



P.P.F. Survey on Paediatric Bladder and Bowel Care (PBBC) Service in Torbay

About the survey-

Parents/carers were asked only to comment on their experiences since July 2011. This was done to gauge the progress made since the last P.P.F. survey.

The age range of respondents' children was from 4-18 years, male and female, with almost every age between represented. Surveys were sent to all PPF members and parent/carers with a child at Combe Pafford or Mayfield, and 25 parents/carers responded. There was the same number of responses as received last year. The respondents' children represented a wide range of disabilities, including Down's Syndrome, Cerebral Palsy, S.L.D., A.S.C., Global Developmental Delay and Ataxia. Although the sample size is relatively small, the P.P.F. considers the survey to be representative.

Of the 25 respondents, the vast majority (76%) said their children needed help with continence during the day and at night, with 20% saying 'only at night' and 4% 'during the daytime' only. 48% of respondents said they had been referred to the PBBC before July 2011 and (52%) had only experienced the service since it was commissioned by Torbay Children's Services last year.

The Results, Analysis and Recommendations-

Communication

1.) Ease of referral to PBBC

Easy	48%
Difficult	8%
N/A	44%

As referred pre-July 2011 (pre PBBC commissioned)

Quote from a parent-

'I tried to get everything sorted before my child's 4th birthday (as they are severely disabled and it was clear they would need support from PBBC) via the school nurse, and requested samples, etc... I still didn't get nappies until a month after his birthday despite my efforts to get it organised.'

Analysis-

This is a big improvement on last year's results, where 32% found it difficult to be referred for continence support. There is still some way to go as 8% still had difficulty in getting referred.

Recommendations-

PBBC could continue to raise awareness of how to refer to PBBC with GP's, paediatricians, pre-school key workers, etc. Leaflets describing the service and how a child can be referred to it should be made available in outpatient's department and at SEN group. The PPF would like to see leaflets available within the next 6 months.

2.) Do you have the contact details (names, phone number, and e-mail) of your PBBC professional?

Yes	68%
No	28%
Declined to respond	4%

Quotes from parents-

‘Not given e-mail address.’

‘Letters show two different addresses. Not sure where she’s actually based.’

Analysis-

The majority (68%) of parents had the information they needed to contact their child’s continence professional. This is very encouraging.

Recommendations- Ensure that *all* parents/carers are routinely given the name, contact landline and mobile phone numbers, e-mail address and postal address of their PBBC professional. This could very easily and cheaply be done via a small business card. The PPF would like to see this done within the next 6 months.

3.) Have you found it easy to contact PBBC since July 2011?

Yes	76%
No	8%
N/A or Declined to answer	16%

Quotes from parents-

‘I’ve been able to phone on mobile number and either leave a message or have my call answered.’

‘Getting through to the right person by landline took a bit longer.’

‘Contact with Carrie Williams is very good- if you leave a message she always gets back to you.’

‘Carrie usually returns my e-mails and calls. However, she often hurries the calls- I think due to her heavy workload.’

Analysis-

Most parents (76%) reported finding it easy to contact their PBBC professional since referral. Last survey 48% of people weren’t clear who to contact and 20% found it difficult to make contact so communication has much improved and the PBBC have made good progress in being available for those families who need help.

Recommendations-

Carrie Williams should be congratulated as several parents said she was reliable at getting back to them when they had left messages. She clearly works hard. The PPF would like to see the PBBC build on this success so that *all* parents feel well supported and have the time to be heard.

Products

4.) Does your child use continence products?

Yes	96%
No	4%

5.) Do the products you receive suit your child’s needs?

Yes	68%
No	32%

Quotes from parents-

‘The Libero were great but my child outgrew them. They stop at a certain size and different, uncomfortable nappies were provided which rubbed and aggravated my child’s chronic eczema. The pull-ups we tried were huge so now I buy Dry-Nites every week with my shopping.’
‘Pull-ups would be better than Tena slips!’
‘Poor fit’

Analysis-

Most parents are happy with their child’s products. However, quite a large number (32%) are not.

Recommendations-

It seems many parents would like more choice of products and that some parents are still experiencing problems with fit, which could possibly be resolved with re-assessment.

