

Family Voice Peterborough: Hospital and hydrotherapy - working with and independently of their Local Involvement Network (LINK)

Family Voice Peterborough have worked on their own to improve health services on issues affecting only their members, and with their Local Involvement Network (LINK) on issues affecting a wider group of people. The following examples illustrate the advantage of working this way.

NB From April 2013, Healthwatch will take over responsibility for public and patient involvement from LINK.

Improving inpatient stay - working directly with hospital practitioners

Family Voice Peterborough invited senior ward staff from the children's ward at their local hospital to attend their annual conference. This provided an opportunity for staff to hear first hand from parents about their experiences when their children were inpatients on the ward. It was less intimidating for parents to feedback this way rather than approach the hospital as individuals.

Many of the difficulties families faced related to needing support which took into account their child's disability. For example, children with autism were being put on wards with other children rather than in a single room. The noise and activity from the people around them was causing these children to become very distressed which triggered challenging behaviour. The ward did have a sensory room where the children could go, but this was locked at the weekend.

Following this event the senior nurse invited parents to a follow up meeting, to discuss these issues further.

The following has been implemented:

- The hospital had a disability learning advisor who could advise ward staff on support needs of adults with learning disabilities, but she was not involved when children were admitted. She is now notified when disabled children are to be admitted and helps coordinate their support with ward staff.
- The sensory room is available to children with additional needs at the weekend.
- Ward staff are receiving training around autism and sensory integration, so they understand what might be a problem for children with neurodisability and how to avoid them.

Since the meeting, parents of children with autism have said they were given a single room and felt they had a better experience than on previous hospital stays.

Sharing the workload with LINK or Healthwatch

The chair of the parent carer forum sits on the management board of LINK. This allows for close working and cooperation between the two organisations. Both LINKs and parent carer forums are run by volunteers, who have limited time and capacity. Rather than compete with each other for volunteers' time, they have found ways to share the workload between them.

Some examples of this are:

- A steering group member of the parent carer forum attended a national carers event – and fed back the findings to both Family Voice and Link.
- A member of the parent carer forum was pursuing a complaint about her own care in adult services. The LINK asked her to feedback to LINK about her experience of pursuing a complaint.
- One volunteer member of the LINK has become involved in supporting the work of the forum. She attends forum events, listens to parents and is happy to help write reports on what she has heard and to make recommendations.
- LINK were going to inspect the local hospital to look at nutrition for patients on the ward. Family Voice told LINK about the problems all parents faced in not being able to get anything to eat while they were staying with their children on the hospital ward. Parents who could not leave their children could go for long periods without any food.
- LINKs included the children's ward in their inspection, asked children about their experience of food and asked additional questions about nutritional support for parent carers. Following their report some refreshment has been made available to parents on the children's ward. Parents make a financial donation when using the facility to cover the costs of this.

Hydrotherapy for all –working with LINKs and other community organisations

The hydrotherapy pool in Peterborough closed down and there was no alternative facility in the area. LINK formed a Task and Finish Group with representatives from the local authority, professionals in hydrotherapy, NHS Peterborough and local charities including the parent carer forum.

They discovered there was a hydrotherapy pool in a special school in Peterborough that was only used one day a week. It was also in urgent need of modernising. The Task and Finish Group discussed making the pool available to both children and adults with long term conditions who would benefit from being able to use a hydrotherapy pool. A local community group offered to take over management of the pool and funding was sought to refurbish it.

The pool was refurbished and an 'open week' arranged to showcase the facility. The community organisations encouraged their members to try out the hydrotherapy pool and gathered feedback from them. Comments were collected from people with a range of medical conditions, including arthritis, cancer, joint replacements and people recovering from car accidents, as well as disabled children, young people and adults.

LINK then sent letters to over 100 local GPs to raise awareness of the need for hydrotherapy and to ask their assistance in securing its long term funding. LINKs used the evidence for the benefits of this gathered by the community organisations.

Individuals with long term medical conditions can self refer to use the hydrotherapy facilities for a small charge. NHS Peterborough has also agreed to commission a NHS hydrotherapy service there. This means GPs in Peterborough and the surrounding areas are able to refer suitable patients for two sessions of hydrotherapy at the hydrotherapy pool with an aquatic physiotherapist. Patients living in Lincolnshire can also make use of this as NHS Lincolnshire have agreed to commission as an associate of this arrangement.

For more details about the service see
<http://www.sgchp.btck.co.uk/>

It would have been very difficult for parent carer forums to justify the expense of running a hydrotherapy pool solely for disabled children. By working through LINKs with other community organisations they have helped in getting a facility for the whole community which disabled children can now access during weekends and school holidays, as well as during term time.