



Improving hospital experience for children / young people with autism and their families

Contact: France Binns - Therapeutic & Specialised Play Consultant/Professional lead &: Autism Project Manager/lead, Royal Manchester Children's Hospital

Email: Frances.Binns@cmft.nhs.uk

Background

Health Play Specialists can help children understand and cope with hospital/healthcare procedures. Children and young people who require additional help or refuse to comply with medical treatment are referred to the Therapeutic & Specialised Play Services.

The Therapeutic & Specialised Play Services observed that a large proportion of children being referred to them had a diagnosis of Autism or Asperger. Healthcare professionals often labelled these children/young people as 'difficult / challenging' but the Health Play specialists considered the root cause was that staff did not understand or have the knowledge and skills about autism and how to communicate and support these children/young people whilst in hospital. Not having these skills can lead to varying operational challenges which could include: bolting from theatre, refusing blood tests/x rays. This had implications for equality of access, delays in treatment, health and safety, poor patient experience, unsatisfactory care, stressed staff and safeguarding of children and young people.

"Most people will not think that accessing medical services for disabled children is stressful, but for a child with complex needs, autism, learning difficulties and speech problems the whole experience for both the child and their carers can be daunting and frightening when doctors and nurses do not have the knowledge and understanding of autism."

Parent

The Health Play Specialists submitted a proposal to the hospital clinical governance team and equality & diversity committee to explore this further.

Learning from patient experience

A multi-disciplinary group (ASIG) was set up to improve the quality for children and young people and their families with autism to lead on this work which included a surgeon, dentist, radiologist, play specialists, registered nurses and parents. It was an added bonus that everyone who volunteered to participate in this group had a special interest in autism.

The MDT group were involved in a patient/public involvement focus group with parent/carers of children/young people with autism who shared their experiences of attending the hospital and their child's journey. The group invited senior colleagues and representatives from the patient advice liaison services to these events. Using patient stories was very powerful enabling all in attendance to gain a much better understanding of the challenges and difficulties faced by the families and that it was important that action was taken to resolve their concerns.

The multi-disciplinary group also worked in partnership with Salford University to organise a stakeholder event for parent/carers with clinical and Primary Care Trust staff. Parent/Carers spoke at this event about their different personal experiences and the challenges and problems they faced.

Following working collaboratively with Salford University has led to the development of a designated RMCH autism standard and protocols/pathways. These pathways have been introduced across many areas including outpatients, paediatric emergency department (PED) and in the elective treatment centre.

Working with parent/carers to improve their experience

The Health play specialists worked with parent/carers to develop questions to identify important information regarding the child's individual specific needs for example what might upset their child and what might prove difficult when attending the hospital and different areas for treatment. These questions enable the development of a personal centred assessment form which health play specialists complete with parents/carers. The completed assessment is made available to professionals in the front of the child's notes for all clinical staff to read so that they are aware of the child's/young persons individual needs.

This person centred assessment form includes a traffic light list of information about the child on the front page including in red anything the child dislikes. The form also includes information about how the child communicates, any fears/obsessions and situations likely to trigger the child/young person to behave angrily, aggressively or go into a tantrum.

The person centred assessment and pathways are reviewed and updated regularly in partnership with parent groups. This ensures that parents/professionals are informed about the scheme and provides the opportunity to ask them whether the questions are relevant and if any further changes are required so that the smallest of changes can be captured and considered.

"I was really impressed with the nature of the questionnaire and the depth of the questions they asked. It made me feel a little more at ease."

Parent

Implementing across the hospital

A communication 'Dos and Don'ts' list was developed in partnership with Salford University to provide top tips for success.

Champions have been identified who are crucial to the ongoing development of the service who also take on the role of local expert.

Access to resources is essential, particularly with the creation of 'Social Stories' and pictorial communication tools to familiarise the child with what to expect and visual timetables to illustrate the order of events that will take place throughout the day. A good example being www.widgit.com.

"We had pictures of the ward and staff which had been sent to me by the hospital play services which helped me explain to Marley what different staff did."

Parent

Children/young people and families are also offered a hospital 'pre-visit' to explore the areas of the hospital they will encounter on their admission/clinic day. This helps children to familiarise themselves with the situation as for many children with Autism, new ideas and situations can create anxiety.

When the health play specialist and ward/departmental staff are informed of the child's/young persons individual needs, quieter areas are identified or alternatives to help make reasonable adjustments to support the child's needs and alleviate any behaviour outbursts.

The multi-disciplinary group helped to disseminate the new procedure out to their clinical teams. This has included explaining to staff of all disciplines the problems children/young people and their families have experienced and how this new standard approach can lead to a better experience not only for the children/young people and their families but also for all staff. This in turn would also lead to less incidents and complaints being reported.

The Autism project lead also visited local parent groups, professional teams and forums to tell them about the process and ask them to tell parents/carers about the improving services for autism so they know how to inform the hospital teams and request a personal assessment for their child.

The quality improvement team are also informing GP's and professionals in the education setting asking them to inform families and alert the hospital if a child/young person has autism when writing referral letters.

Monitoring for effectiveness

All parents/children with autism attending hospital are asked to complete a service user evaluation about their experience with an aspiration to incorporate this in an audit in the near future. The local National Autistic Society have been asked to assess if RMCH is 'Autism friendly'.

"Unlike most other children, Marley did not have to wear a theatre gown as this was not seen as an essential part of the operation. It helped me and Marley as he was able to watch his favourite Ben Ten DVD on his portable DVD player whilst being anaesthetised. These concessions to Marley's autism meant that he did not go into the operating theatre upset and more confused than he already was"

Parent

Outcomes

The introduction of the scheme has helped staff to understand and provide improved support to children and young people with autism so they are more likely to comply with medical procedures. It has led to an increase in the workload for Health Play Specialists but there have been benefits for all staff as these children and young people are less likely to get distressed making it easier for them to attend the hospital and access health care and for staff to carry out medical procedures.

If you want a copy of the person centred assessment forms and Autism standard and pathways email Frances.Binns@cmft.nhs.uk at Royal Manchester Children's Hospital.



This is one of a series of case studies showing how parents helped improve health services for disabled children. You can browse all of these in our Success Stories section at

www.cafamily.org.uk/parentcarerparticipation

Contact a Family

209-211 City Road, London, EC1V 1JN

Tel 020 7608 8700

Fax 020 7608 8701

Email info@cafamily.org.uk

www.cafamily.org.uk

Incorporating The Lady Hoare Trust

Registered Office: 209-211 City Road, London, EC1V 1JN

Registered Charity Number: 284912 Company Limited by guarantee

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