6.) Have you had any issues with the quality of the products you receive?

Yes	36%
No	56%
Declined to respond	8%

Quotes from parents-

‘Sometimes leak, sometimes tabs rip off when fitting, mostly OK’
‘Pads- the tabs rip regularly and the also came undone regularly and rubbed along tummy, making it sore. The absorbency was also very poor- always leaked at the front. Now on pull-ups- absorbency is better and no more chaffing.’
‘Every day we have problems with poor tabs, absorbency and tissue variability.’
‘I use more nappies as the quality is so poor. They come apart at night as my child is very active. The products are not effective for children on liquid feeds.’
‘Nappy splits or leaks or both.’
‘Ripping or leaking at least once a day.’
‘Absorbency not great.’
‘The pads come away at the front, leaving tabs done up, which is how they come to rub. Pull-ups suit my child much better.’

Analysis- Whilst most (56%) of parents are happy with the products supplied, a large number (36%) are not. There are clearly some issues with the products. Our last survey also evidenced problems with quality, with 40% of respondents complaining. One parent commented at last year’s PPF Continence Event ‘I was keen to hear about the new service in the hope that it was going to improve but the professionals presented as completely sold on the idea that they had all the answers and were ‘dismissive’ of the parent/carer views at the event. Any mention of poor quality service was not well received. The effectiveness of the pads was *not* up for discussion even though so many parents complained.’ The PPF understand that the PBBC have now renewed their contract with Tena for a further 3 years without consulting the parents who use these products despite promising (at the Continence Event) to involve parents in deciding to whom the contract would be awarded when it was due for renewal. If there are issues with the quality of products, parents will use more products, which is less economical. There are also knock-on costs involved in products ripping and leaking as the child’s carers have to do more washing and their child can become sore.

Recommendations-

The PPF feel the issue of quality should be raised with Tena urgently and that when the contract is next due for renewal, service users should be actively involved in deciding to whom the contract is awarded. Those who actually use the products should be routinely asked if they have any issues

with quality' as the renewal of the contract should not solely be based on buying the cheapest products and the quality of products must also be taken into consideration!

7.) Have you been offered samples?

Yes	56%
No	36%
N/A	8%

Quotes from parents-

'Only offered one sample.'

'I was offered samples but they never came.'

Analysis-

Most (56%) parents had been offered samples of different products/sizes to help them find the best product/fit to suit their child's needs. A significant number (36%) had not. However, this is a massive improvement on last year's results when 72% of respondents had never been offered samples.

Recommendation-

The PPF would like to thank the PBBC for this excellent progress in offering samples to try. We feel there are still too many families (36%) who are not offered samples to try and the PPF would like to see the PBBC continuing to offer samples routinely as this is an excellent way of helping families find the right products to suit their child's needs. Children need to try several samples to find the one most suited to their needs. Furthermore, the fact that so many more parents have been offered samples than last year proves that there is an issue with the quality of the products as leakage and products ripping cannot just be explained by poor fit. Perhaps when the contract is due for renewal, the PBBC could push for an agreement that samples will be made available to try at no cost to PBBC, if this agreement does not already exist. Samples are surely the key to children getting the products that are most suited to their needs.

8.) Have you had problems getting your child re-assessed for products?

Yes	20%
No	60%
N/A	20%

Quotes from parents-

'An appointment for PBBC nurse came through just when I noticed I needed next size up so it was great timing. I was offered samples but was happy with Libero so just requested the next size.'

'Not sure where to go (for re-assessment).'

'My son wasn't on their list. He was assessed back in October 2010; I tried re-ordering in October 2011, but am still waiting.'

'Phoned twice in last two months for re-assessment.'

'I was told my child no longer needed products! School said my child was doing well so they stopped products at home too, without my knowledge or input! I have to buy them myself now.'

Analysis-

Most (60%) parents had experienced no problems in re-assessment. The PBBC are to be congratulated for this improvement as last survey (2011) only 44% of parents had found it easy, but there is still room for improvement.

