detailed places to access support and the contact details of the research team.

Part 1 - Sensory Environment training for staff within Alder Hey Children's NHS Foundation Trust

Between 20/05/2022 and 09/06/2022 sensory environment training was delivered to Alder Hey Children's NHS Foundation Trust clinical and non-clinical staff by NDTi. Training was delivered both in person (two sessions) and via an online platform (delivered in two sessions) and was developed with families and staff. Topics included awareness of the social/emotional impact having autism can have on a child or young person and their family; increasing confidence in supporting a child or young person (and their family) who has sensory differences; and becoming intuitive about sensory environments to identify small potential changes with big impact.

Aim

To explore the self-reported impact of the sensory environment training on clinical and nonclinical staff.

Objectives

- To assess staff's pre-training self-reported knowledge, confidence and understanding of children and young peoples' sensory needs within the trust.
- To examine staff's post-training self-reported knowledge, confidence and understanding of children and young peoples' sensory needs within the trust.
- To identify any changes staff perceive are needed to further improve the experience of children and young people with sensory needs within the trust.

Methods

A short online survey was administered through Survey Monkey, which was completed immediately before and after the training session whether the training was delivered online or in person. A short participant information sheet was placed at the beginning of the survey to ensure that staff were aware of what taking part involved, that participation was voluntary and anonymous, and exactly what would happen to the information they shared. There was also a link to a longer participant information sheet housed on Figshare, which provided additional details about how the information collected as part of the project would be managed.

The pre-training survey link with the embedded short information sheet was shared with attendees at the beginning of the session and the post-training survey link at the end. It was made clear to session attendees that participation was voluntary and anonymous. The pre- and post-training surveys were linked via a self-generated identification code (SGID) as a participant ID. Participants were asked to create a unique code from the first letter of the month they were born and the last four digits of their phone number or a memorable date (DDMMYY). We developed this approach as relying only on initials or text has been shown to be unreliable (Schnell et al. 2010; Yurek et al. 2008). As there was only a short amount of time between both the surveys being completed we hoped respondents would not forget their self-allocated participant ID.

The surveys focussed on staff's pre- and post-training self-reported knowledge, confidence and understanding in relation to supporting children and young people with sensory needs within the hospital. The survey also collected the self-reported short-term impact of the sensory environment training, plans for any future sensory/environment improvements, identified ongoing support needs of staff and their views on any facilitators, and barriers and challenges to implementing potential changes. We hoped that as the surveys were anonymous, this would facilitate a platform for staff to share their honest views. The only demographic information collected was the professional group of the participant, how long they have worked at Alder Hey Children's NHS Foundation Trust and whether they attended the sensory environment training in person or via an online session.

Findings

The staff who took part in the training survey

Using the unique ID that staff entered into the survey to enable matching of the pre and post surveys, the pre-training surveys were completed by 74 people and both pre- and post-training surveys by 42 people. There were six post-training surveys which could not be matched to a pre-training survey. The number of responses for the questions on department (n=84) and role (n=78) are higher than the total 74 people who participated, as some people provided additional information in the 'other' section or ticked more than one option.

The staff who took part identified themselves as working in outpatients (n=34), inpatients (n=16),

emergency department (n=2) and critical care (n=2). The 30 staff who chose 'other' stated their department as: mental health/psychology (n=8), community nursing and physiotherapy (n=8), academy/institute/research (n=5), across site/combination of in/out patients/community (n=3), administrators (n=2), theatre/theatre recovery (n=2), discharge team (n=1), and play service (n=1).

The staff identified their roles as allied healthcare professionals (n=33) and nurses (n=15). Those who chose 'other' provided their role as: health practitioner/therapist/psychologist (n=8), administrator/receptionist/concierge (n=5), academy/institute/research (n=5), play service (n=3), phlebotomist/HTA phlebotomist (n=3), audiologist (n=2), mental health events coordinator (n=2), health care assistant (n=1), and operations manager (n=1). The majority of staff had worked at Alder Hey Children's NHS Foundation Trust for over 5 years (n=28), the rest were less than 2 years (n=26) or 2–5 years (n=19). The majority of training was complete online (n=73), with one person completing it face-to-face (n=1). Due to all staff receiving the same training and small numbers for some departments and roles, the responses are reported as one group. Any different views identified between patient facing and non-patient facing staff groups or work setting have been clearly described.





Responses from the 'before the training' survey

Those who attended training were asked **what do you hope to gain from today's session?** The majority of the 70 responses related to gaining a better understanding, knowledge or skills to support children, young people and families and improve their experience: "A deeper understanding of sensory differences and how I can adapt my work to ensure the best patient centred care". Staff also felt that if children and young people were more relaxed it would improve the effectiveness of appointments leading to better care: "Better understanding of creating a relaxed environment for children with additional needs which will allow us to obtain more hearing test information from them." Staff identified that training could support them to adapt their practice and/or the service to better meet the needs of the children and young people: "I hope to increase my knowledge of sensory differences and be more aware of how I can help to make Alder Hey more accessible and be more adaptable for needs".

The Alder Hey Children's NHS Foundation Trust staff attending the training were asked **what is your understanding of the term 'sensory need'?** Many of the 68 responses showed an awareness of this term relating to how children and young people were receiving and processing sensory information from the environment through their senses and how this may impact on them or create "overload" or "hypersensitivity". Some listed the senses which can be impacted or gave a number of them ranging from five to eight: "A need to understand and support an individual's sensory challenges. I'm aware of the 8 different senses that can be impacted." Two staff members linked it to learning disabilities, autism spectrum disorder (ASD), or "an impairment of a child". Many others spoke of it being when a child or young person has difficulties or additional needs: "where a child has additional needs regarding their environment around them". Some staff highlighted the impact on the child or young person and their ability to engage and regulate in challenging environments: "A sensory need is when a person's sensory needs impact their day to day life and it impacts their ability to engage in activities of daily living." One staff member spoke of a sensory need as "a need to feel part in the world".

Staff were asked to share their views of **anything important about the sensory training you are about to have.** There were 19 responses, many of which indicated that staff were keen to learn and use new knowledge to implement new approaches in practice, after the "*much needed training*". They highlighted issues they were looking forward to learning more about to help them improve the experience of children, young people and families including: "*Autism awareness training*", "*needs of children with sensory difficulties*", "*hearing children/young people's views of sensory environment at Alder Hey and how we can improve their experience*", "*considering this as a trust and the everyday reasonable adjustments that can make a difference for children and young people*", "*if colour and lights are talked about*", "*skills and tips for working virtually with children with sensory needs*". Some staff also referred to taking any skills learnt out into other settings such as schools: "*Will be great to see if there is anything we can take to inform schools as we do not have a hospital base*".

One staff member wrote of needing to know if a child or young person had needs: "it would be useful to have an indicator on so as you are aware of child needs regarding sensory issues". Staff were keen to learn from lived experience: "I am looking forward to learning about this from a different point of view" and "interested to see if we are delivering services in the way that children want".

Two staff members wrote about learning more about autism which they or a family member have: "I am autistic and therefore would be interested to find out more details of how my sensory needs affect me in a way I've never thought of before" and "I have an autistic son so have some knowledge but require further help and information".

Reported change in knowledge, communication and confidence as a result of attending the training session.

Before and after the sensory training session, staff were asked to rate their:

- knowledge of the factors which can impact the experience of a child or young person with a sensory need when they visit the hospital on a 100 point visual analogue scale with anchors of 'I know nothing' to 'I feel very knowledgeable';
- knowledge of communication approaches with children and young people with sensory needs when they visit the hospital with anchors of 'I know nothing' to 'I feel very knowledgeable'; and
- confidence in supporting a child or young person with sensory needs when they come to your department/ward with anchors of 'I am not confident at all' to 'I am very confident'

After undergoing the training there was an increase in staff's reported level of knowledge of factors which can impact a child or young person with sensory needs, knowledge of communication approaches to use with children and young people with sensory needs, and their confidence in supporting a child or young person with sensory needs in the trust.

A series of paired t-test was run for the 42 staff who completed the surveys before and after the training to examine any statistically significant change between the reported levels of knowledge and confidence. There was a significant increase in the level of knowledge of factors (t(41)=-9.626, p<.0001), knowledge of communication (t(40)=-10.544, p<.0001), and confidence (t(40)=-8.539, p<.0001) reported after the training. The table below (Table 1) shows the average mean score and the range of scores, before and after training. For example, the average mean score for knowledge of factors before training was 52.40 out of 100, with scores ranging from 0 to 90; this increased to an average mean score of 81.86 out of 100, with scores ranging from 34 to 100. It is worth noting that although the average mean scores significantly improved for both knowledge and confidence, the range of scores show that some staff reported feeling less knowledgeable and confident.

Table 1. Reported change in knowledge, communication and confidence as a result of attending the training session.

Scale	Before Training Average mean and range of scores	After Training Average mean and range of scores
Knowledge of factors (n=42)	52.40 (0-90)	81.86 (34–100)
Knowledge of communication (n=41)	51.78 (0–90)	79.27 (34–100)
Confidence (n=41)	54.44 (0–100)	79.80 (23–100)

Responses to the 'after the training' survey

Staff were asked to report **the most useful piece of information in the training session.** There were 47 responses. Staff comments were around the power of hearing the lived experiences of children and young people with sensory needs, their families and staff members; the learning

gained from the information shared about sensory needs and autism; what is needed to adapt environments or practice and the benefits of learning through discussion.

Hearing from experts by experience through the presentations, video and animation were highlighted as "very powerful", "thought provoking", and "reinforced how impactful the sensory environment can be on a person's wellbeing and functioning". The animation was viewed as "fab" and impactful. Many staff reported learning about "the different sensory processing needs", "the overall impact of all the different senses", "how [people] react and what they react to", and generally "being made aware of all the challenges that people face when visiting the hospital". One staff member also commented on the need for further learning: "I am not from an ASD background, I feel it is important to keep learning about it".

