Bristol Royal Hospital For Children

NHS University Hospitals Bristol NHS Foundation Trust

LIAISE Family Support Team
Level 2, Bristol Royal Hospital for Children

Bristol Royal Hospital for Children Emergency Department
Creating a soft consulting space for children and young people with disabilities and complex needs, learning difficulties and mental health needs

Feedback from Parent Focus Groups
16th and 19th May 2018

Introduction

The Bristol Children's Emergency Department is the gateway to the Children's Hospital and provides immediate care to the sickest children within our city. Many of the children who visit the Department have individual needs including children with disabilities, complex needs, learning difficulties and those with mental health support needs. A visit to the Emergency Department for these children can be especially difficult for them and their families. The Emergency Department Team (doctors, nurses and managers) with financial support from The Grand Appeal are working to refurbishment one of our existing consulting cubicles to create a multi-functional space. This would then create a safer environment to better meet the needs of children and young people who may require a more specialised environment with increased safeguards.

The Emergency Department were keen to work in partnership with parents and carers to develop this space. This should ensure that the current space meets their needs as much as possible within the current remit, and allow the team to capture ideas for the future as part of the hospital long term development plan.

Feedback on mental health needs has already been sought through the Children's Mental Health Operational Group, working in liaison with the Mason Unit at Southmead Hospital.

Two focus groups were held, the first with parents of children with complex needs and disabilities, and the next with parents of children with autistic spectrum disorders (ASD). These sessions were led by Rachel Sunley Consultant in Paediatric Emergency Medicine and Lisa Smith from LIAISE. Initial ideas and suggestions were put forward to families but families were also actively encouraged to view the space and bring their own ideas and suggestions to ensure the space is created with the child and families views foremost. Families were positive about the scheme, feeling that it was very much needed and had the potential to make a very difficult day feel much more positive and manageable for both patient and family.

Feedback received

Children with disabilities and complex needs	Children with ASD
Physical environment	
Ceiling track XY hoist to avoid parents and carers lifting – parent to bring their own sling. Possibility of donation of second hand hoist if suitable. Staff to be trained and suitable to be operated by one person.	
Wheelchair storage – not enough space to use environment practically if wheelchair and bed are in the room	Storage space for buggies
Soft empty space into which things are brought where possible – options of bed/no bed, chair/no chair etc. depending on situation	Option to remove bed and sit on the floor – bean bags may be a risk as may be thrown about. Range of seating available for parents to use or not – stored outside of space and brought in as needed.
Keen the space flexible so it can be customised to suit the needs of the patient – kit kept in boxes with menu so parents can choose what they need	Needs to be a safe blank canvas – scope to change and adapt the room for each patient and as patient stay progresses to mitigate boredom or frustration.

	Neutral soft wall colours – not reflective or shiny under lights which might cause glare
Lighting to be adaptable – no bright fluorescent lights but softer, with options for static or fluid colour (as in Ward 30), or projection which can be tailored to the patient's preference. Shadow lighting would be good if possible (as in Sanctuary on Level 4).	Calm lighting, not fluorescent – also ability to dim would be helpful
Real window to be made safe and options for colour to improve privacy and reduce distraction	No window sill to minimise risk of climbing – option of slope or installing inner screen?
Can the sink be boxed in or made smaller – risk of harm for patients who headbang? Also letterbox for disposal of paper towels rather than a bin	No touch taps would be helpful
Door – needs to be push or slide but no handles easy to get a large wheelchair through	Needs to form safe barrier that parents can contain their child but still allow easy access for staff. ?potential to slide into pillar. Door lock needs to be high up – requiring two hands to open?
Internal blind on door window for privacy – twist version rather than cord operated	
Ceiling colour to be considered – many patients may end up looking at this for long periods of time – projection, wither static or moving?	Simple repetitive movement projection good for distraction e.g. monkey in café at Bristol Zoo
USB socket for parent to charge personal mobile or ipad for patient. Neds to be out of reach for child and avoid any trailing cables	
Flooring – padded mat or soft flooring – robust enough to wheel in beds or chairs but soft enough to sit on comfortably for a reasonable length of time	Soft floor covering, perhaps with textures for sensory experience. Needs to cushion any falls.