Recommendations-

Again, re-assessment is a key part of ensuring the products provided are suitable. All parents should be routinely asked if the products supplied are still meeting their child's needs. Whilst most children

are now being re-assessed when needed, the PPF would like to see a reduction in the number who are not, as 20% are still experiencing difficulties. Before a decision is made to stop supplying products, both parents and school should be consulted.

9.) Have you had any problems with re-ordering products?

Yes	24%
No	60%
N/A	16%

Quotes from parents-

‘On my recent order the automated system did not process my order. When there was no sign of delivery after 7 days, I rang and queried. I was told the system had not updated and someone would ring me the following morning to sort it out. By lunchtime no one had phoned so I rang and they had no record that I had phoned to complain! She then sorted out getting a delivery for me. I had to buy nappies from the supermarket due to the order being nearly two weeks late.’

‘Didn’t have patient no. as didn’t realise it had changed.’

‘Silly 12 week ordering period. They don’t seem to understand that sometimes children use more nappies and run out before the 12 week period. Should be more flexible.’

‘I have more than one disabled child and wanted products delivered at the same time- difficult!’

‘Difficult to re-order online, easier via phone.’

‘It’s very easy (to re-order)’

Analysis-

Most parents (60%) had found re-ordering easy.

Recommendations-

The re-ordering system is relatively new as they have changed the way you re-order. Some of the difficulties experienced could be due to the embedding of the new system and may be resolved in time. The 24% who had experienced difficulties is too large a number, and the PPF would like to see this number reduced by the next survey. Parents should pass details of any future re-ordering problems on to the PBBC for investigation.

10.) Have you ever run out of products?

Yes	36%
No	60%
N/A	4%

Quotes from parents-

‘I have run out of nappies every time and wondered if it is school or respite using too many. But PBBC checked for me at my recent appointment and said I was only down for 4 a day, so she has now upped me to 5 a day, so this should make all the difference and hopefully I won’t run out any more.’

‘Because of absorbency- needs more than she gets- every time we run out.’

‘Due to illness- twice.’

‘I couldn’t get the size changed in time. Had to re-order only half as the others were too small. I had to pay £80 for more. Not happy.’

‘Frequently happens- extra used in respite, school, etc.’

‘Needs more than amount allowed and when I phoned to get team to phone me they never called.’

‘Always run out of products about 3 weeks before my next delivery and buy extra pads in the supermarket.’

‘Some parents re-order every 3 months regardless of whether they have run out and take the surplus products into Mayfield School to pass on. This helps those who run out of products before their

delivery is due, but gives a false impression of allocation. If everyone's allocation was realistic, there would be no need to do this.'

Analysis-

More respondents reported running out of products (36%) than in last year's survey (20%, 2011). From the quotes above there seem to be two main issues- firstly that some children are not allocated enough nappies on a regular basis and secondly that there is not enough flexibility in the system to meet emergency needs such as illness or an urgent need to change product. These points were raised a year ago, so it is disappointing that progress has not been made in this area.

Recommendations-

The allocation needs to be realistic and parents should not be faced with running out every time. This allocation should be re-assessed regularly and at least yearly on a routine basis. There should be flexibility and empathy for specific circumstances so that if a parent contacts the PBBC because their child has run out due to illness or growth, it is possible to arrange for them to be quickly supplied extra products. At the 2011 PPF Continence Event the PBBC Service promised that 'there is no cap on the number of nappies/pads supplied.' If this is so, there should be no difficulty in giving all users a realistic allocation of products, preventing the problem of regularly running out of products before the re-ordering date.

11.) Have you experienced any problems with delivery of products?

Yes	4%
No	84%
N/A	12%

Analysis-

There are very few issues (4%) with delivery. The only problem reported were parents requesting a delivery too early (i.e. they had run out of products allocated to their child before they should have). The delivery service is working very effectively and parents are happy with it.

12a.) Have you experienced any problems with storage of products?

Yes	8%
No	76%
N/A	16%

12b.) How frequently would you prefer delivery?

Once monthly (this option was not offered, but one parent wrote it on)	4%
Bi-monthly	36%
Same as now (once every 3 months)	48%
N/A	12%

Quotes from parents-

'They are all under the bed.'

'We have limited space at home.'