Other learning seen as useful included how to identify areas which may trigger problems for those with sensory needs, such as "awareness of the overwhelming experiences for the environment and flooring. Lights around the room" and "to consider all senses, including smell". Staff recognised the importance of applying this awareness to practice by thinking about how to "adapt places not suitable for sensory diverse individuals to make it comfortable and welcoming". It was also acknowledged that "sensory needs can affect our staff and colleagues as well as our patients".

Learning through discussion was really appreciated and staff were reassured that "*a lot of departments experience the same issues*". The opportunity for staff to talk together and draw on the different knowledge and experience available was highly valued "*opportunity to learn about other offers within Alder Hey*", along with a feeling of motivation that "*as staff members we can and really want to make a difference*". The quiz was viewed as a useful tool for learning.

Staff were asked to report whether **there was anything else which should have been covered/discussed in the training.** There were 20 responses, which included 12 staff saying they had enjoyed the training and "*no, it was very informative*", although some acknowledged that "further support may be needed going forward". Suggestions for future training areas included: "Barriers that get in the way of being able to offer sensory support and how to problem solve this"; "how best to support parents with ASD"; more information on the basics including terminology especially "for new staff members or staff completely inexperienced in sensory/ASC conditions...as some of the language was unfamiliar"; strategies to support children and young people, including how to calm, "and play sessions to carry out with children with ASD" with guidance on the toys or equipment to use; how to "work virtually with children with sensory differences" and "more in depth information on each sensory area such as proprioception, vestibular etc". It was also suggested that there be "a map of the hospital showing areas where the project had made progress and areas yet to be involved in the project".

"The training has reinforced how impactful the sensory environment can be on a person's wellbeing and functioning". (Alder Hey staff member)

Staff were asked to report on the **impact they thought the training had had on them.** There were 42 responses. Staff reported that the training had improved their knowledge and understanding of "how our patients/carers and colleagues may be impacted by sensory overload", "environmental factors", "the importance of a child's inner world with autism" and was "very beneficial in understanding the young people's experiences with sensory differences". The additional knowledge made staff feel more aware of the issues and increased confidence "around supporting people with sensory differences" and "how we may be able to change things to make it better for our patients with sensory differences". For those with some knowledge and experience in the area, it "reinforced my understanding of sensory needs and the need for adaptions and accommodations to be explicitly offered and delivered".



Some staff felt "invigorated" by the training and "more determination to make a difference to the experience of each patient". Others spoke of reflection and "recognising the things we already do well and ways we can further improve". They saw areas of practice which could be improved by individual changes such as being "more curious about children's sensory needs" and "carefully considering the language I use or the approach I take". Other ideas for service delivery were also highlighted including "communication and preparation before appointments will make the patients' experience so much more positive, for themselves and their parents" and thinking about how "to improve the environment even more". One staff member wrote of being "able to communicate my learning to schools to help inform how we work with children with sensory differences". Another of "how our service (ASD assessment team) could support this (e.g. info sharing with consent)".

As one staff member put it "I thought the training was exceptional. I think every member of this trust needs to partake of it".

Staff were asked whether their understanding of the term 'sensory needs' changed as a result of the training? If yes, how? 34 (46%) ticked 'Yes' and 14 ticked 'No'. Of those who ticked yes, 26 provided responses to say how.

For most staff, their understanding had changed due to becoming more aware and developing a deeper level of understanding such as "*how much of a spectrum it is*", "*acknowledging the hypo/hyper distinction*", and understanding there can be range of triggers for individuals including visual, sound, textures, the floor, and other environmental factors so "*the patient's environment should not be overlooked*". Some staff felt they had "*increased understanding from the patients journey perspective*" through the stories told in the training.

"I thought the training was exceptional. I think every member of this Trust needs to partake of it'" (Alder Hey staff member)

The deeper understanding of sensory needs raised awareness making staff more "conscious of impacts" and "how preparation and understanding can make a big difference". One staff member described how this will improve their practice through increased confidence "to ask what needs children/families have and offer adjustments as much as possible or as required". For some staff, it "refreshed information for me" as they understood sensory needs before the training.



Staff who attended the training were asked to share their views of **any changes they thought would be helpful to improve the experiences of children and young people with sensory needs who attend your department.** There were 39 responses but some did not provide detail. The suggestions encompassed visit planning and family support, environment and staffing resources, strategic planning and development, changes in community teams.

"More funding is needed for resources and information about specific sensory differences that patients have so we are able to fully support them" (Alder Hey staff member)

To support children, young people and families visiting Alder Hey Children's NHS Foundation Trust it was suggested that there be clear communication at the appointment invitation stage, prior to attendance, to gather any information on sensory needs so this can be shared with the clinical area and any appropriate adaptions made where possible. It was also felt that more information could be shared ahead of a visit using "*social stories to explain to children*" about their appointment or "*a video of the process from entering the hospital to going home with a walk through with a family*" would help to make families aware of the reality of visiting a busy hospital so they knew "*what to expect*". Another suggestion was for the "*in touch system to flag up sensory differences with patients*" to help inform staff as soon as possible. Tools which would support

families to wait in the best place for them included "*buzzers for waiting*". Where adjustments cannot be made, staff should "*explain why this is the case to the family and young person and ask if there is anything we could do instead*".

In terms of the environment and staffing resources, many of the suggestions were about "more funding for resources and information about specific sensory differences that patients have so we are able to fully support". This ranged from a significant spend on an area "specifically for children with sensory needs with a team fully understanding of their needs, distractions available, and a service that can allow clinicians to receive an overview of an individual's needs prior to attending" to other targeted resources in areas of the hospital such as physical spaces and equipment: "more quiet areas and sensory rooms", "more reusable/cleanable sensory toys/equipment available in the waiting area", "weighted toys/shoulder wraps", "communication cards" and "adjusting lights and how the room is organised, light projectors, range of different furnishings". Utilising a garden near to outpatients or having a safe space while children and young people wait for surgery was recommended, and to think about the location of different services: "my department is in the basement, we are often overlooked and forgotten...as a team we do need to be more proactive in sensory awareness". The fire alarm process was also viewed as "not ideal". Improvements to the environment such as "better signage", "less busy waiting areas", "easily accessible route finding e.g. the outpatients department could be colour coded, variety of decor - keep some rooms bland". Other staff mentioned a new building which may improve visits for families "not having to walk across a noisy building site to reach appointment" and a need to have "more information about new building we are due to move into so we can prepare updated info leaflets for families and young people".

Staff training and communication was viewed as very important, as was "being curious about what works for them and not assuming you are addressing the most appropriate sensory need". In addition to service specific suggestions, strategic planning and development was also identified as important including the "need to audit dynamically to perpetuate change" and use of a hospital passport to facilitate information being available on Meditech. To ensure future development and response to children, young people and family needs, it was suggested to conduct regular evaluations "to ask all children how we could improve things for them after they have attended any department".

"We need to think how you change the culture as a whole rather than exclusively making minor physical adaptions" (Alder Hey staff member)

For staff working in the community, the training led to suggestions of putting together "a leaflet

with some ideas for supporting children and young people with sensory needs and how to create a beneficial environment in schools" to share learning and create wider improvements.

Staff were asked to share their views about **anything else important about the sensory training you have just had.** There were 25 responses which provided positive feedback about the training, passion to make changes moving forward, and some suggestions for future training and support of staff. Staff views have been reported in an earlier section but additional feedback received here included appreciation for including staff who are not patient-facing as this felt like "how you change the culture as a whole rather than exclusively making minor physical adaptions". There was also appreciation for "including staff and parent sensory differences too!"

For future training it was suggested that "breakout rooms would have been useful in groups of shared departments" to explore the different experiences of different teams. It was felt to be essential that "all staff working with patients are provided knowledge about individual needs of patients" and that "more training should be available". One staff member suggested that it would be helpful to direct staff "to links that we could use and recommend to parents also".

Some staff appreciated the opportunity to meet other colleagues from across the trust and to hear how the project is aiming to support children, young people and families who are impacted by sensory processing differences. It was also seen as a strength of the project that it "*is taking such a neurodiversity-affirming approach in language used and in its collaboration with autistic people*". Staff are keen to "*see changes implemented from a Trust perspective*" as currently they can mainly see only the changes in their own areas.

"It [the training] is taking such a neurodiversity-affirming approach in language used and in its collaboration with autistic people." (Alder Hey staff member)

Key points from the Sensory Environment training for staff survey

- After the training staff reported improved knowledge and understanding of the lived experience of children and young people with sensory needs, and increased confidence to identify areas where support could be improved.
- After the training, staff left motivated to make a difference, with ideas for areas of practice which could be improved.
- Staff identified the most useful information in the training was the opportunity to hear the

lived experiences of children and young people with sensory needs, families and staff, with the video and animation being very powerful.

- Most staff reported the training met their expectations. One area identified in the pretraining survey not covered was working virtually with children and young people with sensory differences, this was requested for future training.
- Other future training areas to support continued learning including barriers to offering sensory support and how to overcome them, how to support parents/carers with ASD, strategies to support children and young people including with toys or equipment, and greater depth of learning to build on the original session.
- To improve the experiences of children and young people with sensory needs staff felt identification of needs prior to attendance was key, along with resources such as social stories or a video to support the family to prepare the child or young person for the visit. Other improvements included flags in the in-touch system and use of buzzers when waiting; better signage, quiet areas, and sensitively decorated rooms and improved communication with families around needs and adaptations.
- Funding for further environmental changes and provision of equipment, along with development of a knowledgeable team to support continued improvements and roll out.
- Future training was seen as important along with spreading the training to all staff so the culture of the trust would change in addition to any physical adaptions.



Part 2- Sensory Friendly Environment Alterations

This part of the evaluation focussed on the environment and resource alterations linked to the Alder Hey Children's NHS Foundation Trust sensory environment project. The evaluation was conducted in the clinical areas identified by the Alder Hey sensory project team, and included inpatient areas and outpatient areas. This part of the evaluation involved children and young people, parents/carers and the staff working in the departments/clinical areas.

