



## **P.P.F. Continance Survey- Results & Recommendations**

### **The Sample:**

The sample size was 25 parents (excluding one parent who gave a comment instead of completing the questionnaire). The respondents' children had a wide range of disabilities, including Down's syndrome, other syndromes, Cerebral Palsy and Children having an Autistic Spectrum Condition. The children surveyed were aged from 3-18 years, male and female. Although the sample size was relatively small, the P.P.F. feel that the survey is representative.

### **1.) Children needing continence support during the**

Day (raw score 2) 8%

Night (raw score 2) 8%

Both (raw score 21) 84%

The vast majority of children needed continence support both during the day and at night.

### **Communication:**

#### **2.) Ease of getting referred for continence support**

Easy (raw score 17) 68%

Difficult (raw score 8) 32%

**Quotes from parents-** 'Only found the Continance Service through hours of my time- I literally hunted down the service myself. The school nurse and health visitor were useless. The most help I got was from ERIC, which I found myself on the internet. I think the Continance Service phone numbers should be in the Early Support blue folder given to parents at the child's diagnosis.'

'I think someone from the Continance Service should get in contact with parents of disabled children well in advance of their 4<sup>th</sup> birthday so you are prepared and have what you need in place when they turn 4 and do not have to wait months after they turn 4 to get it all set up.'

'I think Continance Service nappies should be available to severely disabled children from 3 years of age. I am having problems getting nappies that fit him or absorb enough, they often leak.'

'Parents should be given a service leaflet explaining what they can expect and who is delivering the service.'

‘You never see the Continence Service at any parent information events- they should be there handing out information. There are good leaflets available e.g. those from Promocon.’

‘I hope the contact information for the Continence Service is routinely given to parents of disabled children, including children with A.S.D., by GPs.’

‘I was still trying to squeeze him into the biggest supermarket nappies I could buy aged 6. At the next paediatrician’s appointment I asked about access to bigger NHS nappies, but it took many more months of me being persistent and being passed from the GP to the paediatrician to the school nurse, before I was finally referred (by a different paediatrician).’

‘We are originally from out of the area. We do not know what is available. Until my friend intervened we were struggling to fit our child into supermarket nappies. No professionals initiated access to the NHS nappies despite his disability.’

Most parents found it easy to get referred for continence support, but a significant number (32%) did not.

*Action needed!* The PPF would like to see this figure reduced so that parents are not left unsupported.

### **3.) Clear who to contact now for continence support**

Clear (raw score 12) 48%

Not clear (raw score 12) 48%

Declined to answer (raw score 1) 4%

An equal percentage of parents reported that they were clear (48%) who to contact now for continence support as those who were not clear (48%).

**Quotes from parents-** ‘How do you contact the Continence Service if your child is home-educated- there is no clear referral system in place? A new system needs to be put in place so you can self-refer initially and when you need reassessment.’

‘No idea who to contact- is it Ros Archer still?’

‘I kept getting passed from person to person when I tried to change the size of the pull-ups.’

*Action needed! P.P.F. Recommendation-* this could easily be resolved by giving out a list of contact details (phone numbers, names and emails) at the first appointment and to give them out to every parent at their next appointment to ensure the existing gaps in parents knowledge of who to contact are quickly filled. There needs to be a system by which children who are home-educated can be referred to the Continence Service and be reassessed when needed.

### **4.) Ease of making contact with continence service once referred**

Easy (raw score 15) 60%

Difficult (raw score 5) 20%

Declined to answer (raw score 5) 20%

**Quotes from parents-** ‘There is no e-mail facility that I know of.’

‘They return calls when a message has been left.’

‘The only phone number I have is the one to re-order nappies. How do you get a referral?’

Most parents found contacting their continence professional easy, however there is room for improvement.

*Action needed! P.P.F. Recommendation-* once the recommendations raised in question 3 are implemented, parents should find it easier to contact their continence professional. Several parents reported that their child’s continence needs were being met through paediatricians and there seems to be some confusion over who to contact. It needs to be clearer whether families should go to the Continence Service or paediatricians for help.