'Luckily I do have a big house.'

'I'm lucky to have a garage to store the products in, but it does take up a lot of room storing 3 month's supply of pads.'

'I am able to store surplus in the loft until needed.'

Analysis-

Most parents (76%) were managing to store the products. Storage is not an issue if you have plenty of space. For the small minority (8%) who don't have a lot of room, storing a 3 month supply of products can present a real issue. Whilst many parents (40%) would prefer more frequent deliveries

than they currently receive, the PPF accept that the PBBC service stated at the 2011 Continence Event that this was not cost effective. However, there should be the flexibility in the system to allow a more frequent delivery system (say bi-monthly) to those who are assessed as being in genuine need of it, for example families living in cramped accommodation where the storage of products is eating into their living space.

Recommendations-

When the contract is next due for renewal (or before if possible), push for bi-monthly deliveries for those in genuine need. At the 2011 PPF Continence Event the PBBC Service admitted that ‘deliveries had been set at once every 3 months (by the previous Continence Service) to save money but that when the contract was due for renewal and parents could give their viewpoint.’ It is a shame that the contract was renewed without this viewpoint being taken on board.

Medication

13.) Does/has your child take/n continence medication since July 2011?

Yes	48% (includes one child just about to start on medication)
No	52%

Analysis-

Almost half of the children (48%) were taking medication to help with their continence. This is a big increase on last year’s results where only 20% of children were taking medication for their continence. There seems to be an emphasis on medication since the PBBC service was commissioned.

14a.) Have you experienced any issues with your child’s medication?

Yes	8%
No	40%
N/A (don’t take med.)	52%

14b.) Do you believe the medication is helping with their continence?

Yes	32%
No	12%
Not sure	4%
N/A (don’t take med.)	52%

14c.) Has your PBBC Service professional made it clear to you what level of improvement you should expect to see in your child’s continence on this medication?

Yes	28%
No	20%
N/A (don’t take med.)	52%

14d.) Do you feel your child’s medication is properly monitored?

Yes	24%
No	20%
N/A (don’t take/too early to tell)	56%

Quotes from parents-

‘My child was prescribed Movicol for constipation and I feel everything comes back to ‘she’s constipated’ even when things, to me, point to the contrary. They seem very keen on ‘de-impaction’ which is generally unpleasant for both parent and child and doesn’t actually solve the problem.’
‘Unfortunately, my child reacted to Lyrinel xl, causing palpitations and arrhythmia. He’s now been advised not to take it again.’

‘We (and our child) found faecal de-impaction with Movicol messy and stressful. Despite reaching 3 days at 12 sachets a day, my child never reached the clear gravy stage, but we were advised to start reducing. It’s strange as we didn’t think our child was constipated before taking Movicol as they poohed almost daily but we followed Carrie’s advice as we were glad to have the advice of a PBBC service professional. I guess they must have been a bit constipated, but I’m not convinced that Movicol has made or is currently making a big difference in solving my child’s bladder issues. We continue to give it (and other medication) as you have to trust in the advice you’re given, but ideally we’d prefer our child not to be medicated.’

‘My child is poohing more due to the medication, and then we run out of nappies.’

‘I have been left largely to decide on the amount of Movicol given. It’s not well monitored.’

‘I was told the expectation was that we would have dry nights once starting on medication, but my child was never dry once on meds. We were told to continue with the medication. There was some improvement, but no where near the level suggested. Medication didn’t solve things.’

‘I think the PBBC Service *do* try to monitor medication, but are unable to given their heavy workload. They have only seen my child once in a year.’

‘I think there is a heavy emphasis on medication now. It was the first thing they tried, before toilet training or alarms or anything else.’

‘Medication only needed for a short period. Helped my child- not so constipated.’

Analysis-

A minority of parents (8%) reported issues experienced with their child’s medication. Some parents seemed concerned that there was an over-emphasis on children being constipated and faecal de-impaction with Movicol. It is worrying that 16% of respondents felt the medication was not helping or they were not sure if it was helping. 20% of respondents also complained of not being clear of the level of improvement their child was expected to make within a short time of starting on their medication. 20% of parents felt that their child’s medication was not being properly monitored.