Aim

To explore children, young people, parents/carers and staff perceptions on any of the environmental changes which had taken place as part of the sensory project and examine their views on future developments needed within the department and hospital.

Children and Young People with Sensory Needs

Recruitment

Our recruitment processes were informed by the PPIE consultations which clearly identified that reading lengthy information sheets and filling in paper consent forms would not be appropriate in busy clinical areas and may cause additional burden for families. The team were aware that children and young people with sensory needs may have cognitive impairment and so the information sheets and instructions were designed to be easy to understand and simple. Children and young people with sensory needs and their parents/carers who entered the selected clinical areas were handed a flyer about the evaluation by a member of Alder Hey Hospital staff. The one page flyer briefly explained what the evaluation was about and outlined the different ways they could share their views if they wanted to take part. At this point a member of the evaluation team approached them to see if they would like to join in, provided any further information about each method and answered any questions about taking part. If the child or young person was too anxious or did not want to take part at the time, then the team member reassured them this was fine and left the flyer and an activity sheet with the parents/carers in case they changed their mind and wanted to share their views later.

Objectives

- To explore the experiences of children and young people when in the hospital to identify positive and negative aspects of the sensory environment and any resources or equipment, including any opinions or views of the environmental alterations made as part of the project.
- To identify any changes needed to further improve the experience of children and young people with sensory needs within the hospital service.

Methods

Children and young people were given a choice of how to engage and share their views as part of the project. The range of methods were selected to enable children and young people who may have a range of communication and sensory needs to take part. Children and young people were able to choose to engage with one or several of the following methods.

An activity booklet (Figure 1)) was developed to provide a way for children and young people to 'draw and/or write' or 'draw, write and tell' to share their views and experiences about their visit to Alder Hey Hospital. The activity booklet was designed with input from young people as part of the PPIE consultation. The activity booklet asked the children and young people how they felt before and during their visit (using emojis), what helped them during their visit, what could have been better, what was good or could have been better about the environment and any resources, what was good and could have been better about interactions with the staff.

Alder Hey sensory project Short Activity Book for children We would like you to tell us what it is like when you visit Alder Hey, and what could make it better.	How did you feel waiting for your appointment? (circle how you felt)	If you complete this booklet after you have left the hospital ask your mum/dad carer to scar this QR code to send it to the team.
We would like you to think about sensory things like lighting, noise, smells and seeing the staff. Anything you write down or draw is helpful, so please be honest and add as much information as you can! How did you feel coming into the hospital?		Please write or draw what you find most difficult when visiting
(circle how you felt) Can you tell us what made you feel this way?	How did you feel seeing the staff? (circle how you felt) Can You tell us what made Can You tell us what made	Alder Hey, thinking about lights, sounds, smells and other sensory things
What could have made this better?	What could have made this better?	Whatever you think is okay (there is no right answer) When I go to hospital the worst thing is When I go to hospital the best thing is I wish that when I went to hospital

Figure 1; Activity book for children and young people

The activity booklet could be completed by children and young people while waiting in a department/clinical area, after their appointment or visit or later at home by their parents/carers by uploading pages anonymously to a secure platform. In some cases, where time allowed and a child or young person was keen to talk, the research assistant checked their meaning of any drawings or written work and in some cases noted down additional information spoken by the child. The activity booklets were anonymous and did not contain any identifiable information, if a child added any names, initials or identifiable information this was permanently marked off using permanent marker pen before being scanned in and saved on the secure drive.

We had planned to use several other methods to gain the views of children and young people. We had planned to use large sheets of paper within the departments to prompt children and young people to share their views about their journey through the hospital using creative materials. Whilst we had developed the large sheets and prepared child-friendly materials (low odour non-staining washable pens and stickers), finding space in the busy departments was challenging and the throughput in departments did not enable children and young people the time to engage in these creative activities. We also included the opportunity for children and young people to take photos of good and challenging things within the hospital environment and upload them anonymously to a Survey Monkey platform. These photos were not to include any people. However, no children or young people chose to share their views using this method.

A short sheet was handed to all children and young people and parents before they left the hospital which detailed possible places to access support and contact details of the research team and independent point of contact at Edge Hill University.

Analysis

Qualitative data were analysed using content analysis techniques (Hseih & Shannon 2005). Analysis was led by the research assistant and then independently checked by a second member of the evaluation team.

Findings

A total of 31 children and young people (girls=19; boys=12) completed activity sheets from a range of inpatient and outpatient departments across the hospital. Their ages ranged from 6–15 years of age. Data were collected on different days of the week (Monday–Friday) over nine separate visits. Although the larger sheets were available for children and young people to draw on, they proved impractical for the areas within the hospital where children and young people were recruited. No children or young people chose to either take or upload photographs as part of the project.

Children and young people were asked to share **how they felt about coming to hospital** on a range of smiley faces. There was an even split between children and young people who described being either 'happy' or 'neutral' (n=14) and those who were 'unhappy', 'angry' or 'worried' (n=13). Four children or young people chose not to respond to this section. Children and young people who indicated they were happy (n=7) about their visit, identified that "*I had information to read which made it feel better*" and "*there are toys to play with*". Their written and spoken comments indicated that "*access to wards could be better*".



Children and young people who described being unhappy (n=9) about their hospital visit linked this to there being "too many people", to not "being told what will happen before we arrive" and that they "don't know the staff". Children and young people who described feeling angry (n=2), identified that they were "scared" and 'hate' going to hospital ("I hate it here"), and that the hospital should "be more welcoming". Children and young people who described being worried (n=2) about coming to hospital shared that they wanted "someone to comfort me" and drew a picture of staff with no facial features alongside a picture of a smiling face. Children and young people who indicated that they felt 'neutral' (n=7) about coming to hospital cited "not having my family with me" and "not having anything to do". They also reported that having "more information", "if there were snacks available" and if there was "calm music", "kids music" or "football on TV", their experience would have been better.







Children and young people were asked how they **felt about waiting for their appointment**, by rating on a range of smiley faces. The majority of children and young people were either 'unhappy', 'angry' or 'worried' (n=20), with those indicating that they were 'happy' or 'neutral' evenly split (n=4 each). Three children or young people chose not to complete this section. Children and young people who reported being happy (n=4) while waiting for their appointment, reported "*I like hospital*" and that having "*toys to play with*" and being able "*to learn stuff*" would have made their experience even better. Those who indicated that they felt 'neutral' (n=4) about waiting for their appointment identified that although "*I know why I am here and what is going to happen*", some still wanted "*more information before I arrive*" and there is "*nothing to do while I am waiting*" and it "*should be quicker*".

Those who indicated they were unhappy while waiting (n=9) identified that this was because they felt "anxious", "nervous", "worried", "scared" and/or "because I wait for ages and I'm in pain". Children and young people who were angry while waiting (n=4) recognised this was because it was "boring", but it was sometimes due to their own impatience "I am inpatient". Children and young people who felt angry wanted "more toys" and "comfortable chairs".

Those children and young people who reported they were worried while waiting (n=7), linked this to taking too long "I felt screamy and annoyed because I just wanted to get this over with", too many people ("there is a lot of people and it is very annoying") and having to "wait for ages". Children and young people were also worried because they "don't like missing school to go to appointments". Children and young people suggested that "having someone professional to talk to" or "if there's food or drink to offer while I'm waiting I'll feel better". They felt it might be better if they "get quicker service", had "a play / appointment waiting area for only specific aged children to stay in" and "maybe a text or call if running very late so I don't miss too much school".



Children and young people were asked to report **how they felt when seeing the staff in the hospital** by rating on a smiley face scale. The majority of children and young people indicated that they were 'happy' (n=18). This was linked to staff being "very kind and nice to me" and "they were really kind and helpful" and "asked me how I felt". Five children or young people in this group wrote down "nothing" when asked about what could have made their visit even better. Children and young people who chose the neutral face (n=4) recognised that staff "were nice" but indicated that "I would really \P more time". Children and young people who indicated feeling unhappy (n=2) talked about being scared of staff "they were scary". Children and young people who were angry (n=2) wrote "leave me alone" and "I don't want to [see the staff]". One child/young person indicated feeling worried, drawing a picture of themself alone in an examination room. Children and young people thought it might be better if there was access to "stickers and toys" and the consultation rooms were decorated in a more child-friendly manner (drew a picture of a teddy bear, a flower and a heart). Four children or young people did not complete this section.

Children and young people were asked to share their views about **who or what made the hospital visit easier** by writing in an open text space on the activity sheets. Children and young people identified the support of their family "*my grandparents, my mum, my brother, me, my dad*" (n=16), the staff ("*the staff were really happy*") (n=4), having access to entertainment "*TVs are good – something to distract*" (n=4), their pets (children drew pictures of cats and dogs) (n=2), their own toys (children drew pictures of their teddy bears) (n=2), and food ("*like the food*") (n=1). Some children and young people identified more than one thing, with one child/young person writing "*I don't know*" and seven children or young peopler not completing the section. Children and young people were asked to write their views about the **things that were most difficult about visiting hospital** in an open text space on the activity sheets. The "smelly food" in the public waiting areas (n=3) was identified, with drawings of a burger / coffee cup with lines coming off them indicating smells. Children and young people mentioned difficulties associated with car parking (n=3,) "parking big" and being bored (n=2) "there is nothing to do and play with", "*TV off*" and "wait" with a deliberate scribble in the text space. The lighting (n=4) was identified as "too much bright lighting", along with noise (n=4) "too noise, too loud, shhh" and temperature (n=1) "too hot". One child/young person wrote "When I was at the hospital, I heard children cry and it made me scared because I thought it might happen to me". Another noted that "the Playstation don't connect to wifi" and "games limited". One child/young person drew a picture of a toilet roll as they were worried about the cleanliness of the toilets. Not having enough information about their visit (n=2) "information not explained", "staff forgetting to do stuff" (n=1) and missing school (n=1) "I hate missing school. Could I get a Sunday appointment?" also made children and young people's experiences of visiting hospital difficult. Four children or young people did not complete this section.

