

PARENTS PARTICIPATION



FORUM

WORKING TO IMPROVE THE LIVES
OF ALL DISABLED/SEN CHILDREN
IN TORBAY

Parent Participation Forum

Continence Event Report

The Grand Hotel
Torquay

01.11.2011



CONTINENCE EVENT, THE GRAND HOTEL, TORQUAY

Thursday 3RD November 2011

BACKGROUND

In July 2011, the PPF conducted a survey of its members to hear their experiences of the continence service. Following this, a number of action points and recommendations were drawn up which the PPF was anxious to discuss with the Care Trust.¹

In September 2012, the new Paediatric Bladder, Bowel and Continence Service for South Devon was launched, and the Primary Care Trust asked the PPF for the opportunity to meet with parents to introduce this new service.

AIMS OF THE EVENT

Consequently, the PPF Steering Group organised the event to :

- give parents and professionals the opportunity to raise any current issues they may have and to make suggestions or improvements that they would like to see
- inform parents and professionals of the new Torbay Paediatric Bowel and Bladder Continence Service and the pathway for this service
- meet the Lead Nurse for the new service and to be advised about any new ways of working and intended improved outcomes for disabled children and their families

AUDIENCE

The event was open to all parent/carers of children with a special educational need or disability, not just PPF members, and all professionals who work with them

¹ (Copies of the Results and Recommendations document are available from pm4ppf@hotmail.com)

GUEST SPEAKERS

INTEGRATED BLADDER AND BOWEL CARE SERVICES TEAM

Claire Lindsay (Senior Specialist Paediatric Bladder and Bowel Care Nurse) and her team were invited to introduce the service and answer parents' questions and concerns

CHILDREN'S INTEGRATED SERVICE – OCCUPATIONAL THERAPY

Louise Smith (Children's Occupational Therapy Team Leader) was invited to attend to outline the support the service is able to give families with continence aids and adaptations, and to bring a selection of equipment that can be provided to help children with toileting.

FAMILY INFORMATION SERVICE

Charlotte Partridge, Manager, Family Information Service was also invited to consult with parents, and sign-post them to other help that may be appropriate

INVITATIONS TO PARENT/CARERS

Invitations were sent to all PPF members and to support groups (AsrUS, Play Torbay, Torplay, Downsouth etc) for forwarding to their members, and Steering Group members forwarded invitations to all their contacts.

Copies of the invitation were sent to the School Nurses at Mayfield, Combe Pafford and Torbay special schools to be sent home in the children's school bags

Flyers and invitations were e-mailed to all School Nurses and SENCO's in the Bay, inviting them to attend and asking them to print off and distribute invitations to appropriate children to take home in their school bags

Flyers and invitations were also e-mailed to Portage Workers, Advisory Teachers and Keyworkers, again inviting them to attend and asking them to distribute invitations to appropriate three year olds.

The PPF also requested Torbay Care Trust to mailshot all Torbay parents currently accessing the continence service.

INVITATIONS TO PROFESSIONALS

In addition to the professionals listed above, all members of the Children's Integrated Service were invited, as well as the Children's Disability Champion, local councillors, Special Educational Needs Team, and Torbay Care Trust.

Tena, the current supplier of continence aids was also invited, but was unable to attend.

FORMAT OF THE EVENT

Each guest speaker had a slot to introduce their service²

There was also a 'cocktail party' session where parents were invited to write comments and questions on Post-it notes, and stick these onto flip charts, by category. Claire Lindsay then addressed as many of these comments as time allowed; the rest were answered after the event. A transcript of the Post-its and Claire's responses is below.

Elizabeth Payne (Service Manager, Children's Integrated Service) gave an overview of the Service, which now includes CAHMS and educational psychologists

The three guest speakers and DeCiDe each had a stand at the event to consult with parents, display information and give out leaflets

The PPF and DeCiDe also took the opportunity to recruit new members

For the complete agenda for the event, see Appendix 2, (this had to be re-arranged on the day as the Continence team were unable to stay for the afternoon session.)

THE NUMBERS

ATTENDANCE

Guest Speakers	3
Parent/Carers	31
Professionals	11 (See appendix 1)

RECRUITMENT

New PPF members enrolled	2
New DeCiDe members enrolled	1

² Copies of the OT Powerpoint presentation are available from pm4ppf@hotmail.com

YOUR CHANCE TO HAVE YOUR SAY – ON A POST-IT!

AND RESPONSES FROM CLAIRE LINDSAY

Flip chart 1 – PRODUCTS (Type, Quality, Quantity etc)

Q : One-off supply of washable/reusable

Q : Products not re-useable so would sometimes need more if promoting good toilet practices

Q : Would initially need more nappies to aid toilet training

Q : Do you provide pads for children that are 'toilet-timed' at school, for respite, shopping, horse-riding

A : Request an individual assessment for your child. Washable shorts are an option – we supply six pairs every six months

Q : Butt plug – what?? Would you use one??

Q : Cost prices for one-off products, ie Swim Nappies

Q : Swim nappies should be a right, I would NOT use a butt plug on my son

Q : I think you should be able to get swim nappies for children with special needs

Q : Can no longer buy swim nappies that fit my son – so we simply don't take him swimming. He has had loose stools for 8 years plus, and no known medical reason for this

A : Children accept and appreciate anal plugs to enable them to enjoy swimming

Q : What happens with periods etc in girls

A : Parent/carer should supply sanitary protection

Q : Is it true you won't supply products if a child needs just one pad overnight

Q : I think you should be able to get nappies for night if children are continent during the day

A : Request an individual assessment for your child

Q : Current nappies do not hold full night – have to wake (him) up in night to go to loo

Q : My son leaks his nappy at night, I have to change his bedding everyday – need advice on absorbency

A : Again request an individual assessment to discuss different product or medication

Q : Do you provide mattress covers? Gloves?