Recommendations-

16% of parents feeling that their child’s medication is not helping, or they are not sure that it is helping, is too large a percentage. It is possible that some children are taking medication unnecessarily or that they have not yet found the best medication to help them. With 20% of parents reporting that their PBBC service professional has not made it clear what level of improvement they can expect within a short period of starting on their medication, it is also clear that many parents lack confidence in their child’s medication as they are unsure as to what impact it should be making. The PPF would like to see more parents feeling confident that their child’s medication is making a positive difference to their continence. PBBC service professionals should always meet the children before prescribing medication and listen to parents’ views carefully. Children should be seen at least once a year. Parents put their trust in PBBC service professionals that they are prescribing the right medication to help their child. It is worrying that 20% of respondents felt that their child’s medication was not being properly monitored. Last survey only 4% felt this (although far fewer respondents’ children were taking medication then). Given that there has been a shift towards medication since the PBBC service was commissioned, it is important that any medication given must be properly monitored, both the need for it and the level of improvement expected properly explained, and that parents’ views are heard.

Toilet Training

15a.) Do you feel your child’s PBBC service professional understands their needs and has sufficient training and experience to help them improve/achieve continence?

Yes	32%
No	24%
Not sure	24%
Declined to respond	20%

15b.) Do you feel there has been sufficient emphasis on toilet training as opposed to medication or products (nappies)?

Yes	64%
No	4%
N/A (parent consider their child to be too severely disabled to toilet train)	16%
Declined to respond	16%

15c.) Have you been offered a bed-wetting alarm to try (if appropriate)?

Yes	16%
No	52%
N/A (not needed/suitable)	32%

Quotes from parents-

'They seem frustrated by his slow progress- their expectations are high and possibly unrealistic. We've had a lot of advice and have tried to follow everything they've advised, but haven't achieved continence yet. We've been told our child should only wee hourly, but *how* can you make them wait? Sometimes they're dancing for the loo again ten minutes after last weeing- how do you get them to wait another 50 mins? I feel a failure.'

'They've only met our child once, briefly and I've only had one face-to-face appointment with Carrie myself since July 2011.'

'She does things at her own rate! Pump fed overnight so it will be more difficult to toilet train.'

'No help at all.'

'I noticed on the ERIC website that you can buy toilet training watches that remind you when to wee but they are rather expensive- could the PBBC Service buy some to loan out?'

'Although I've had three meetings with Carrie Williams she has never asked to see my child and my child has never been spoken to or examined. I believe when I have said my child has behavioural issues I have been ignored.'

'We are using a bedwetting alarm (7th week so far). The first week the bed was soaked twice nightly and we were all shattered. Gradually there was an improvement until we got a couple of dry nights weekly, but since returning to school progress has gone backwards and we've had lots of soaking beds again. We'll persevere, but are tired and our child's been tired in school. I'm not sure how long we're meant to carry on, but if there's no improvement soon, we'll have to revert to nappies as it's utterly exhausting being up in the night and all the extra washing, showering, etc. involved.'

'Some children with very severe needs will never be toilet trained and it's very upsetting for them to keep trying and failing.'

'I have got nice ideas and guidance from PBBC Service nurse and it is useful as well! My son's toilet control problem is becoming better now. Thank you to all of you.'

'It's all done via text book and not done on the individual. We find toilet availability an issue. We cannot leave door gates open for the use of the toilet because of the danger aspect of hot kettles, ovens, etc. and at home he will not use PECS to use to the toilets, he goes on the floor. I was told by Carrie to let him clear it up, but he's severely disabled and cannot possibly clear up poo. He smears it, wipes it on furniture, himself, etc. and a lot of the time it is runny. In the end the O.T. provided us with a commode and now he poohs in there.'

'There are arbitrary rules re. products and ultimately no savings are made by their approach as other services have to pick up the cost and consequences to families.'