### **Products:**

#### **5.) Does your child use products (nappies, pads, etc.)**

Yes (raw score 24) 96%

No (raw score 1) 4%

Almost all parents surveyed (96%) said their child used products such as nappies and pads.

#### **6.) Were you given a choice of products**

Yes (raw score 6) 24%

No (raw score 18) 72%

Declined to answer (1) 4%

**Quotes from parents-** ‘We wanted to change make as the ones we were supplied gave our child a rash. They were unwilling to let us have the make we wanted.’

‘We were offered two sizes but only one brand. My child can still fit supermarket nappy sizes and I would prefer vouchers to use to buy my own nappies as I was very happy with the fit and absorbency of Sainsbury’s own brand.’

‘The previous supplier provided additional night time inserts to prevent leakage. My child is only liquid fed. Tena has no comparable product. The product is not adequate for his need. Leakage is a problem day and night. There is a lot of washing and work. I have had extra input from Tena but they do not provide the quality or design of product he needs to keep him dry and comfortable.’

Most parents (72%) said they had not been given a choice over which products (nappies etc.) their child wore.

*Action needed! PPF Recommendation-* all parents should be offered a range of products where there is more than one product available. Children’s needs are different and a very small number of children who have specialist needs may

need products from a different supplier to usual. This should be catered for. Samples should be given for parents to try out so they can ensure their child gets the best product to meet their needs in terms of fit, comfort, absorbency and quality.

### **7.) Do the products suit your child's needs**

Yes (raw score 16) 64%

No (raw score 7) 28%

Declined to answer (2) 8%

**Quotes from parents-** 'My child's nappies often leak, usually at least once a week, which creates extra laundry. He is slim and uses Tena Slip Super Small size, which only comes in one absorbency, which is not absorbent enough. All the bigger sizes come in two absorbencies, but he is too slim for them. He was allocated two per night to allow us to change him in the night, but this costs the Continence Service extra money and disturbs his sleep. It would be better if they came in two absorbencies and he could have the most absorbent.'

'The nappies are the wrong size and not absorbent enough.'

'Need new size- shot up.'

Most parents felt the products they were using did meet their child's needs (64%), however, there are too many parents (28%) who felt that the products did not suit their child's needs.

*Action needed! P.P.F. Recommendation-* we would like to see this figure (28%) reduced. At every appointment the continence professional should ask the parents and (if appropriate) child if the products are meeting their needs and samples should be offered if the response is no. Following the recommendations in question 6 should also help avoid so many parents having to use unsuitable products as if they are offered samples at the first appointment they may be able to get the right products at the outset.

### **8.) Do you receive all the products your child needs**

Yes (raw score 8) 32%

No (raw score 17) 68%

**Examples of quotes from parents-** 'I squeeze my child into the biggest swim nappies I can buy in the supermarket as she loves swimming and hydrotherapy and goes at least twice a week.'

'School require swim nappies.'

'I bought some stuff for swimming but it is no good and so we don't go swimming.'

'We need swim nappies. My son has grown out of the ones you can buy in a supermarket.'

'We need a mattress protector and protective gloves.'

‘I bought a mattress protector and a washable Kylie square, but when the nappy leaks I end up washing the Kylie and all the bedding and it isn’t dry in time for bedtime- can you get disposable Kylies?’

‘We need nappies for our child for when they are travelling as pads are difficult to change when travelling.’

‘My child needs panty liner incontinence pads as she can’t always hold on long enough when out. I was told this was not an option as she is 9 and she still uses pull-ups on long journeys etc.’

Most parents (68%) did not receive all the products their child needed. The main issue seemed to be parents needing swim nappies. Although these can easily be purchased in supermarkets for babies and toddlers, they are not easily purchased for older, bigger children. Swimming and hydrotherapy is often part of the weekly care plan for disabled children, so it is important that this need is catered for.

*Action needed! P.P.F. Recommendation-* The P.P.F. request that the Torbay Continence Service investigate whether any other authorities fund swim nappies and consider the possibility of supplying swim nappies to the relatively small number of disabled children in Torbay who need them as part of their Care Plan. Parents should also be offered disposable mattress protectors (Kylies) to help with the extra washing.

