

# Highland Children's Forum Report for Rocket Science on the experience of children, young people and their parents of specialist children's health services



Happy at the OT

This report is a follow up to the consultation event held by Rocket Science in the Town House Inverness in January 2007. Due to the low turn out of parents and children at the event, the Highland Children's Forum undertook to do some follow up consultation with parents and children. 7 children and young people took part and 14 parents were spoken to. The range of medical needs children had in this study include those with profound and complex impairment, rare

genetic disorders, cancer, specialist operations, brain damage, epilepsy and sensory impairment. The children were aged between 4 and 17 years old.

An introduction to the Action Framework for Health, the steering group for specialist children's services and the National Plan was given to both children and parents in an age appropriate way. Parents were asked about the professionals their children had accessed, about the accessibility of health services, the age appropriateness of the service and models of care that could be used in the future. Children were asked about what services they used and how they felt about them. Stickers were used for children for whom that was appropriate. Children were then asked about what was good about their health treatment and what was not so good. They were also given the opportunity to talk about what might make it better.

The parents had generally had a good experience of services, there had not been long waiting times, professionals had been supportive and helpful and children had

received the help they needed, with only a few exceptions.

There was a problem identified by the parents of children with complex conditions when their child was in hospital. These parents were experienced in their child's care and treatment and had become experts in recognising their child's needs, knowing when certain treatments were necessary. Sometimes in hospitals nurses were unable to carry out certain procedures, for example catheterisation, and the child had to wait in great discomfort for a doctor to do this. Sometimes the hospital doctor, who was not specialised in the child's condition, would want to change medication when this had been carefully worked out by the specialist. So for example when a child had an epileptic fit in the ward, the doctor wanted to prescribe diazepam, but the child had a protocol for when diazepam was needed. Also, some children with complex needs have no means of communicating them to anyone other than the parent who has learned to read the signs. Some children may be at risk from frequent epileptic fits or other incidents. The parents of these children felt that they could not leave the child's bedside as the

nursing staff were not able to provide adequate supervision or understand the child's needs. This puts an enormous pressure on families to ensure 24 hour care of their child in hospital.



physiotherapist



angry



happy

"Hard work"

"Pleased when I managed 430 steps"

Some children had seen specialists who knew about the child's condition but were not trained in paediatrics. Other children had seen paediatric consultants who were not specialised in the child's condition but received back up from a specialist from another area. The parents spoken to felt the care was better when the consultant was qualified in paediatrics with support from a specialist in the condition. They felt that paediatric trained consultants saw the child in a holistic way and tended to be more positive in their outlook for the child.

Two parents shared concerns about the cleanliness of wards. Both

parents commented on blood or other body fluids being on the floor or bed frame and not properly cleaned up. One parent had been in an English hospital for six weeks with her child and had only seen the floor cleaned once. Other hospitals in their experience were cleaner.

One parent discussed the “Red alert” system for NHS 24, which should mean the child by-passes triage and is seen quickly. In reality the child still often has a long wait.



Key worker  
Happy to see her  
She is sad about me

Most of the parents and children spoken to had received some medical care outside of the area. This was often in Scottish hospitals, but three children had had to travel to London and one to Manchester as well for treatment. When the child was seen elsewhere in Scotland, parents had been able to organise their own transport and reclaim the money and it had not been too difficult. There was sometimes hospital accommodation for families which was a huge benefit especially

if the child was in for weeks. However, one parent had shared a bed with their child in hospital and another had tried to sleep in a very uncomfortable camp bed next to their child. The families that had travelled to England had had a worse experience. There seemed to be difficulty in coordinating the hospital stay. Parents were not able to speak to someone who could give them the information about when they had to be there, how long they would be there and so on. It took a considerable amount of the parent’s time to organise the transport and accommodation. No hospital accommodation was offered. Sometimes a child required more than one outpatient department in a London hospital but these were not arranged to take place on the same day. So the parents and child had to make two journeys down to London to stay overnight for one appointment each time.

The disruption to family life is enormous when one parent and child are away at a hospital. Families have other children, work, pets and so on to organise as well as their own transport and accommodation; all while offering care to a sick child. Other children at home can be upset and worried and also feel left out.

When a child can be treated at the local hospital, life is much easier for families to manage. One parent, whose child received chemotherapy in Glasgow over two eight week stays, had been told that the reason the treatment could not be carried out in Inverness was because there was no one able to carry out the bone marrow test and lumbar puncture. She has two other young children at home, and is a single working parent. Considering the huge disruption to their family life, she wondered if it would not have been easier if the bone marrow doctor had come to Inverness to carry out the procedure.



I didn't like  
the injections



Other families had had consultants from other areas see their child at Inverness, for example heart specialists. One parent, after a stressful visit to Aberdeen, was offered a network meeting for her child, where the experts came together in Inverness and agreed a plan of action for her child. This was

a much better experience for the child, the parent and the rest of the family. However, parents recognised how busy consultants were and that such meetings would be difficult to arrange.

