

Continence Service in Gloucestershire

Background

Gloucestershire Parent Carers Council were contacted by parents after the continence service brought in new restrictions on continence products they provided. Some children were being supplied with products which did not fit properly and leaked. Others could no longer receive pull ups, which was preventing them from being toilet trained and affecting their self esteem.

The forum asked its members to tell them about their experience of the continence service. The forum collated these comments into a report which they took to the Patient and Liaison Service (PALS), asking whether they could work with them to improve the service.

A small working group was set up to review the entire continence pathway. This included the Children and Young people's general manager, senior paediatric nurse, specialist paediatric continence nurses, school nurse, lead for adult continence service and commissioner for the continence service. Four parents were invited to sit on this group as well as the forum's parent participation support worker.

What they did

The group met four times to discuss any problems raised and find ways of resolving them. Actions agreed from each meeting were immediately implemented. The group has agreed to meet for a final meeting once all the agreed actions have run for a while.

Deborah Livingstone from the Gloucestershire Parent Carers Council forum said:

'When we first met, the professionals appeared a little defensive as they thought we had got them in the room to complain. This quickly changed as they realised we wanted to work with them to find ways to improve the service.'

The table below shows the problems the working group identified within the service and the practical solutions found to resolve them. These are problems commonly reported to Contact a Family from families across the UK.

Why this worked

The small working group allowed for meaningful dialogue to take place between families and the different professionals involved, so they understood what the problems were and how they could be resolved. The professionals had sufficient seniority to quickly implement changes to the service. Parents and professionals quickly saw improvements in the service and the benefits of working together in this way.

Other commissioners in Gloucestershire have heard about the benefits of working this way and have approached the forum wanting to work with them on other services. The forum is now involved in improving the 'home to school transport' and 'speech and language therapy' services.

Problems /Solutions

The following problems and solutions were identified:

Queries

Parents ringing the Service left messages which were not returned as the continence nurses did not have time to answer the phone. There is now an email address for people to email enquiries which are responded to within 24 hours.

Referrals

Many families and professionals thought families should go to their GP for a referral but they can only be referred by their health visitor, school nurse, learning disability nurse or consultant. Information was provided to let everyone know this.

Assessments

The protocol being followed meant all children being referred had to first be treated for constipation. This is because children referred to the continence service are often incontinent because of poor diet. The parents wanted a process which took into account the cause of the problem, for example delayed development due to learning disability, or poor muscle control in children with cerebral palsy.

It was agreed the protocol should be applied in a more holistic way around individual children's needs rather than it being assumed all the children referred to the Service had constipation.

continues overleaf

Problems /Solutions continued...

It was also agreed that more health visitors, school nurses and learning disability nurses would be trained to carry out assessments and prescribe products, so only more specialist cases had to be referred to the continence service. This would make the Service more efficient and cost effective.

Choice of products

Children of a certain size could not get products to fit them. This was because one major product supplier had failed to register with the Trust, so it was impossible for the service to order their products. The Head of Procurement has been asked to source a product that would fit this need. The forum is also approaching this provider direct to find out why they had not registered as a supplier.

Pull ups were only being provided for children being toilet trained around the ages of four to five. The parents explained that children with learning disability can take longer to be toilet trained and become continent when they are older than other children. Older children with pull ups can be more independent at school and when taking part in social activities which increases their confidence and self esteem.

It was agreed the restrictions around pulls ups would be removed. The manager for the adult service is now investigating providing pull ups for the adult service.

An audit tool is being piloted for parents to complete, which allows them to indicate any issues with products being trialled, (for example, fit, comfort, leaks, etcetera).

Number of products

Some families had been told that there was a limit on the number of products that could be provided. This was actually not the case but not all professionals were aware of this. It has now been made clear that families can receive more than four products a day, if there is a clinical need.

Deliveries

People were being restricted to deliveries on only certain days of the week and the delivery service would not pick up returns. Delivery/collections now occur two to three times per week and are no longer grouped on certain days of the week for certain postcodes, allowing more flexibility to meet families needs.

Products to be returned can also now be collected and picked up from any location and not limited to the address they were delivered to.

A scheme was piloted where families could opt to have a personal budget and purchase their products direct rather than rely on the delivery service. Some families preferred this approach as they could purchase their nappies at the supermarket or chemist. This proved popular with the families who took part and is being considered as an option for the future.

Complaints and monitoring

Any family not happy with the service is now encouraged by the continence nurses to email them so they can resolve the problem. Families are also encouraged to copy the parent carers forum into these emails so they can monitor the number and types of complaints. Since the new system has been in place the forum says the number of complaints has dwindled.