### **9.) Do you have any issues with the quality of products (tabs ripping, leaks)**

Yes (raw score 13) 52%

No (raw score 10) 40%

Declined to answer (raw score 2) 8%

#### **Quotes from parents-** ‘Sometimes the tabs snap and the nappies leak.’

‘The elastic waistband is a bit loose.’

‘Quality dreadful since contract left Hartman (Moulicare Products). They are rough, often faulty and leak.’

‘The tabs rip and they often leak.’

‘Pull-ups bunch up/break up during the day or when very wet.’

‘At night time pull ups are not very absorbent.’

There is clearly an issue with the quality of the products being provided by Torbay Continence Service, with most of the parents who responded (52%) stating that they have had problems. Some of the difficulties experienced could be attributed to parents having been given products that are not suited to their child’s needs (for example, incorrectly sized nappies are more likely to leak, children using nappies that are not absorbent enough for their needs, not being allocated enough nappies so having to use them for longer periods than is recommended) and if they were provided with sufficient quantities of a more suitable product, the quality issues could improve.

*Action needed! P.P.F. Recommendation-* The P.P.F. request that the Torbay Continence Service first resolve the issues of children not always being given sufficient suitable products and then if quality continues to be an issue, investigate the possibility of changing product provider. Tena could also be contacted to request that they make a greater range of products, for example, Tena Slip Super Slim nappies only come in one absorbency, which is not sufficiently absorbent for all children. All sizes bigger than this come in two absorbencies.

**10.) Were you given several samples of different products (sizes, absorbencies, styles) to try when your child was first assessed?**

Yes (raw score 5) 20%

No (raw score 18) 72%

Declined to answer (2) 8%

**Quotes from parents-** ‘We were posted several samples of different styles and fits. This allowed us to try them out and find the best fit. The only difficulty was they kept arriving out of the blue and we had no idea what we were going to be testing.’

‘I can sign a document giving permission for my child to have an operation, but I can’t choose what nappies I put her in!’

‘We had no samples. A nurse took only the weight of my son, over the phone, not taking into account his shape, so his nappies are too small as his waist is bigger than she allowed for.’

Most parents (72%) were never given samples of different products and sizes to try when their child was first assessed as needing products, yet it is possible for Tena to post out several samples to test for suitability.

*Action needed! P.P.F. Recommendation-* Every parent whose child needs products, should be routinely offered samples to try and given clear guidelines on how to order the product which they find most suitable. This could help resolve some of the quality issues mentioned in question 9. Existing users should also be offered samples to try if they express that the products they currently receive are not meeting their child’s needs.

**11.) Do you find it easy getting reassessed for products when your child needs it due to growth, a change of needs, etc.?**

Yes (raw score 11) 44%

No (raw score 9) 36%

Declined to answer or not yet needed a reassessment (raw score 5) 20%

**Quotes from parents-** ‘My child has never been regularly reassessed- perhaps twice only in 10 years- and then only when I have insisted.’

‘I can ring for a prescription for controlled drugs but I can’t phone to change the absorbency, size or amount of nappies my child receives- it’s so annoying!’  
‘The school nurse is meant to reassess his nappy needs, but doesn’t seem to know what to do.’  
‘I haven’t had problems, I have always just said she’s got bigger.’  
‘No one told us when and how to re-assess.’

Most parents (44%) had no problems in getting their children reassessed for products when needed. However, a high percentage (36%) experienced difficulty in getting reassessed.

*Action needed! P.P.F. Recommendation-* We would like to see the percentage of parents who had difficulty in getting their child reassessed for products (36%) significantly reduced. It would help if parents were equipped with contact numbers so they could phone for a reassessment appointment. It would also help if the continence nurse verbally checked whether the products are still meeting the child’s needs at each appointment.

## **12.) Have you experienced difficulty in reordering products?**

Yes (raw score 5) 20%

No (raw score 15) 60%

Declined to answer/not yet needed to reorder (5) 20%

**Quotes from parents-** ‘One time they sent the wrong nappies and changed our account, and we had to take the unwanted nappies back to Newton Abbot hospital ourselves.’

Most parents (60%) had not had difficulties when reordering, but there is still room for improvement with 20% experiencing difficulties.