When I was at the hospital, I heard children cry and it made me scared because I thought it might happen to me"

(Child with sensory needs)

Children and young people were prompted to consider the worst thing about going to hospital

in a sentence completion question. Children and young people indicated that the "waiting time" (n=7) was an issue for them ("it tax [takes] ages"). The same number of children and young people (n=7) identified something healthcare-related to either "needles" (n=3), "the pain in me" (n=2), feeling "hurt" (n=1) or "being ill" (n=1). The hospital was described as "noisy" (n=2), with "the smell" (n=2) and "the lights" (n=1) being cited as most difficult for some children and young people. They were anxious about "missing school" (n=3) to attend appointments and one child/young person reported not liking it when staff were "not listening" to them. Whilst two cited "everything" as being difficult, three children or young people did not complete the question.





Children and young people were asked to consider **the best thing about going to hospital** in a sentence completion question. Children and young people indicated that interacting with staff (n=8) was most important to them, "friendly staff" and "kind staff", "chatting to the doctors" and "meeting new people" were all cited as the best thing about going to hospital. "The hospital food" generally, and having "ice cream" and "hot chocolate" was reported as the best thing by six children or young people. Children and young people also cited liking to "play with sensory toys" (n=1) and "getting recovered" and "going home" (n=2), as the best thing about going to hospital. One child/young person reported "nothing" was best, and one reported "I don't know". Five children and young people the question.





Children and young people were asked to share in an open text space **what would have made their visit better.** They were asked to complete the sentence 'I wish that when I went to hospital...' There were few 'consensus' answers as their wish-lists were very individual and personal. Children and young people wished "*it was fun*" (n=1) and that there were "toys and books" to use (n=2), "*stickers*" (n=1), "*Ipads*" (n=1), and "*more eating areas*" (n=1) along with "*more children spaces*" (n=1) where "*it is quiet*" (n=1), "*darker*" (n=1) or they could "*play out*" (n=1). One child/young person wished for "*no people*" to be around, whereas others wished "*more people spoke to me*" (n=1) and took the time to "*listen*" to them (n=1). One child/young person wished that "*the injection didn't hurt*", whilst another wished that "*they could stop my wobbles forever*". One answered "*I don't know*". Seven children or young people did not complete the question.

Key points from children and young people

- Children and young people wanted the hospital to feel more welcoming with rooms and walls decorated in a more child-friendly manner. Children and young people identified many environmental issues that made visiting the hospital difficult, there was too much noise, the smell of the food and drink in the public waiting areas was nauseating, the lighting was too bright, the ambient temperature was too hot and the wifi was unreliable.
- Children and young people wanted to be well-informed about why they had to go to hospital and not having enough information about their visit created difficulties for some.
- Children and young people experienced long delays and wanted shorter waiting times. Whilst waiting, thery identified that comfortable age-specific areas would make them feel better about coming to hospital and decrease the likelihood that they would feel upset and/or worried.
- Children and young people identified that seeing friendly, happy, smiling staff really helped their hospital experience. Children and young people wanted staff to talk to them more often and to feel like staff were listening to them when they were talking.
- Not being able to have weekend appointments made some children and young people worry about missing school.



Parents/carers of children and young people with sensory needs

Recruitment

As mentioned above, our PPIE consultations identified that reading lengthy information sheets and filling in paper consent forms would add extra burden for parents/carers and so our recruitment methods were sensitive to the stress that parents/carers may be experiencing when attending hospital. Parents/carers of children with sensory needs were handed a flyer about the evaluation by a member of Alder Hey Children's NHS Foundation Trust staff. The one page flyer briefly explained what the evaluation was about and outlined the different ways they could share their views if they wanted to take part. At this point a member of the evaluation team approached them to see if they would like to join in, providing further information about each method and answering any questions about taking part. In cases where a member of the evaluation team was not present, there was a version of the flyer created which contained an overview of the different ways to take part and links to the full information sheets and the survey for parents/carers to share their views.

Objectives

- To explore the experiences of parents/carers when in the hospital to identify positive and negative aspects of the sensory environment and resources, including any opinions or views of the environmental alterations made as part of the project.
- To identify any changes needed to further improve the experience of children and young

people with sensory needs within the hospital service.

Methods

Parents/carers were also given choice and flexibility of how to engage and share their views, this was in recognition that they were supporting their child during their hospital visit and may be in a rush to leave the hospital after the appointment/visit. The range of methods also recognised that some sensory needs may be generational.

There was a short online survey to gain the views of parents/carers of the sensory environment and resources within the hospital department they were visiting, the interactions between themselves, their child and the staff, the impact on their child when visiting the hospital and any improvements which they felt could be made to improve a hospital visit for children and young people with sensory needs. The survey was accessible through a QR code on the study information and could be completed during their visit within the respective department or after they left Alder Hey Hospital. This flexibility was in recognition that parents/carers may be looking after an anxious child or young person within a busy department. The survey started with a brief overview of key information about taking part, the survey was anonymous and only asked for minimal demographic information which did not identify participants. There was a link to an extended information sheet on a university platform should the parents/carers want further information about how their information would be handled as part of the project. We had also intended to use a wall or table top paper journey map to prompt parents/carers to share their views of their journey through the hospital by writing directly onto the sheet or by using post-it notes. As described previously, due to the busy departments, space and time to engage with the paper sheets was limited. We also invited parents/carers to take photos of good and challenging things within the environment and upload them anonymously onto an online survey platform. No parents/carers chose to engage with this method.

Analysis

Qualitative data were analysed using content analysis techniques (Hseih & Shannon 2005). Analysis was led by one team member and then independently checked by a second member of the evaluation team. The closed answer responses were analysed using descriptive statistics (frequencies and percentages).

Findings

38 parents/carers shared their views in the online survey. The ages of their children ranged between 3-16 years (mean age 10.4 years). The parents/carers had visited a range of hospital departments with their child including the outpatients (n=26), inpatient wards (n=7), and emergency department (n=5). The parents/carers also identified that they visited Alder Hey Children's NHS Foundation Trust with their child at different frequencies; with many families visiting less than 4 times a year (n=23), whilst others visited between 5-8 times a year (n=9), and some families visiting more than 8 times a year (n=8).

We asked parents/carers if they had visited the department they were in before if they had **noticed any differences**, of the 36 parents/carers who had visited the department before, 11 (30.5%) had noticed a difference and 25 (69.5%) had not noticed any differences. Those who reported a difference within the department identified mainly negative differences, including that "the plastic dividers between chairs and all the toys have gone (I assume this is due to Covid)" (n=1), the absence of toys was noted by another parents/carers who stated "Since covid, understandably the toys and books etc have been removed from waiting areas. This makes it even harder to wait to be seen for a child with sensory needs who already struggles. Distractions are needed to keep them calm". Some of the comments on changes were linked to departments being "busier than before" (n=2), "a lot more busy and noisy" (n=1) and with "very long waiting times and alarms going off for around 10 minutes with no action or response and without being asked if we could be helped to reduce the stress for my child who is very obviously severely disabled and distressed by the environment". One parents/carers commented that the addition of "new planting" was good as their child "loves plants and colours".



The parents/carers were asked in an open text format **what could improve the environment** within the hospital for their child. Five parents/carers commented that no improvements were needed. Many comments of what could be improved were orientated around the need for more child-friendly elements within the hospital, particularly within the waiting rooms such as televisions (n-5), toys (n= 3), spaces to play (n=3), books (n=2), more activities (n=1), an outdoor space (n=1) and better seating "where you are looking out the window not facing anyone", or not "having to share a seat with someone" (n=1). Parents/carers also identified the need for quiet spaces (n=6), sensory areas (n=4), "quieter announcements" (n=1), an entrance that was "less hectic" (n=1) and for the "volume to be tuned down on bleeping notifications" (n=1). Suggested improvements also included the need for less "waiting around" (n=1) and for staff to be "more patient" (n=1), have "more awareness" (n=1) and "more understanding of hidden disabilities" (n=1) as well as "better communication about what is happening" (n=1) and "more explanation about different things available for children" (n=1).

"The hospital rooms are very clinical and boring when you walk in. There should be child friendly decorations, uniforms with child friendly characters or patterns and colourful or character bedding"

(Parent/carer of child with sensory needs)

Parents/carers were asked in a closed question if they had **had the chance to speak or tell a member of staff about their child's needs** before they came to hospital, 16 (42.1%) parents/carers had spoken to staff before their child's visit, however, 22 (57.9%) had not had the opportunity to speak to staff about their child's needs. Some of the parents/carers provided extra information about the communication with staff before their hospital visit. This was mainly positive with helpful calls with the learning disability nurses, link disability nurse, speech and language service and the community matron. These calls were seen to "massively help, especially before huge decision making appointments" (n=1) and offered "important support through appointments. Before the LD team was in place, there was little to no support with these issues" (n=1). In one instance a parent commented that despite a call they felt that they were "not sure if staff were fully aware of his needs".

Parents/carers were asked in a closed question whether **any adjustments or additional support had been put in place to support their child** during their visit, only 12 (31.6%) parents/carers reported that adjustments or support had been offered to their child with the majority of parents/carers (n=26, 68.4%) reporting that their child had not been offered reasonable adjustments.

The survey asked parents/carers, who had visited the department before with their child, if they had **noticed any changes to the way staff communicated with their child**. Of the 32 parents/carers who responded, 3 (9.4%) reported they had noticed a difference and 29 (90.6%) had not noticed a difference in how staff communicated with their child.