	Clock – must not tick and perhaps with shutters or boxed in. Can be helpful in managing time but not always. Sandtimers in a box may help.
	Dark 'den' space for those who need to entirely reduce sensory input and will feel safer in a small contained space.
Medical Equipment	
Medical equipment to be hidden in a way that it can be accessed if needed, e.g. monitoring, oxygen. Potential to box it into wall with drop down or airline style doors.	Medical equipment to be safely stored out of the way of child
Key medical equipment re: managing a child who is deteriorating needs to be in the room but can other things be outside?	
Can all the medical equipment be in one place so that it is clear that it is separate from the other things in the room? Also at high level out of reach?	It would usually help to be able to do everything medical in once place – services come into space rather than needing to leave space to access services, although this may depend on mood
Can the 'bed' look a little different or not be used at all if not needed as some patients with associate this with bad experiences?	
	Visual assessment of pain and emotion – make this flexible for different age ranges. Some children may not be willing to respond if too 'babyish'.
Play and distraction	
Sensory input needs to chill, not stimulate	Tactile toys

Distraction for pain management	
Weighted items for calming – blankets etc	Bags of calm (Sirona), weighted blankets
Fiddle activities – fidget spinners etc	Stress squeezy toys – selection of shapes, sizes and colours
Adolescents box and things for parents too – colour therapy, ipads, wifi apps, books	Ipads and access to wifi – range of complexity for drawing and colouring to suit different age ranges
Scope to be creative with walls – dado rail with magnetic or chalk board option underneath for colouring, magnet play, textured tiles at lower level, below dado rail etc. No static pictures	Communication tools – scope to use PECS or Makaton symbols on magnets to create visual expectation of pathway and show when it changes. Texture options would also be good – also lego. Don't use cartoons – have real images.
Scope for flooring to include sound mat or magic carpet?	Piano mat would be fun as an option. Sound activities – giggle stick, rainmakers – perhaps have a noisy plan and a quiet play box?
Wind spinners from the ceiling with airflow to make them move (that don't get in the way of the hoist)	Hand fans to create air movement
Music –option to play your own playlist. Headphones (?Bluetooth) for music to block out babies crying or general ear defenders to manage noise.	Child would be anxious about noise from other patients – can room be soundproofed. Ear defenders or music a good option or access to own apps and files via ipad/wifi
	Sand timers for managing 'time out' of needed
Fibre optic lights as an option – range of settings	Light toys such as Simon and similar games

Systems and processes	
Who gets it? Process will need some form of alert or priority process and messaging must be clear that use of the room is subject to availability. Link to existing systems, e.g triage, passport – don't create new ones.	Need system of fair usage – may be frustrating if know room is there but don't get to use it
Cleaning – space must be suitable for easy deep cleaning and this should be commissioned as part of ongoing project plan.	
Who supports families in using – nursing team available but needs to be clear to parents what is available – develop 'menu' style info for parents and clear labelling	Clear guide for parents as to what is in the room – parents to make decisions about what is used in discussion with their child. Minimise contacts from staff – patient likely to feel more comfortable with one or two members of staff caring for them
	Room to be open to sibling too
Monitor unmet need in order to feed into 5/10 year plan as well as seeking feedback from families who use the space. Use parent carer groups	Need to be able to show benefits from use of space – feedback system or review?
Ensure there is a system to replenish consumables and items which may get lost or broken – ED play specialist to help maintain and monitor room and reorder as needed but cover needed for holidays/out of hours/sickness	High risk of things getting broken – need to ensure items purchased are robust and will be safe if they go get broken e.g. no sharp edges

The groups also revisited the refurbished resuscitation room and the family room which can be used by parent while their child is in resus. Families commented that the refurbished space felt much less clinical and more ward like. They were happy to see there was easy access to distraction in the form of the TV screens. They felt the family room was also a much improved environment, including the flexibility of lighting, the 'window' displays and the use of colour and soft furnishings. Comments were made that the environment felt calming and offered a sense of light and space, despite being windowless. It was noted that this space could be used for 'time out' for parent carers if not otherwise in use by families accessing resus.

Comments were made about the current challenges in the waiting area and whether there was any scope to mitigate some of the issues experienced by families when the department is busy but the room was not available such as access to headphones if they have not brought their own etc.

Key providers recommended by families included Rompa, Spacekraft and TFH. Families would be very keen to work with us in helping to choose the distraction items for use in the room.