*Action needed! P.P.F. Recommendation-* Parents need a phone number to call in case of difficulties re-ordering.

## **13.) Have you ever run out of products?**

Yes (raw score 5) 20%

No (raw score 15) 60%

Declined to answer (2) 8%

**Quotes from parents-** ‘We run out if my child has a stomach bug or a urine infection.’

‘My daughter has a set amount of pads per day. As part of her disability she has problems with her bowels. We have asked for more pads- either per day or when she is ill- and have been refused.’

‘We need to be re-assessed for nappies so that we don’t run out by the end of the month.’

‘We have run out as we provide nappies for Saturday Club playscheme and school, so don’t have many for home. I wonder if school use them for other pupils or maybe change more frequently than we have supplies for.’

‘When she was younger she was allocated 3 nappies each day, which you could use in a morning if they poo as frequently as she did.’

‘We run out every 2 months, before the new delivery comes through. My son has loose stools due to his disability. We have to buy extra, but can’t always get them.’

‘Initially the amount my child needed was a guessing game so we ran out a week before we could order more.’

Most parents (60%) have sufficient products.

*Action needed! P.P.F. Recommendation-* A small but significant number of parents 20% have not been allocated sufficient products to suit their child’s needs. This is wrong as it is a basic human right to be dry and clean. The allocation seems too rigid and does not allow for times of illness, when a child needs extra products to normal. This urgently needs addressing, again by checking at each appointment whether the quantity allocated is still sufficient and having a system by which parents can quickly get supplies in times of illness.

#### **14.) Have you had difficulties with the delivery of products?**

Yes (raw score 3) 12%

No (raw score 20) 80%

Declined to answer (raw score 2) 8%

**Examples of quotes from parents-** ‘The wrong size was delivered and not taken back when the correct size was sent.’

‘Delivery has been fine, except the very first delivery, when the products arrived unexpectedly and then a letter arrived the next day telling us the date they would be delivered- the date was the day before the letter arrived!’

‘You get given the delivery date- there is no discussion or choice.’

The vast majority of parents (80%) reported no delivery problems.

*Action needed! P.P.F. Recommendation-* A small number of parents (12%) have experienced difficulties with delivery. There needs to be a clear system as to what parents should do if they have a delivery problem, with contact numbers, which is given to every parent whose child uses products.

#### **15.) Have you experienced difficulties with the storage of products?**

Yes (raw score 9) 36%

No (raw score 14) 56%

Declined to answer (raw score 2) 8%

**Examples of quotes from parents-** ‘I have nowhere to store products. They are usually along my hallway, but this can impair my child’s movement.’

‘Storage is difficult as we only live in a small bungalow and my child’s bedroom is very small.’

‘Storage is an issue as we don’t have much space.’

‘We have to keep them in the attic and my partner puts them all up there and gets a pack down when we need it- not ideal.’

‘I have to store them in the shed as too many at once are delivered.’

‘We live in a very small bungalow with 3 children and it is on the market- it is very difficult to store 2 large boxes when they are delivered.’

‘We always have storage problems. Our son’s bedroom has to be ‘decorated’ with boxes and cardboard packs.’

Another parent commented on difficulty in disposing of soiled products; ‘parents need information on disposal of incontinence products- is there a special bin or collection service as my household waste bin gets full quickly.’

*Action needed! P.P.F. Recommendation-* A significant number of parents (36%) are having difficulty in storing the products they need for their child. There needs to be some flexibility in how frequently products are delivered as some families do not have the space to easily store three month’s supply of products in their homes. See next question! Parents also need information on how they should dispose of soiled products and whether they are eligible for soiled waste bins and collections.

#### **16.) How frequently would you prefer products to be delivered?**

Once a month (raw score 11) 44%

Once every two months (raw score 4) 16%

Same as now- once every three months (raw score 4) 16%

**Examples of quotes from parents-** ‘Would prefer once a month delivery, but with no extra phoning necessary, as it will cost me phone calls.’

Most parents (44%) would prefer products to be delivered more frequently (once a month) to avoid having to try to store large quantities of products in their homes.