Parents/carers were asked in an open text question to share what their child found most challenging about interacting with staff in the hospital. Whilst there were a few mentions of positive communication and children and young people being able to "speak her mind freely", there were a wide range of issues mentioned highlighting the high levels of difficulty experienced by these children and young people when communicating with staff in the hospital. Many of the parents/carers' comments were focussed on the difficulty associated with their child being "examined or touched in anyway" (n=3), especially when "staff are doing obs/physical exam and don't explain each step beforehand or give reassurance", even "staff being close" could cause anxiety. In some cases, parents/carers explicitly mentioned that their child's sensory difficulties with being touched had been "disregarded so they can just examine quickly". Parents/carers also reported that their child was often not able to communicate with staff, "he doesn't like speaking" in strange places" and this could result with children and young people "getting frustrated and upset (nonverbal and doesn't understand)" or "not being understood by staff" or challenges in "not trusting them". Staff were reported as "talking too quickly" (n=3) using "words they don't understand" (n=2) "they want him to look at them and sit still". In some cases the difficulties in communication had led to children being excluded or side-lined in the interaction; "the staff

usually talk to me and not her", "they just talk to me" and "he is non-verbal and has no expressive or receptive language. The staff barely engage with him".

"My son finds any examinations very traumatic as he is very afraid. Blood tests and the removal of dressings are extremely traumatic for him. He also finds it difficult sometimes when I am talking to the doctor as he does not like me talking to other people and gets angry""

(Parent/carer of a child with sensory needs)

Parents/carers identified that staff were not always able to adjust their approaches or communication for children and young people with additional needs "staff are unable to pivot their regular procedures to adapt to my child's needs – not engaging" and there is a need for "staff to be re-trained for children with additional needs". Parents/carers also reported that additional explanation and information about "What's coming next, new people and new places" and "what they expect from her" was needed and often not provided. Several responses were linked to the additional difficulties face masks (n=3) and "scary uniforms" (n=1) had on effective communication with children and young people.

parents/carers were asked to report in an open text question **what helped their child communicate with staff when they came to the hospital.** Again there were a wide range of comments and experiences shared. Many of the comments were orientated on the importance of "staff taking their time to talk to him directly", to "speak slowly", "not in their face", "calmly", "informally" and "in a friendly manner". These initial interactions were reported as essential to "gain trust" and "get to know" a child or young person and "even if they do not respond, he understands everything", they should not be "treated differently". It was reported as important for staff to "speak to a child first then talk afterwards to parents rather than the other way around", this acknowledged that whilst parents/carers have in-depth knowledge about their child to share and an important role in "interpreting and expressing what my child needs", it was good to speak directly to a child or young person first.

"ALL staff taking the time to read the hospital passport and any other info sent through from the LD team. ALL staff should be aware of the small adjustments needed for the child/young person to have a successful appointment" (Parent/carer of a child with sensory needs)

It was also reported that it was important for staff to use "simple language and instructions", "*keywords*" and to "show and demonstrate equipment" to help the children and young people

understand what was going to happen. It was important for staff to "listen to what she is saying to them" and be willing to "take time to answer questions". A couple of parents/carers explained how members of the "LD team now attend appointments with us and it is much better and my son has been much happier".

Parents/carers were asked to share their views in an open text response of **what could be done to improve interactions and communication with staff at the hospital for their child**. Six parents/carers commented that no improvements were needed as "the staff have always been brilliant with my son" and "they do an amazing job". However, many parents/carers identified aspects of communication which could be improved, this included better signposting within the system to "flag to staff" that their child had additional sensory needs, including "an alert on my child's records, which automatically pops up to inform staff of my child's issues", "so they know their needs before the appointment". A flagging system would help when information "is never on his notes so I always have to tell each medical professional we see all about him" and "having to explain constantly when seeing different people". One parent/carer highlighted how communication would be improved through "ALL staff taking the time to read the hospital passport and any other info sent through from the LD team. ALL staff should be aware of the small adjustments needed for the child/young person to have a successful appointment" Parents/carers also raised specific barriers to communication such as staff not knowing Makaton or British Sign Language and that "all staff should know how to sign" as well as "masks making it difficult to communicate". Many comments related to a need for staff to have increased understanding and awareness of children and young people's needs, including "more awareness around ND but specifically sensory processing difficulties", "more awareness of complex needs". Parents/carers also reported that there was wide variation in the approach of staff to their child "staff should be consistent in their approach", and "staff ought to be more child focussed" in their communicate with them and maybe have the same member of staff throughout, not lots of different staff". Parents/carers also commented that as well as there being some difficulties in communication with children and young people with sensory needs, there were also challenges in the way staff communicated with parents "as a parent I have often felt ignored or disregarded as soon as I tell the staff about his issues".

Equipment and resources

The survey asked parents/carers to report if their child **had used any equipment or resources** like sensory rooms, the 'InTouch' app, toy boxes, backpacks or information resources during their visit. Of the 37 parents/carers who responded, 9 (24.3%) reported that their child had used such equipment/resources, but 28 (75.7%) parents/carers reported that their child had not. Parents/carers who identified that their child had been offered any adjustments or additional support were asked to share what their child had accessed in an open text question. The responses identified that additional staff had been present "with toys", "to play and distract" or "play therapists came to calm down challenging behaviour". Other additional staff input included the presence of the learning disability team (n=3), who "helped to support us", "made sure we had what we needed" and "advocated for us on the day".

"Everything being arranged in advance, with the support of health psychology and the LD team, but not all of the staff interacting with him at the appointment were aware of his needs and the adjustments needed" (Parent/carer of a child with sensory needs)

Some parents/carers reported that their child had been offered "a sensory space to wait" (n=1), a quiet room to wait in (n=1), "less staff in the room", a "shorter wait" and could access adjustments such as "headphones" and a "special hospital bed". However one parent/carer highlighted that despite "everything being arranged in advance, with the support of health psychology and the LD team, but not all of the staff interacting with him at the appointment were aware of his needs and the adjustments needed".

Parents/carers were asked **what resources or equipment had been accessed by their child** in an open text question. Some parents/carers (n=4) commented that they had not known that any such resources were available, with the following parent stating "there were none available…in the building for children with neurodevelopmental difficulties….". Other parents/carers (n=2) identified that their child had "used the sensory room, which was a great calming experience" or had been able to access a box of "sensory toys which were a great distraction", a "box full of games and puzzles that my child loved" or a "fabulous Mobile X-box and an excellent play therapist". Other resources which were mentioned included a "backpack on the wheelchair", "sensory lights" and a "DVD to watch".

Parents/carers were asked in an open text question to share **what their child found most challenging about their visit to hospital** and their responses indicated that many aspects of the visit to hospital were difficult for their child. Many children and young people (n=12) were reported as finding the noise within the hospital and departments overwhelming as described by the following parent, "*He gets particularly triggered by young children and babies crying, people laughing*". Many parents/carers (n=15) also reported that their child found the "*waiting in the waiting areas*" really challenging as there could be "*really long waits*" with "*nothing to do*" and there were "*not many quiet areas*" to go to. Parents/carers also described how the bright lights (n=3), the smells (n=2), and having to walk around between departments (n=2) made the hospital visit challenging for their child. In some cases it was "*the whole experience*" which was reported as challenging. One parent/carer reported that their visit was made difficult due to the "*staff not*

being understanding of complex needs". However some parents/carers (n=3) reported that their child enjoyed or was "*excited*" for their visits to the hospital and they liked the "*comfy seats*" and the "*TV shows*".

"He gets particularly triggered by young children and babies crying, people laughing" (Parent/carer of a child with sensory needs)

Parents/carers were asked to report in an open text response question **what helped their child when they visited the hospital** and parents/carers reported a wide range of factors which helped to support their child. Some parents/carers (n=5) reported that it was the "well trained and understanding" staff who helped their child the most, with some referring specifically to support from the "LD & ASC team", "specialist nurses" and the "play specialist". One parent/carer described the importance of staff "listening to the parents on the best approaches" to help their child. Some parents/carers (n=3) also reported that the therapy dog helped their child. Other parents/carers (n=8) commented on **environmental features which helped their child**, including "*a quiet space to wait*", a "*quiet atmosphere and space*" and a "*sensory room*" within the department. One parent/carer described how there was "*nowhere for us to keep our child safe whilst waiting*". Short waiting times were viewed by parents/carers (n=5) as really helpful to prevent their child becoming overwhelmed within "busy, noisy departments", and one parent/carer described the benefits of "*being able to wait in the car*" as it helped their child remain calm while waiting. Parents/carers also mentioned that they brought items to the hospital to help support their child, these items included headphones (n=4), IPads/tablets (n=3) and "*home comforts*" (n=1).

Parents/carers also identified that "*explaining very simply*" what would happen during a visit helped reduce their child's anxiety and developing an "*exit plan*" of "*what next*" helped focus attention away from the doctor.

Key points from parents/carers about the sensory environment

- Many of the parents/carers had not noticed a difference in the environment within Alder Hey Hospital for their child with sensory needs and faced high levels of challenge in attending the hospital with their child.
- The parents/carers identified many challenges within the environment which impacted on their child's visit, these included the loud noise, bright lights, strong smells, long waiting times, lack of toys and things to do in departments, and not having any quiet spaces for their child to remain calm and not become overwhelmed.
- Parents/carers reported that sensory toys, systems to reduce the waiting time, a quiet place to wait, headphones and the ability to dim lights was very helpful to their child and enabled them to remain calm.
- Parents/carers also identified challenges in the way that Alder Hey Hospital staff communicated with them and their child during visits. Some parents/carers reported feeling disregarded and dismissed when they tried to advocate for their child's needs and staff were reported as ignoring their child and barely engaging with them.
- Parents/carers also discussed examples of staff spending time, talking calmly and slowly, building trust and communicating directly with their child based on their individual needs. Some parents/carers specifically mentioned the learning disability team as an important support mechanism for their child to have a positive experience of appointments.