Parents had felt that professionals had treated their children in an age appropriate way. They felt that things were explained to the child and that the child was listened to. When the child had refused treatment, they had stopped for a while and maybe tried again later. The child was respected in this. Parents did feel that the play equipment for children was not always appropriate. There seems to be quite a lot for very young children and again adolescents seemed to be quite well catered for. There seemed to be less available for children in between. One parent felt that in this day and age, internet access should be available to children and parents so that they could use email and MSN to contact friends and family.



When I first went to the  
theatre. They put sleeping  
milk through the cannula and I  
just went to sleep

Looking at future trends and what might be an improved model of care, parents felt that if technology could

be used to bring specialist expertise to the paediatric consultants in their area, whether through telemedicine or video conferencing or whatever, that this would have enormous benefits for their child and family.

Parents also felt that it would be helpful if they had one point of contact, one person who knew their child, knew the details about appointments and treatments, someone able to coordinate the transport and accommodation or provide information and answer questions.

I liked  
the gas



happy

Theatre

Parents who attended the Birnie Centre, Inverness felt that the provision there was an excellent model of care and should be copied in other more rural areas. The Birnie offers a comprehensive and coordinated service for the ongoing assessment and support of children with special needs and their families. Parents could bring their child to the playgroup and they could see the

paediatrician and the various therapists in the same place. The parents felt they also got an enormous amount of support from one another. There was a hospital social worker available, a keyworker who was fantastic at supporting families and helping them with benefits and so on. They felt in this caring environment that their needs were noticed too.

The children and young people spoken to also highly praised the medical professionals they had seen. There were a lot of smiley face stickers used to express how children felt about professionals when they saw them. Where the children had expressed other feelings such as worry or fear or anger, it was when a professional had to carry out a procedure the child did not like or where a therapist was asking the child to do something that was difficult or they thought they could not manage. The children were worried by pain and procedures that had to be done. Anything with needles seems to be especially upsetting.

Most of the children had felt that things had been explained to them and they had understood what was going to happen. Children had a bit

of control over how and when treatment could be carried out. One young person aged 11, who has had 14 operations and is due to have another, was beginning to find out about consent. He did not think he wanted to consent to further operations. His mum was not sure if he was ready to be able to give informed consent. One child who had only been two when he had his operation had not had anything explained in advance. He did not know he was going to have the operation. The operation was on his face and when he woke up he was so cross that he pulled out his stitches. Even three years later he remembers and is now very worried by health appointments in case someone does something he doesn't know about.

Those young people who had stayed in the adolescent ward had been pleased with it and felt that there were good things for them to do there. Some were too ill at the time to take advantage of them. The very young children had also enjoyed the toys and equipment provided for them. Those children in between had not felt there was so much for them to do. They wanted play stations and game consuls, things they would be doing at home.

The children had mixed feelings about the comfort of the ward. Some had had comfy beds and some had not. The colour of the walls was cold reported two girls, the younger of whom would wish the hospital to be painted pink, although she conceded the boys could have a blue part. Children enjoyed an outside area accessible from the ward.



Most of the children had had some disruption to their schooling both by in patient time and outpatient appointments. For children in a more rural setting this disruption was greater as any outpatient appointment was at least one full day off school, and often required an overnight stay. Some children had some school work offered in hospital but they had still fallen behind a bit.

Children had mixed feelings about the hospital food. Some children had

quite liked it but others had not. One child felt there was not enough fresh food, it was all “hospitally”.

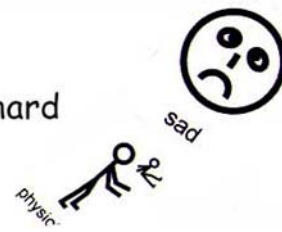
Children found it hard to answer a question about what might make it better. One child had looked astonished and said that children not getting ill would be better. Generally a more homely décor, the provision of play stations and game consuls and better food would help. The child who had had so many operations wanted there to be less people in the anaesthetic room before theatre, the room is crowded.

Overall from this small study the things people would like are:

- As much care as possible offered locally by professionals with paediatric experience, with support from specialists from further afield
- A keyworker for families, one point of contact for families to speak to about their child’s condition and treatment; someone who can coordinate out of area appointments
- Parent’s of children with complex needs require more support when their child is in hospital

- Wards need to be more homely with better equipment for 5 to 11 year olds.
- Wards need to be cleaner
- Fresh well prepared food should be available
- The child should be seen holistically and the needs of the whole family recognised
- More family centres such as the Birnie Centre around the Highland area

Physio  
Sad  
It was hard  
work



However, in conclusion both parents and children were on the whole very pleased with the service they received. A lot of praise was given to individual medical professionals who were felt to have “gone on the extra mile” in the service they provided. Parents were glad to be in the Highland area and were not confident that they would receive such a high standard of care if they lived elsewhere. The Birnie Centre in particular is seen as an ideal model of care which could be copied elsewhere in the country.