*Action needed! P.P.F. Recommendation-* The P.P.F. would like the Continence Service to contact the product provider and negotiate more frequent delivery for those families who do not have the capacity to easily store large quantities in their homes.

#### **17.) Is your child allocated sufficient products to meet their needs?**

Yes (raw score 16) 64%

No (raw score 7) 28%

Declined to answer (raw score 2) 8%

**Quotes from parents-** ‘Their allocation is not based on a realistic idea of need- a child that soils little but often needs lots of nappies, not just a set amount of 4 a day.’

‘I like her to be clean. It’s everyone’s right to feel clean and have dignity. But as I only get a certain amount of nappies I have to limit changes daily so that I have enough in the event of a bug. Also, my child has a shunt which releases fluid and goes through the nappies. I have never been asked how many nappies I use or need.’

‘His needs need to be reassessed due to a change in toilet habit.’

Most parents felt their child received sufficient products.

*P.P.F. Recommendation-* Some children (28%) are not allocated sufficient products to meet their needs, which puts an unnecessary strain on their families. All children should receive the amount of products they require. We would like the continence nurse to check at each child’s next appointment whether they have been allocated enough products. Some of the difficulties may be due to the child’s needs changing over time, so it is important that the child’s needs are regularly reviewed and that parents can have a telephone number of who to contact if there is a sudden change in needs.

### **Medication**

#### **18.) Does your child take continence medication?**

Yes (raw score 5) 20%

No (raw score 20) 80%

**Quotes from parents-** ‘I never knew you could get medication to help with continence.’

#### **19.) Have you had any issues with your child’s medication?**

Yes (raw score 1) 4%

No/don’t take medication (raw score 24) 96%

#### **20.) Is the medication helping your child?**

Yes (raw score 5) 20%

No (raw score 0) 0%

Don’t take medication (raw score 20) 80%

‘We were so grateful for the medication (Oxybutynin)- we could get to town without having to stop the car for him to use the toilet- he began to get his life back and we ours.’

‘Desmotabs helped but didn’t solve incontinence.’

**21.) Are you clear what level of improvement you should expect to see in your child's continence on the medication?**

Yes (raw score 0) 0%

No (raw score 5) 20%

Don't take medication (raw score 20) 80%

**Quotes from parents-** 'We never really knew what to expect. The medication (Desmomelts) didn't seem to be making a difference. In the end, they doubled the dose, which helped, but by then he'd been taking it for months.'

None of the parents whose children were taking continence medication were clear about what level of improvement they should expect to see in their child's continence on the medication!

*Action needed! P.P.F. Recommendation-* When medication is prescribed, parents should be told what level of improvement is expected in their child's continence on the medication.

**22.) Do you feel your child's medication is properly monitored?**

Yes (raw score 3) 12%

No (raw score 1) 4%

Don't take medication/Declined to answer (raw score 21) 84%

**Quotes from parents-** 'We only saw the paediatrician at that time. The appointments were many months apart. It wasn't monitored closely enough.'

**23.) Did you have any difficulty with the recent recall of liquid Oxybutynin?**

Yes (raw score 1) 4%

No/N/A (raw score 24) 96%

**Toilet Training**

**24.) Do you feel your child's continence professional understands their needs and has sufficient training and experience to help them achieve/improve their continence?**

Yes (raw score 6) 24%

No (raw score 11) 44%

N/A/Declined to answer (raw score 8) 32%

**Quotes from parents-** 'Soiling wasn't addressed.'

'They have never discussed it with me. Never mentioned it even.'

Sadly, most parents (44%) did not feel that their continence professional understood their child's needs fully/had sufficient training and experience to help their child achieve/improve their continence.

*Action needed! P.P.F. Recommendation-* Hopefully, with the appointment of a new continence nurse (Dionne) for Torbay, parental confidence will improve. However, we would suggest that more time is allocated for the professional to talk to parents and get to know their child's needs and reassure parents that they appreciate the issues involved. Dionne will need to be offered regular training in the different needs of disabled children, to improve her awareness of the issues involved.

