

Reading Families' Forum

A voice for families of children and young people with special educational needs and/or disabilities

COFFEE MORNING 11th NOVEMBER 2020 VIA ZOOM

Karen O'Leary, Patient Experience Team at the Royal Berkshire Hospital joined the coffee morning to get parent carer feedback on visiting the hospital. Five parent carers attended with Autism Berkshire and Dingley's Promise.

Our feedback in brief:

Positives:

Families' views are listened to in children's services

Playroom and specialist play staff are great.

Nursing staff and doctors are friendly, patient and kind.

Sometimes children with additional needs have been seen quickly and toys and books in waiting areas are helpful.

What needs to change

Accessibility eg: doors being wide enough for wheelchairs in audiology etc and enough room in paediatric A&E for wheelchairs and other equipment that the child needs, plus teenagers who need space. The building is subject to a separate consultation which we have fed into.

Hoists need to be charged and available in all areas of the hospital inc A&E.

Slings designed for the child to enable safe and comfortable transfers have been refused – Karen will liaise with the hospital about this.

Some parents have had to fill in long forms or give information multiple times to different staff in one stay.

Parents would like support from nursing staff in caring for child when exhausted – Karen is doing a programme of training with staff to help them understand carers' needs but do ask staff.

Would be useful to have a summary of health needs for children with complex needs – can ask paediatrician to do this, especially prior to transition to adulthood.

Resus has little privacy, with families hearing emotionally challenging situations such as attempts at resuscitation

Quicker clinic letters.

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More awareness of autism eg earlier appointments to minimise waiting. Appointments are auto-generated but carers, including parent carers, are entitled to ask for appointments to be changed to fit in with families' needs.

Questions

Can parent carers stay with young people on adult wards? – YES

How will young people's complex needs covering several disciplines be met in adult wards? Usually, adults are placed in a ward according to the presenting concern, with doctors from other disciplines visiting as needed but Karen will check.

How will care plans be adhered to in adult wards? – again Karen will check.

Supports available

Jane Wooldridge, Learning Disability Nurse, can help navigate appointments eg: to minimise delay in being seen at blood test clinic

Carers are entitled to meal vouchers and drinks on children and adult wards as well as discounted– this happens for parent carers that staff know well but less well for those that they do not know. ASK!

Leaflet "I am a Carer" tells you what you can expect. It is being updated and Karen will send us a copy when finished. Wards should have a copy of the current leaflet.

Also discussed how to work out if child has special educational needs and should have support when they start school. The graduated documents on the Local Offer set out what Reading schools should provide for all children and what requires extra support

https://servicesguide.reading.gov.uk/kb5/reading/directory/advice.page?id=YU16_nsBEBQ

Dingley's Promise have family support worker who attended the coffee morning, Paula Chambers, paula.chambers@dingley.org.uk

Next coffee morning: Wednesday 16th December 10:30 – 11:45 with Susanne Diegal, from KIDS Mediation

To book email fran.morgan.rff@gmail.com

RB 13/11/2020.

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