Analysis-

An alarming 24% of respondents felt that their child's PBBC Service professional *did not* understand their child's needs or have enough training or experience to help improve their child's continence and a further 24% were 'not sure', totally 48%! Last survey 44% of respondents felt their PBBC Service professional did not have the ability to help their child. The vast majority of respondents who considered their child could benefit from toilet training felt that there *was* sufficient emphasis on toilet training as opposed to over-reliance on products or medication. This is a big improvement on last survey's results, where 32% felt there was insufficient emphasis. 16% of

respondents had been offered a bed-wetting alarm to try, double the numbers who were offered one in the 2011 PPF continence survey.

Recommendations-

PBBC Service professionals need to do more to raise parental confidence that they both understand disabled children's needs and have sufficient training and experience to help them achieve/improve confidence. The PPF suggest there is a need for further and regular training about certain disabilities or disability awareness. One parent suggested that the PBBC Service dedicate a day's course in toileting for parents of disabled children and provide symbols and routine boards to help prepare parents.' Another parent suggested having toilet training watches made available to loan out. It may be appropriate for more parents to be offered bed-wetting alarms to try. PBBC Service professionals need to listen to parents more as they know their child best. Individual needs must be taken into consideration. PBBC Service staff need more time allocated to visit children and their parents to discuss how best to help them- once yearly is insufficient. Last survey the PPF recommended that PBBC Service professionals had sufficient time allocated to them to talk to parents, understand their child's needs and offer reassurance that they appreciated the issues involved. It seems that many parents of disabled children don't feel this is happening. It may be the there is a need to employ more PBBC Service nurses to help reduce the workload to allow more time to meet with disabled children and their carers to fully understand their needs. In 2012 double the numbers of carers were offered bedwetting alarms to try, compared to 2011. We recommended this in our last survey, so it is encouraging that it is happening and we recommend it continues. It is also very encouraging that the vast majority of parents felt that there *was* sufficient emphasis on toilet training now (as opposed to 32% saying they felt there was *not* sufficient emphasis in 2011 survey) - the PBBC Service should be congratulated on this improvement, although we must remember that some children will not achieve continence and that it is distressing for them to keep trying and failing.

Support

16a.) Do you feel the PBBC Service has offered you sufficient emotional support in dealing with your child's incontinence?

Yes	32%
No	20%
Not wanted/needed	48%

16b.) Do you feel the PBBC Service has offered your child sufficient emotional support in dealing with their incontinence?

Yes	20%
No	20%
Not wanted/needed	60%

16c.) Have PBBC Service given you details of how to apply for financial help towards the cost of incontinence?

Yes	12%
No	68%
Not wanted/needed	20%

16d.) Do you think the PBBC Service should give information about financial support for incontinence routinely?

Yes	84%
No	0%
Not sure	16%

Quotes-

'Don't need support from PBBC Service- School help us.'

'I did not know any emotional support or financial help existed.'

'The PBBC Service lack empathy, don't understand the children's needs and only consider budgets.'

'My child has no speech and limited understanding so wouldn't benefit from emotional support.'

'They don't seem to have the time to offer support. I don't think they understand what it's like in reality.'

'I'd like more visits and support from my continence professional, but she's overworked and only has time for brief telephone clinics, which isn't really adequate. I think they need to employ more staff so there's time for more face to face visits.'

'Emotional support for us has never been discussed.'

'Now he's older he's becoming more aware and more secretive about his continence issues. He's embarrassed and doesn't want friends to come in case they see his toileting charts and bubbles.'

Analysis-

Just over half of respondents wanted/needed emotional support in dealing with their child's incontinence, however, of these, 20% felt that they were not getting sufficient support from the PBBC Service. In the 2011 PPF survey 84% of respondents said they were not getting enough emotional support, so this represents an improvement. Most carers (60%) felt that their child did not need emotional support from PBBC Service in dealing with their incontinence, however, of the 40% whose children did need support, only half (20%) were receiving it. Again, this represents an improvement against the 2011 PPF survey, where 64% felt their child was not getting enough emotional support. Most (68%) of parents had never been given details of how to apply for financial help towards the cost of incontinence and a huge number (84%) of respondents felt this should be a routine part of the PBBC Service's role.