**25.) Do you feel there is enough emphasis on toilet training?**

Yes (raw score 5) 20%

No (raw score 8) 32%

N/A/Declined to answer (raw score 12) 48%

**Quotes from parents-** 'They should talk to you earlier at the 'normal' potty training age so it is not a taboo subject.'

'I would like my child to try one of those necklaces with a button to push when you need the toilet.'

'When I first took her out of nappies at night, I asked about washable 'Kylies' but they were not available through the NHS and no one offered advice about where to buy them. If these were available on the NHS as a 'one-off' product it would probably save money in the long run as Mum's may be more willing to take pads off at night.'

'If more money was given to providing information and advice you (Torbay Continence Service) would probably end up forking out a lot less on nappies. Toilet training has been the most frustrating and difficult experience so far in my child's disability.'

'We're always having to get him to wee in drains and bushes when out as there aren't enough public toilets and he can't always wait until we get to the toilet. It's harder as he gets older and I feel like I've failed as a parent.'

'So many families' lives are totally controlled by toileting issues- this needs major investment by the P.C.T..'

'I have never been given any guidance on how to start toilet training.'

'There was help for night time incontinence only.'

'We would like our son, at 15, to come out of pull ups. No advice was given at puberty.'

'No nurse would ask how we were doing, if we had any issues and the nurse said she can't offer any toilet training programme- only nappies. I need a person to assess my child from scratch.'

Of those parents who responded, most (32%) felt there should be more emphasis on toilet training as opposed to reliance on products or medication.

*Action needed! P.P.F. Recommendation-* Although a child has a disability, parents still want them to improve/achieve continence, and welcome advice on

toilet training. The P.P.F. would like to see all parents given advice on toilet training, where this could be appropriate for the child. This could help save money on products and medication and improve the child's confidence.

**26.) Has your child ever been offered a bedwetting alarm or any other device?**

Yes (raw score 2) 8%

No (raw score 13) 52%

Declined to answer/N/A for child (raw score 10) 40%

**Quotes from parents-** 'I had to write to ask my child's Paediatrician for a bedwetting alarm. The school nurse had no idea what I was talking about when I asked her for one.'

Most children (52%) have never been offered a bedwetting alarm to try.

*P.P.F. Recommendation-* Where appropriate to the child's ability, more children should be offered a bedwetting alarm or similar device to try to help children improve/achieve continence.

**Support**

**27.) Do you feel you receive sufficient emotional support in dealing with the extra demands of a child who has not achieved continence?**

Yes (raw score 2) 8%

No (raw score 21) 84%

N/A/Declined to answer (raw score 2) 8%

**Examples of quotes from parents-** 'No help or emotional support offered.'  
'Torbay is definitely not giving the help and information we need.'

'Some days I could cry. Sometimes we have several days on the trot of waking to find him soaked through and having to strip, wash and make the bed again. I dread him saying Mummy my nappy's leaked.'

'I feel I have been battling with them to get the services I need, rather than supported.'

'There is no support- no one asks what problems we have.'

Sadly, the vast majority of parents (84%) felt that they did not receive sufficient or any support from the continence service in dealing with the extra demands of a child who has not achieved continence.

*Action needed! P.P.F. Recommendation-* There needs to be more support for parents of children whose child have not yet achieved continence as it places additional strain on the family. Whether this is the role of the Continence Service is debatable, but the need is clearly there. The P.P.F. felt that this role should be

provided by the Continence Service as otherwise it could be overlooked and it is part of meeting continence needs.

**28.) Do you feel your child receives sufficient emotional support in dealing with their continence difficulties and the implications of not being continent when most/many of their peers are?**

Yes (raw score 2) 8%

No (raw score 16) 64%

N/A to child (raw score 7) 28%

**Examples of quotes from parents-** ‘children need more emotional support from the Continence Service, especially in the teenage stage.’

‘We (the parents) have to deal with **all** the emotions.’

‘I worry about if he’s still wetting when they start going on school residential. Will the school let him go and will he be embarrassed and get teased about wearing nappies?’

‘One of the biggest problems for a child with incontinence is low self esteem and social isolation. I think that it is very important to receive support with this during childhood.’

