

## Birmingham Children's Hospital : Improving the hospital experience for children & young people who have a learning disability and their families

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### Background

Following the Mencap 'death by indifference' report, Birmingham Children's hospital decided to review and improve the experience of children who have a learning disability and their parents when attending hospital.

They formed a steering group, which included representatives of hospital governors and staff, Child & Adolescent Mental Health Service (CAMHS) and parents of children with learning disabilities including representatives from ICAN a local parent carer forum. The steering group also included members from the voluntary sector - Contact a Family West Midlands, Mencap and SENSE.

The steering group met regularly to discuss different ways of improving the hospital experience for children who have a learning disability.

### Gathering the evidence:

They sought feedback from parents and children and young people about their experiences of visiting the hospital.

They also commissioned a parent led organisation called 'Include Me Too' to consult with parents of children with learning disabilities and write a report about their experiences of visiting the hospital.

Young people who have learning disabilities were invited to carry out an audit of the hospital. They were given the freedom to visit any department and ward and comment on how friendly the staff were and how well they felt they could support children and young people with additional needs.

This feedback provided evidence of what needed to change.

### Developing resources

A learning disability nurse was appointed to develop resources and work with hospital staff to improve how children & young people with learning disabilities and their families were supported.

She helped develop:

- **A Hospital Passport**, using the hospital experiences collected from children, young people and their families. It is available on the Hospital intranet and will shortly be available on the hospital internet site.
- **A communication toolkit** to help hospital staff carry out assessments of patients who have difficulties in communicating. The toolkit includes advice on how to keep language simple as well as cards and pictorial aids, including ones to assist with conversations about dying.
- An **intranet resource** so personalised communications can be made available to explain to children and young people their treatment options, regimes or routines while in the hospital.
- **Picture Exchange Communication material (PECS) and /easy read material** are also available on the intranet and can be printed on all wards.
- An **E-Learning resource** for staff about learning disability - which staff can access via the hospital intranet.

### Training of hospital staff

A one day disability awareness training course was developed where hospital staff find out about:

- the problems families can experience when visiting hospital - using the experiences of families gathered as evidence
- why reasonable adjustments are required - disability discrimination act, reducing health inequalities, health and safety
- the role of occupational therapists and physiotherapists in supporting children and young people with disabilities

Children and young people with learning disabilities join for part of the day to explain to hospital staff how they like to be communicated with.

Staff can also take part in simulation workshops around communicating with people with learning disabilities and / or challenging behaviour

#### Raj Jhamat, Learning Disability Liaison Nurse at Birmingham Children's Hospital says:

"paediatric nurses have considerable clinical expertise but might not receive training about learning disability. My role is to share my expertise with them, so they can incorporate this in their clinical work."

## Hospital procedures

These have been adapted so:

- All letters sent from the hospital for outpatient appointments and inpatient admission asks parents of children with learning disabilities who might find hospital difficult to get in touch with the appropriate department before their visit. This means the child's additional needs can be assessed and if necessary additional support put in place.
- Surgery day cases: surgical teams are advised to let learning disability patients be first on the list for surgery if possible, to reduce their time waiting.
- Accident & Emergency give out hospital passport to any patient with a learning disability who attends A&E and does not have a hospital passport
- Flag system - all wards and department have to fill in a form for patients with learning disabilities. This includes a checklist of questions to ask about both the child's and parents care needs. This assessment is sent to the learning disability liaison nurse and detail put on the database so the information is shared with other departments.

## Monitoring

The hospital have implemented 'quality walkabouts', where the disability learning nurse, her manager, and a representative from Mencap go on walkabout about the hospital. They try to identify children with learning disabilities and ask them about their experiences, and what the hospital could do to improve their experience. There are plans to include parents and children and young people in future walkabouts.

The hospital also intends to ask the children and young people to repeat the audit and compare this to the results of the first audit, to measure the improvement that has been made.

The learning disability nurse regularly asks parents known to her about how they find the service and whether it has improved since these processes have been put in place.

## Outcomes

- More families are making use of the hospital passport which helps them communicate their child's support needs to hospital staff in a simple and effective way.
- Hospital staff are gaining a better understanding of how to support and communicate with children and young people with learning disabilities and their families.
- When children and young people who have learning disabilities visit, the hospital can plan ahead to make sure arrangements are in place to adequately support them. This makes life easier for everyone including hospital staff.

### Birmingham Children's Hospital : Harry's story

Read about how Harry's experience of visiting Birmingham Children's Hospital has improved at [www.cafamily.org.uk/pcp/success](http://www.cafamily.org.uk/pcp/success)

## Why this worked

- The steering group included a range of expertise and experience including hospital management, clinical staff with expertise in learning disability, parents of children with learning disabilities and representatives from local voluntary organisations.
- The steering group gathered input from children and young people with learning disabilities, as well as parents, as they can have different priorities.
- Parents and children and young people's input was used to inform what resources were needed and what changes needed to be made.
- Staff training and changes to hospital procedures were put in place to bring about improvements.
- Processes were put in place to continue to listen to children and young people with learning disabilities and their families.

*This case study has been written to help parent forums work with commissioners and providers to improve local services for disabled children. You can browse more success stories at [www.cafamily.org.uk/parentcarerparticipation](http://www.cafamily.org.uk/parentcarerparticipation)*