Department Staff within Alder Hey working in clinical areas

Recruitment

Staff within Alder Hey Children's NHS Foundation Trust were sent a one page flyer, a brief description of the study and a link to the online survey via their Alder Hey email address, sent via the communications department and members of the sensory project team. There was a link to an extended information sheet on Figshare (University platform) should the staff member want more information about how their information would be handled as part of the project. The survey was designed to be of relevance to clinical and non-clinical staff within the clinical areas participating in the sensory environment project. This approach resulted in a self-selecting sample of staff.

Objectives

- To explore the reported views and experience of staff on the positive and negative aspects of the environment and resources within their department.
- To examine the reported views of staff on the impact of the environment on children, young people and families on their visit within their department.
- To examine the reported views from staff on their confidence and experience of interacting with children and young people with additional sensory needs and families within their department.
- To explore the reported views of the changes made as part of the sensory environment project.
- To identify any changes needed to further improve the experience of children and young people with sensory needs within the hospital service.

Methods

A short online survey sought the perceptions of staff on the positive and negative aspects of the environment and resources on children and young people with sensory needs, including any opinions or views of the environmental alterations made as a result of the sensory environment project. The survey also asked staff about their perceptions of how the environment may impact on children and young people with sensory needs and what could be improved to reduce this impact. The survey was designed to be short to encourage response rates and included space for staff to add open text responses.

Analysis

Qualitative data was analysed using content analysis techniques (Hseih & Shannon 2005). Analysis was led by the research assistant and then independently checked by a second member of the evaluation team.

Findings

A total of thirty-six staff participated in the online survey. Staff represented community services (n-14), the outpatients department (n=13), inpatient wards (n=7), and the emergency department (n=2), comprising of allied health professionals (n=21), play specialists (n=4), nurses (n=4), speech and language therapists (n=2), optometrists (n=2), therapy assistants (n=1), medical staff (n=1) and management (n=1). Ten staff, representing all four areas, had completed the sensory training at Alder Hey Children's NHS Foundation Trust as part of the project and twenty-six had not.

Staff were asked to report, in an open text format **what children and young people with sensory needs found most challenging when they visit Alder Hey**, many staff identified that the bright lighting (n=12) and multiple loud noises and echoing (n=30), particularly in the atrium, would likely contribute to "sensory overload for some children and young people". "It is quite a large open space on entering the main building, with multiple noises and smells and varying numbers of people. I feel it may be a sensory overload for some of our young people". Staff indicated that the waiting areas are not child-friendly, with limited quiet spaces to wait in "crowded waiting area, long waits, lack of toys/quiet space". Children, young people and their families not knowing what will happen next, interacting with unfamiliar people, the 'in touch' procedure ("All of it! Sounds, bright lights, touch/procedures in particular"), long waiting times and a lack of toys to play with "The size, the noise, how busy it is and the lack of entertainment" were also reported by staff as challenges for children and young people visiting Alder Hey Children's NHS Foundation Trust.

"It is quite a large open space on entering the main building, with multiple noises and smells and varying numbers of people. I feel it may be a sensory overload for some of our young people"

(Alder Hey Staff Member)

Staff were asked to report, in an open text format, **what children and young people with sensory needs found most challenging when they visited their specific department**, staff on inpatient wards (n=7) identified that noise is the main challenge "*The lights, sound of machines beeping, the noise of ward round, noise of cleaning equipment, noise of other patients*". Bright lighting is also an issue, as is "*having to share a bay with other patients when no side rooms are available as there is often a lot going on*". The heating is difficult to regulate "*either very cold with air con on or hot/stuffy, with some spaces having no way to change temperature*" and the atmosphere on inpatient wards was described as neither calm nor relaxing.



Staff in the outpatient department (n=5) identified that "the ceiling lights, the busy waiting area and the lack of multi sensory provision" are the most challenging aspects for children and young people visiting the department. It was also noted that children and young people sometimes have to wait multiple times for a single appointment, and that there is a "lack of quiet waiting space, a lack of entertainment and a lack of toys" to distract them whilst waiting or having procedures. Conversely, staff based outside the main hospital building (n=2) identified that "children often comment on the dire surroundings in the building, stating there is a funny smell and it's dirty". Further, "there is a lack of natural light in most clinic rooms" whereas "the lights in the main clinic corridor are very bright and this can be overwhelming" and "children with sensory needs can find it challenging".

"There are no quiet areas, dimmed lighting, soft spaces to relax, appointments at quiet hospital times or staff trained ready to meet and guide children with sensory needs". (Alder Hey Staff Member)

Lighting, noises and busy waiting rooms were also identified by staff in community services (n=12) as potential challenges. Staff identified a *"lack of adapted waiting areas"* in *"small compact*

waiting rooms with chairs facing each other". Where quiet waiting areas are available, they are "not necessarily enclosed" and are still effectively public spaces. "Some rooms can be quite cluttered with equipment/toys", but there is a notable lack of access to sensory toys "no sensory equipment in clinic rooms (we have requested wobble cushions)". "There are no quiet areas, dimmed lighting, soft spaces to relax, appointments at quiet hospital times or staff trained ready to meet and guide children with sensory needs". Staff in the emergency department (n=2) specifically suggested that "everything" was a challenge and that "the wards are not designed for children and young people who have sensory needs".

Staff were asked to comment in an open text question, **what would help children and young people with sensory needs when they visited their department**, staff on the inpatient wards (n=5) thought that increasing "the sensitivity of staff", children and young people "not being expected to wait too long and come into a room with minimal distractions", "prior planning so the children know what to expect", "being reassured by staff on arrival" and "being able to sit somewhere quiet" would help children and young people with sensory needs.



Staff in the outpatient department (n=6) indicated that sensory needs should be "identified prior to arriving so a smoother journey can be planned" by "trained staff with kind voices, who are calm and soothing" and "have time to take longer with the children" in "a quiet room, away from the main waiting area" to help children and young people with sensory needs. There should be "visual supports in clinics" as well as "toys available". Staff should "give children access to ear defenders and sunglasses (as required) plus a method of distraction whilst they are waiting" and be able to spend longer time with children and young people with sensory issues in order to meet their needs.

Staff in community services (n=8) agreed with all of the above, adding the importance of having "welcoming staff who try to meet the needs of each child within reason". Pre-planning with "the use of social stories or passports" and reinforcing the need for provision of "a calm relaxing area" with "distraction through use of sensory toys mainly tactual, auditory and visual". Emergency department staff (n=2) agreed that "being welcomed with a smile, having something to handle/play with, having chairs their size to sit on, and having space to move around" was important, as was "having access to sensory activities, sensory diet and sensory breaks if needed".

"Being welcomed with a smile, having something to handle/play with, having chairs their size to sit on, and having space to move around is important" (Alder Hey Staff Member)

Staff were asked to identify in an open text question what they thought could be done to further improve their department to help children and young people with sensory needs, staff on the inpatient wards (n=5) identified that "having visual helpers (real objects and photos) would help children understand what is going to happen". Staff also felt that access to "sensory activities/resources would help them regulate how they are feeling whilst waiting for appointments". Staff also wanted "consistent lighting that is soft and not overwhelmingly bright, or natural light in rooms with blinds, so the environment can be altered to suit the child".

Staff working in the outpatient department (n=6) suggested "having a dedicated calm/quiet room where the lights can be dimmed and there is less noise. Also, having a space for movement breaks and other sensory regulating activities". Staff also noted that "providing a box of equipment that could be used in any space to create a mobile and versatile 'sensory room' type environment would be really helpful. Things like projector toys, lights, fidget toys, etc that could be easily cleaned and reusable".

Staff working in the community (n=4) thought that having "more sensory equipment while patients are waiting", "adjustable lighting in clinic rooms" and "educating staff on all levels" to be more aware of the sensory needs of children and young people would be beneficial. Staff working in the community (n=2) and the emergency department (n=2) felt that "checking for a child's sensory needs before booking a visit" was important "so we can better accommodate them by offering appointments at different times and having a suitable space for the child so they can move around safely if needed".

Staff were asked to report if they had noticed **any changes in the sensory environment within their department as a result of the sensory project**, most staff (n=26) indicated that they had not. Staff who indicated that they had noticed changes (n=7) identified these as the successful provision of sensory boxes "which have proved a great success and are used daily", distracting and stimulating décor on the walls, de-cluttering of clinical areas and having tangible sensory aids "ear defenders and hand fidgets on the premises if/when needed" and "clearer signage" and "the television is on for patients". It was also noted that "staff were more aware" of the sensory needs of some children and young people visiting Alder Hey Hospital.

Staff in Alder Hey were asked, in an open text question, to share their **experiences and perceptions of the challenges associated with communicating with children and young people with sensory needs** within their department. Staff working on inpatient wards (n=4) said there was a "lack of awareness" about how to offer support to children and young people with sensory needs and their families. The "noise level in the department can be high and so there is a requirement to speak louder or shout in the waiting area – this is a challenge for staff and may be unpleasant for children and families". Similarly, "ticking clocks on walls can be really painful for some. Busy environments can be hard. If senses are overwhelmed the children can't concentrate on anything being said".

"The sensory boxes have proved a great success and are used daily" (Alder Hey Staff Member)

In the outpatient department, staff (n=8) cited a "lack of communication training for staff - would love to engage with patients more but have had very limited training 10 yrs ago+ for Makaton" which prevented them being able to explain various procedures to children and young people who "if their sensory need is not met, can become distressed". Aggression was also reported as an issue "once a child has shown signs of aggression to a member of staff they become wary they don't want to get as close or interact the same way" especially when staff were "having to be assertive when they might not like it". Staff felt "more signs/symbols around, ie. more makaton/pecs symbols, more visual cues and tactile objects of reference" would help children and young people in the department. Staff recognised the importance of "helping them to understand what is happening, what they need to do and helping them to feel comfortable" but also felt the "time pressures of clinic and the environment" which meant that they could not spend the time they would like to (or needed) with children and young people with sensory needs.