Recommendations-

The PPF recommend that all parents are routinely offered details of financial and practical support for incontinence, such as capped water bills, the ERIC website, websites providing Kylie's and other waterproof bedding, F.I.S., Family Fund grants towards washing machines and tumble dryers). It would be very easy for the PBBC Service to quickly produce an A4 page of information giving names, websites and phone numbers of sources of financial and practical help for parents and children. This could be given at the first appointment and updated yearly. It should be produced and distributed urgently. This was recommended in the 2011 PPF survey so it's a shame it has not already been produced and made available to all!

The PBBC Service should allocate more time for face-to-face visits so that those families who need extra support can receive it. Telephone appointments should be used less frequently. If necessary, another PBBC nurse should be employed to meet demand and ensure that a good service is being offered. The PBBC Service should show more empathy as incontinence has a major impact on a family.

Educational Setting

17a.) Since July 2011, has your child's PBBC Service professional been invited to your child's Annual Statement Review?

Yes	12%
No	56%
Review not due since July 2011	16%
Don't know	16%

17b.) Did they attend the Annual Statement Review?

Yes	8%
No	60%
Declined to answer	32%

17c.) Since July 2011, has your child's PBBC Service professional ever contacted your child's educational setting to discuss their continence needs?

Yes	20%
No	20%
Don't know	60%

Quotes from parents-

'We are trying a toilet timing technique where he lies on a changing bed and a urine pod is placed over his penis. We started it last year but school stopped doing it. PBBC nurse has reinvigorated our efforts and explained things more fully to get me and school on board. I think school need to support PBBC more and maybe child's T.A. should attend the PBBC appointments too.'

'Our PBBC Service professional was not on the list of people to be invited to our child's Annual Statement Review so I invited them myself and they attended.'

'I invited Carrie to our son's Annual Statement Review. She said she'd attend, but later said she couldn't as she'd double-booked, but that she'd send a report. On the day the school said she hadn't let them know she could no longer come and had not sent a report. As far as I know, she still hasn't sent a report. It's a shame as I could have done with her support in promoting his continence needs in school. However, I spoke about his continence myself and the toilet training we are doing and school are now making an effort to get him to drink three 200ml drinks per school day. I would still like Carrie to speak to them about his toileting programme and frequency as they report he's going around 7 times a day whilst in school. I think schools take more notice of medical professionals than of parents.'

Analysis-

PBBC Service professionals are rarely being invited to children's Annual Statement Reviews (only 12% invited) and are attending even fewer- only 8%! Only 20% of respondents said their PBBC Service professional had definitely been in contact with their child's school to promote their continence needs. This is a very low amount. In the PPF 2011 survey 52% of respondents felt there was insufficient liaison between the continence service and school and it seems that in 2012 this problem still exists.

Recommendations-

There should be more liaison between the PBBC Service and schools. At the PPF 2011 Continence Event the PBBC Service responded that 'Incontinence is a disability as much as speech and language, for instance. Procedures at home must be continued at school by the T.A.' If this is to be achieved, there must be good liaison. Ideally the PBBC Service should *always* make contact with schools if daytime continence is an issue. This was recommended in the 2011 PPF survey so it's disappointing it's not been happening more. If school and home work together children will benefit and their continence needs better met. Of course, schools also need to follow the advice given by the PBBC Service to help make a difference, but many schools *are* willing to take advice on board. If PBBC Service is involved with a child they should routinely be invited to their Annual Statement Review and if they do not feel the need to attend they should send a written report. This matter needs to be raised by the PBBC Service with the SEN Department. Also, schools could be routinely copied into letters, with advice given as to how to manage the child's continence, such as toileting frequency and drinking routines. At the PPF Continence Event the PBBC Service offered to attend Annual Reviews where appropriate, so it's disappointing to learn that only 8% were attended. The

PPF would suggest that, once again, workload is the reason for a lack of liaison between the PBBC Service and school and that there may be a need to employ another continence nurse in Torbay.

Other recommendations-

It would be good to see the PBBC Service listening to the families of disabled children more and conducting their own surveys to ensure they are accountable and are hearing and responding to the views of service users.

Parents should be told how to access the PBBC Service complaints procedure. This information should be offered on the same leaflet as suggested in the recommendations section of question 2.

LB for PPF, 17.9.2012