‘We needed practical help with our child’s wetting as it was day and night, sometimes hourly during the night, and because of disorientation included bedding, clothes and carpets. This undermined his confidence and self-esteem and pads actually gave him some control over managing himself, and did not lead to any regression.’

Again, most parents (64%) reported that their child did not receive the emotional support they felt they needed in dealing with their lack of continence.

*Action needed! P.P.F. Recommendation-* There needs to be more support for children who have not yet achieved continence, especially as they grow older and more aware. Some parents report that their children are not aware or concerned, but for those who are, it is important that they are supported. The continence service could offer this role, but parents and schools can also play a part.

**29.) Have you ever been given details of support for parents of children whose children are not yet continent?**

Yes (raw score 12) 48%

No (raw score 13) 52%

**Quotes from parents-** ‘Why haven’t I (been given details of support)?’

‘The P.P.F. bulletin has been the most helpful in telling me about support.’

‘I would like more information on Grants and capped water bills. Hopefully applying won’t be too difficult.’

Most parents (52%) did not know what support was available to families whose child was not continent.

*Action needed! P.P.F. Recommendation-* At the first appointment, parents should be given a list of support for families whose children are not yet continent, including how to apply for capped water rates, grants from the Family Fund for washing machines and tumble dryers, websites with information (ERIC), etc. This information sheet should also be displayed in the waiting area and made available to school nurses. The P.P.F. would like Torbay Continence Service to draw up a support list.

**30.) Do you think this information should be routinely given by the Continence Nurse as part of the role of the Continence Service?**

Yes (raw score 24) 96%

No (raw score 0) 0%

Declined to answer (raw score 1) 4%

Almost all parents (96%) thought details of support should be routinely given out by the Torbay Continence Service.

*P.P.F. Recommendation-* Details of support should be routinely offered to all families. See recommendations in question 29 above.

**Educational Setting**

**31.) Do you feel your child's setting understands their continence needs and provides the level of continence care they need?**

Yes (raw score 20) 80%

No (raw score 4) 16%

N/A (raw score 1) 4%

**Some quotes from parents-**

‘Sometimes school and holiday club staff would say he couldn’t go to the toilet as he’d been already in the past 20 minutes. They didn’t understand that he needed to go and wasn’t trying to get out of the lesson.’

‘We’ve had conflicting continence advice from the Educational Psychologist, pre-school advisory teachers and health visitor.’

‘When she first started school she was in a mainstream school and they did not understand or want to make provision for her toileting needs.’

‘My child’s school is very understanding.’

‘My child still needs reminders to use the toilet. School assume that because he uses pads he has no control.’

The vast majority (80%) of parents felt their child’s setting met their continence needs.

**32.) Do you feel there is sufficient liaison between the continence service and educational settings?**

Yes (raw score 4) 16%

No (raw score 13) 52%

Don't know/Declined to answer (raw score 8) 32%

**Examples of quotes from parents-** 'They gave my child's school no advice re. management.'

'There isn't any' (liaison between the continence service and schools).

'My child's school did not remind him to drink. He'd go all day without drinking. He worked out that if he didn't drink in school he didn't need the toilet as much so didn't have to keep stopping what he was doing to go to the loo, and he controlled his problem in this way. I never felt the school understood why we wanted him to drink. I think they thought it was easier for him to not need the loo frequently. I wish the Continence Service had been in regular contact with school as I think they might have listened to them more than me.'

'There should be team working with schools/ respite providers, etc.'

Most parents (52%) felt there was not enough liaison between the Continence Service and educational settings (schools).

*Action needed! P.P.F. Recommendation-* There needs to be more liaison between the Continence Service and educational settings to promote children's continence needs. For example, schools need to know that just because a child wears pads, there are steps that can be taken to promote their continence, such as reminding them to toilet regularly. Similarly, some children need reminding to drink regularly during the school day to get their bladder working well. Schools could be copied into letters from the Continence Service/Paediatrician to help promote this.

**Other Recommendations:** The P.P.F. would like to see the Continence Service carry out and act upon their own surveys of parental and user satisfaction with the service and products they offer at least every two years, to ensure that they are accountable and that they are listening to users views.

Parents should have clear access to a complaints procedure if they are experiencing problems.

LB/13.09.11