Staff working in the community (n=6) cited a "lack of understanding" as well as a lack of resources which meant that they were "not always able to make adjustments to meet the children's sensory needs". Staff also suggested that they "often don't know if a child has sensory needs until they arrive and issues become obvious. Often by then the situation may have escalated", negatively impacting any attempts to capture the focus and attention of children and young people who "sometimes are so heightened that they find it very challenging to communicate" with them "in an unfamiliar environment".

"It helps having individualised plans for children and young people and being able to use visuals to communicate" (Alder Hey Staff Member)

Staff working in the emergency department (n=2) identified communication issues rooted in a "lack of focus and attention from the child" especially "when they want to escape". They also noted that there is usually "clinical equipment in the room which is not necessary for the appointment" and this can impact how much children and young people are able to communicate with staff due to them being overwhelmed.

Staff were asked in an open text question **what helped children and young people with sensory needs when they visited their department.** Staff in the inpatient wards (n=7) identified the importance of "kindness" and a "welcoming environment", with staff "being calm" with "no waiting". "Having individualised plans for children and young people and being able to use visuals to communicate" were also cited as helping children and young people when visiting inpatient wards.

Staff working in the outpatient department (n=7) thought it important to maintain a "quiet, calm environment" that was not overwhelming for children, young people and their families. Staff having "awareness of the child's needs so that methods of interaction can be adapted (this relies on the staff having adequate knowledge of sensory issues)" was also recognised as being important, as was the use of "quiet and calm areas" and "getting them familiar with the department". Planning, communication training, and providing a quiet, calm environment with happy staff were all identified as being helpful for children and young people with sensory needs.



Staff working in the community (n=8) also identified these important features, citing the importance of being able to make reasonable adjustments, particularly having "access to sensory lights, sensory toys and to be able to peace the session to their needs". The use of "timelines", "being clear on what is going to happen, allowing children to move around and reducing potential triggers" were also considered important, as was having the "time to build relationships" with children and young people to support them and help them feel comfortable.

Staff in the emergency department (n=1) indicated the importance of "staff being able to access equipment which will help to calm or make children and young people feel comfortable" situated around the hospital to distract or comfort children and young people with sensory needs.

Staff were asked to report if they had **noticed any changes in how staff are communicating with children and young people with sensory needs within their department** as a result of the sensory project. Most staff (n=22) answered that they had not. Of those who had noticed changes (n=9), these included seeing colleagues who were "more aware of sensory needs and recognising when it is sensory and not just behaviour" (community and outpatients). This was observed as staff using "more gentle speech and language, and showing equipment before use", "making use of the sensory boxes and ear defenders and asking for support from colleagues" (emergency department) and using "communication aids, pod books and signing" (community). Staff had also been observed "providing the extra time and reassurance" with some children and young people on the inpatient wards.

Staff were asked to report in an open text question **whether children and young people in their department had access to any additional resources or equipment**, most staff (n=24) answered that they did not. Of those who did (n=7), these resources included a "sensory room, 'Voyager' and sensory boxes / self-soothe boxes" (emergency department and inpatient wards), and "leaflets and quieter waiting spaces" (community). Staff working in the community also noted that "we would be able to work with them in a sensory room but none of the community clinics have a sensory room". Staff further stated that "it is still possible to change the environment by removing distractions". Staff working in the community currently "provide sensory training for parents and have resources for parents to support their understanding".

"We are more aware now of sensory needs and recognising when it is sensory and not just behaviour" (Alder Hey staff Member)

When thinking about **what could be done to improve how staff interact with children and young people with sensory needs** within their department, eighteen staff identified training as the most important priority. It was recognised that "staff must be able to understand what sensory behaviours look like" so that they can "provide strategies to children and their families to help them to remain calm" in the hospital environment. One member of staff working in the community stated that "the interactions within their department were already very good, but they were limited by the environment (e.g. clinic rooms)". "Investment in resources" (e.g. sensory equipment, fidget toys, Makaton training, more clinical time, quiet spaces, better waiting rooms) was also identified by staff working in the community (n=5), on inpatient wards (n=3) and in the outpatients department (n=5).

When thinking about their **impression of the Alder Hey Sensory Environment Project**, roughly half of the staff (n=16) had heard about it, with the majority of those (n=11) feeling excited and positive about how the much-needed work will be beneficial to children and young people "this sounds like a very worthwhile and useful project", "wonderful", "great that this has been recognised". Some staff working in the community (n=2) felt over-looked "peripheral clinics have not been considered and are an afterthought". Of the staff who indicated that they had not heard about the project (n=11), some (n=3) felt disappointed "I had no idea it existed – this is disappointing and a missed opportunity. I find it frustrating that we missed out on this". A member of staff from the emergency department stated that "it is a move in the right direction, I just hope that the recommendations are followed through".

Key points from Alder Hey staff about the sensory environment

• Staff identified that children and young people being 'welcomed' by staff who are aware of a

- child's needs is important. Staff reported feeling that they cannot spend the time they would like to (or need to) with children and young people with sensory needs.
- Most staff identified that environmental factors made visiting the trust difficult for children and young people with sensory needs, these included bright lighting, busy waiting areas and loud noises.
- Staff identified that there was a need for dedicated quiet spaces, with dimmed lights to help children and young people stay calm and relax, particularly within busy departments.
- Reduced waiting times, quieter clinics and having the time to pre-plan a visit with families would help children and young people with sensory needs have a better experience.
- Most staff identified training in sensory needs as an important priority.
- Investment in resources (e.g. sensory equipment, fidget toys, Makaton training, more clinical time, quiet spaces, better waiting rooms) was identified by staff as a priority.
- Successful changes so far have included the provision of sensory boxes, distracting and stimulating décor on the walls, de-cluttering of clinical areas and having tangible sensory aids (e.g. ear defenders, fidget toys, more signage) and televisions for children and young people in waiting areas.
- The majority of staff aware of the sensory project feel excited and positive about how the much-needed work will be beneficial to children and young people with sensory needs.

Part 3 - Alder Hey Sensory Environment Project Team Staff

Recruitment

All members of the Alder Hey Children's NHS Foundation Trust sensory environment project team, including children, young people, parents/carers, charity members and staff were sent an email about the evaluation by the sensory project lead. The email contained a flyer containing a brief description of the study, a link to the online survey and a link to an extended information sheet on Figshare (University platform) should the staff member want more information about how their information would be handled as part of the project.

Objectives

- To explore the reported barriers and facilitators to the project and its implementation from the perceptions of the project team and those involved in delivering the alterations and training.
- To identify the project's biggest achievement(s).
- To explore any challenges to being part of the project team.
- To gather suggestions for future areas of improvement within Alder Hey Children's NHS Foundation Trust.

Methods

A short online survey sought the perceptions of the Alder Hey Children's NHS Foundation Trust sensory project team members on the reported barriers and facilitators encountered during the project period, what could have been done differently as well as their perceptions of the impact of the project on the staff and patients within the hospital. The brief survey also asked for the project team members' opinions about future directions of work within Alder Hey to improve the sensory experience for children and young people. The survey was designed to be short to encourage response rates, the questions were all open questions with space for staff to add text responses. The questions were designed to be accessible to young people, parents and clinical and non-clinical staff.

Analysis

The open text qualitative data was analysed using content analysis techniques (Hseih & Shannon 2005) by one team member and then independently checked by a second member of the evaluation team.



Findings

Ten members of the project team took part in the survey, including one young person. Two of the respondents work at Alder Hey Children's NHS Foundation Trust and eight do not.

Sensory project team members were asked **what do you think worked well in the sensory project?** A key strength identified was the collaborative approach taken to the project which ensured that the project team engaged and listened to children, young people, parents/carers and representatives from across the hospital and community group including the parent/carer forums: "*Everyone had a voice and was listened to*".

The members spoke about the clear leadership of the project and how "having a single project manager really helped because it was clear who was overseeing the delivery plans and checking we were on track". It was felt that the team worked well together and were amenable to change, responding to feedback and making change possible within the budget. The use of online meetings was seen as accessible, and they were conducted with a clear structure and guidance for the next steps throughout which worked well. One member summed up what worked well as "The whole process and people involved".

Members valued how the project provided an opportunity to understand the needs of children and young people with sensory issues and recognised how Covid had impacted on the visit of these children, young people and families, such as the removal of toys in waiting areas and number of parents/carers being limited. The training element of the project was mentioned in the feedback as a strength "training for staff to share with each other the improvements and adjustments that make a difference".

"Everyone had a voice and was listened to"

(Sensory Project Team Member)

Sensory team members were asked what they thought **was the project's biggest achievement**. Members spoke of the collaborative working with families and the value of drawing on lived experience as a key achievement of the project. It was felt that this achievement should be a continuing legacy of the project in future activity such as "*continue the engagement on things like walk throughs*" and the role of young people and families in future training "development of training with and delivered by experts by experience that will have an impact nationally".



The animations developed and used in the training were specifically mentioned as an achievement "Creating the animations and them being used for training – also the fact that they are being well received and people find them valuable and insightful". The project has created "a realisation [for families] that staff want to hear their views and their input as experts on their children really matters". Staff sharing their lived experience "as an autistic person" was also viewed as really powerful.

Other achievements identified were those that could make "impactful change to the medical lives of young people" to "change the way that children and young people experience their time at Alder Hey". These included "coming up with fantastic ideas and working as part of a team" and "implementing changes quickly". The impact of training was valued as it had "inspired hospital staff to re-think the part of the hospital they work in and start to put some of the new ideas in to practice". The importance of working with occupational therapists was highlighted "they've seen how the solutions to many issues are within their own community and staff groups if they reach out". Awareness raising of any work following implementation of changes was also seen as an achievement which would be important to continue.

"Once the senior champion was identified and the Programme Office in Alder Hey really took the project on, that made a big difference"

When asked **can you tell us about anything you found challenging being part of the project team**, some members did not perceive any challenges in being part of the project team. For others, some challenges were identified including time, staff capacity, management of the project communications, and becoming aware of problems within the current service.

The main issue mentioned was time to "do the work" and to "listen well and make meaningful changes in a short timeframe, especially when the restrictions of COVID were still prevalent". Gaining traction with the different teams across Alder Hey at the beginning of the project was slow but "once the senior champion was identified and the Programme Office in Alder Hey really took the project on, that made a big difference". The capacity of the hospital team was a clear challenge for their engagement, "but their commitment and enthusiasm for wanting to make a difference and be engaged meant that they went out of their way to make time to make it work".

A few issues around the management of the project were identified as challenging including "socialising with people I had never met before", "struggled sometimes in knowing who was doing what" due to the size of the team, and not feeling up to date as "sometimes email communications on the progress of the project were slow". One Alder Hey staff member wrote about it being "difficult to hear some of the everyday challenges that access to our hospital poses for our young people" and that there is "so much 'fundamental' work to be done".

"It is difficult to hear some of the everyday challenges that access to our hospital poses for our young people and there is so much 'fundamental' work to be done" (Sensory Project Team Member)

Sensory team members were asked to share what they thought was the **biggest barrier the sensory project faced**. Whilst one member said "*Not sure there was one*", some barriers were identified. The time needed by the team for the work, but also for change at an institutional and system wide level, including IT structures. The latter has led to some desired changes not being implemented within the current project timeline leading to frustration "*but the staff appear keen to continue to address these*" and it was acknowledged that "*the bigger changes will take longer*". Other barriers mentioned included having sufficient people involved in the work, and the ongoing impact of COVID-19 "*on hospital teams, parents, carers and young people*".

Understanding "the wide variety of experiences" and "working out [how] to fully support those in Alder Hey who have appointments in the building ... with solutions for the issue" were identified as challenging.

One member raised that "the general public can be too busy (especially in hospitals) to really reflect and understand the sensory needs of children and young people (adults too)". Therefore, the work is not just about the physical environment, such as difficulty "finding space for quiet areas" and interactions with staff, but also "being able to get people on board to listen to us and positively change their behaviour", although this was viewed as potentially difficult.

It was recognised that the project was operating in a context of "*dedicated staff and resources under real pressure*", so while the opportunity for the work has been identified, there is a "*question* [*around*] what the traction will be [needed] to achieve the ongoing legacy objectives".



Sensory team members were asked **if they could go back, what would they have done differently as part of the sensory project team?** Some team members reported "*Nothing*!".

Some strategic issues which were identified by team members, included having sponsors ready earlier (which wasn't possible due to COVID), clarifying the governance structures between steering group and delivery group and involving a young person on the steering group to continue meaningful engagement of young people. One member mentioned that "*it would have been good to have some face-to-face meetings but these are costly in time and money*". Another, that it would be helpful to "give more detail when giving feedback and also ensure I'm always engaged".

Two members suggested that more time was needed to support the work, with the suggestion of "a dedicated lead/ team, that could have really supported the speed and pace at which we have been able to implement and respond". One member highlighted the lack of engagement with families who may not be attending the hospital: "We have been able to hear from those that do or who try to but not those who find it too hard to even try".

Sensory team members were asked to share their views on, **if you could to back**, **what could the sensory project have done differently?** Some felt "*Nothing*, *they did well*", while others referred to their previous question response. One member felt that the team had evolved and been responsive as they had "*listened to the young people*, *families and staff* "and that there are "*some big changes required which the ongoing internal AH group can progress*".

"We could have incorporated more experts by experience and advocates to share more experiences/opinions"

(Sensory Project Team Member)

In terms of a different approach, a longer lead in and set up time to identify areas and changes before beginning the project and spending the funding was suggested, along with "greater use of parent carers in walk-throughs". It was noted that "some of the ideas at the beginning of the project were great and not all could be realised within the project scope". Other suggestions included additional children and young people involvement "e.g. in artwork, creating maps of the hospital" and to "incorporate more experts by experience and advocates to share more experiences/opinions".



Sensory team members were asked to report what they thought **the sensory project should focus on improving next.** There were several suggestions for future activity which were about continuing and expanding the current project work.

<u>Continuing the project work</u> as "Lots more to do and learn". Areas included:

- Estates and facilities planning to include more accessible sensory rooms, sensory equipment available on wards, waiting rooms, and dimmable lighting options.
- Continuing to review systems and procedures with families and hospital staff to identify areas of further improvement to reduce sensory overload and anxiety.
- All staff receive the training and "understand that every child is different".
- Continue to share and monitor the current work to ensure "embedding the learning and sharing longer term impact".
- Maintaining the current momentum to ensure all the information is acted upon and workstreams maintained, e.g. "*patient waiting systems via InTouch*".

Expanding the work suggestions included:

- The new internal group at Alder Hey Hospital "*needs to ensure sustainability of the changes* and work implemented".
- Developing further resources e.g. "Film for disabilities at Alder Hey. Film for equality at Alder Hey".
- Expand reach to engage with families who have not been attending the hospital to "*hear from people who we haven't heard from yet*".
 Co-production with families of children and young people who are neurodiverse and disabled so they can share their experiences and learning.
- Establishing a staff support group for staff who are neurodiverse and have sensory needs.

Key points from the Sensory Environment Project Team Staff

- Things that worked well included:
 - the collaborative approach taken to the project which ensured that the project team engaged and listened to children, young people, parents/carers and representatives from across the hospital and community groups; clear leadership of the project with a single project manager; identifying a senior champion and programme office in Alder Hey Children's NHS Foundation Trust to drive work internally; importance of working with Occupational Therapists; a responsive and cohesive team who were committed and enthusiastic; use of online meetings with clear structure and plans for next steps.
- The biggest achievement was:
 - the collaborative working with families and use of powerful lived experience stories in the training, video and animation. This aspect of the work was viewed as something that should be a continuing legacy for future activity.

- Other key achievements were:
 - the impact of the training on staff's knowledge and confidence to support this work and working together as part of a team to create solutions and a better experience for children and young people and their families.
- Barriers identified included:
 - time for the work but also for change at an institutional and system wide level, including IT structures; the impact of COVID, and that bigger changes will take longer than the project timeline.
- Challenges included:
 - time to do the work, staff capacity, management of the project communications, and becoming aware of problems within the current service. The restrictions of COVID also made it challenging to listen and create meaningful change in a short timeframe. For some there were challenges around following who was doing what due to the size of the team and not feeling up to date due to slow communications at times.
- Things that could have been done differently or are recommended for future work included:
 - engaging with families who may not be attending the hospital; having a dedicated lead/team to support fast implementation; a longer lead in time; greater use of parents/carers walk-throughs; involving more children and young people in developing resources.



Conclusion

Children and young people reported experiencing many challenges when coming to Alder Hey Hospital including lack of information to prepare for visits and appointments, long waiting times, interactions with staff, and environmental issues such as noise, lighting, smells, temperature and unreliable WIFI. To improve their experience they would like Alder Hey Hospital to feel more welcoming, with friendly, smiling staff, experience shorter waiting times in comfortable agespecific areas, and for there to be adjustments to the environment to improve their experience. Being informed before and during their appointment about what will happen based on their preferences and individual abilities by friendly staff was reported as helping children and young people feel less upset and/or worried. Having access to appropriate toys and spaces helps children and young people feel less bored and more calm whilst they wait for appointments and helps to provide a more '*welcoming*' child-friendly atmosphere.

Many parents/carers who frequently visited Alder Hey reported that they had not noticed any differences within the hospital environment as a result of the sensory project and reported that they continued to face many challenges when attending Alder Hey Hospital with their child with sensory needs. These challenges impacted on their child's appointments and included issues linked to the environment such as loud noises, bright lights, and strong smells and a lack of toys/equipment and also challenges linked to interactions with staff where they or their child felt ignored or staff were unaware of their child's needs and how to support them. Positive experiences were described of where staff had spent time with children and young people, building trust and communicating positively with them. The learning disability team was viewed as an important support mechanism to improve children and young people's appointment experiences. Further work to spread awareness of children and young people, as well as more work to equip staff with skills to communicate effectively with them, would be helpful. Family experiences could also be improved through increased access to resources, an adaptable environment and signposting to support mechanisms within the hospital.

Staff were mindful that children and young people being welcomed by staff who were aware of the child/young person's needs was important to ensure they received the best care possible. However, they identified challenges in delivering this, including having time to spend with children and young people, having enough staff who are trained in sensory needs, and having access to enough quiet spaces and resources to meet with children and young peoples' needs. Staff identified the same environmental issues as parents/carers, adding that addressing these issues, along with the provision of further staff training, must be priority areas for Alder Hey Children's NHS Foundation Trust moving forward.



The sensory environment training was a core element of the Alder Hey Children's NHS Foundation Trust sensory project which led to reported improvements in staff knowledge and understanding of the lived experience of children and young people with sensory needs. The training also increased the confidence of staff to identify areas where support for children and young people with sensory needs and their families could be improved. The lived experience stories from young people and parents/carers, including the video and animation, were described as very powerful and increased the impact of the training. There was strong interest in future training and continued support for staff to underpin future work and ensure change is trust-wide in terms of culture and environment.

The evaluation highlights how the Alder Hey Sensory Environment team has achieved many of its goals despite some barriers being encountered due to resource issues, the impact of COVID, and the need for some institutional and information technology changes for bigger changes. The commitment of all involved, clear project and internal leadership, and the important collaborative engagement with children, young people and families have been facilitators of its success. The sensory environment team has also identified areas for further spread and improvement and will have the opportunity to take the lessons learnt from the current project to drive forward the identified changes needed in the environment, systems and procedures. The team must identify further resources and broaden the engagement with families and staff across the trust to embed the learning and improve the experience of all children and young people and their families when visiting Alder Hey Children's NHS Foundation Trust.

Dissemination and sharing of the findings

The team will be writing an academic paper to share the findings of the project. We will develop a short video to share the key findings of the project. We will present the key findings at professional conference proceedings We will develop short lay summaries of the project and key findings, written with PPIE input, to share widely within and external to Alder Hey Children's NHS Foundation Trust.

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