Q : Why can't we have incontinence pads (for bed overnight) as well as nappies

A : You may be able to get these on prescription. The BBC Service do not supply

Q : (Photo of young man wearing lace edged nappy)– frilly pull-ups supplied to 13 year old boy

Q : Quality – shocking

A : PPF will be invited to be involved with the tendering process when the contract with the current supplier comes up for renewal

Q : Doesn't the 2000 guide lines state that products must be supplied on individual need, not arbitrary limits?

Q : 5 nappies a day – would you like to be wet for 6 hours !!

Q : We run out of pads – the delivery does not last until the next delivery.

This can be expensive and difficult to find pads that fit if the supermarket runs out.

A : The number of nappies/pads supplied will be agreed at your child's assessment. There is no cap on the number of nappies/pads supplied.

Q : My son shreds and eats his nappy content. No other type of nappy available to address this particular problem

A : Discuss washable shorts and KC sleepsuits with your continence nurse

Flip chart 2 – DELIVERY (Volume, Frequency, Storage etc)

Q : Very often forget to call as system is complicated re working days + Tena's computer

A : Parents can call up to 2 weeks before delivery date due. Most people have to phone GP's for repeat prescriptions, this is no different

Q : Too many at once

A : Unfortunately this was part of the new contract to save money – the contract is up for renewal soon and parents can give their view point

Q : Storage in hall, difficult to move wheelchair. 2 year old knocked (them) over and (they) fell on him!

A : As above

Q : Spare nappies or size change need collection

A : The supplier has been paid for the nappies and they cannot be returned

Q : Why can't surplus nappies be "recycled"? ie delivered to clinics, nurseries etc

A : They can be taken to car boot sales, or try E-bay

(Note from PPF: The PPF will have a 'swap shop' page on its web site, so that parents can pass on surplus stock, or supplies their child has grown out of.)

Flip chart 3 – ACCESS TO SERVICE

Q : Paediatrician was going to refer my son, but nothing happened.
How do we refer ourselves?

A : GP's can refer to service

Q : Home ed children have no school nurse or health visitor. Access to info and services limited

A : GP will refer you to the service

Q : Mainstream?

A : TA should meet toileting needs via Individual Education Plan. I am meeting with school nurses for a training session

Q : What is the pathway for complaints?

A : Torbay Care Trust complaints procedure

Q : Despite new service HUGE lack of information STILL

Q : Such a shame you did not mailshot all service users to say ring for an assessment

A : I wanted to slowly phase in the service as there are only x2 nurses and clinics would soon be fully booked.

Q : How have you communicated all the changes to professionals who refer children?

A : There has been a mail-shot to professionals (including service leaflet and satisfaction leaflet), and the leads are meant to cascade the information down through their department

Q : No letters sent out to parents for the clinic at Bidwell. Who decided who could see Carrie? Will this change?

A : The school nurses arranged this. Parents can request assessments/appts

Q : Where is the individual child's need???

A : At each appt we will do our best to meet your child's need

Q : New assessments sound great – not sure there are enough hours to fit in all children!

A : There will be waiting lists as there are only 2 nurses

Flip chart 4 – MEDICATIONS

Q ; Are there meds for help with constipation?

Q : What is available and what do they do?

A : Lots of medication available for bladder and bowel, day and night

Q : I think it's a bit overwhelming when you do the Movicol faecal disimpaction – can we have more support for this process?

A : Following an appointment and treatment plan – there will be regular review and follow-up as required

Q : We can't easily get Desmomelts – the GP says only the paediatrician can provide them, but the paediatrician says the GP should prescribe them

A : GP's are able to prescribe Desmomelts.

Flip chart 5 – SUPPORT TO TOILET TRAIN

Q : Mainstream schools need educating in this area – my child was not supported

A : Incontinence is a disability as much as speech and language, for instance. Procedures at home must be continued at school by the TA. The school will have an Intimate Care Policy. Discuss at annual review.

Q : What help do you give for periods?

A : This is not within the scope of the BBC service

Q : Who helps with starting bladder control and bowel control and when. I don't know how?

A : Discuss at your assessment appointment

Flip chart 6 – EXPERIENCES WITH TOILETING OUT AND ABOUT

Q : We change our children on public toilet floors – do you provide floor mats?

Q : Access to disposable change mats from PCT or OT service

Q : Have to change on dirty toilet floors, are there changing mats available for larger children?

A : The BBC Service does not supply changing mats. We promote active bladder and bowel control, for example leg bags for boys.

Q : Where do we get a boy or girl's bottle from?

A : Your GP can provide these on prescription

Q : Not enough public toilets

Q : Finding a large changing area with change bed is difficult

(Note from PPF: There are two 'Changing Places' in Torbay, at Occombe Farm and Paignton Library)

(Note from PPF: Torbay Disability Information Service (01803 546474, dis.torbay@nhs.net) publish a fact sheet – "Parking and Public Conveniences" and DisabledGo have information on accessible toilets and Changing Places nationally – 0845 270 4627, www.disabledgo.com)

Flip chart 7 – DIRECT PAYMENTS (Purchasing Your Own Products)

Q : How do you get a direct payment?

A : Currently trialling vouchers for nappies in Cornwall, but not pro-active advice.

(Note from PPF: Elizabeth Payne will review this with Rebecca Harty from the Primary Care Trust)

Q : Cost price for extra products

Flip chart 8 – SPECIFIC ISSUES

These have all been dealt with on other Flip charts.

EVALUATION OF THE EVENT

Parents were asked to complete an evaluation form, - see appendix 3 for an analysis of the results

WHAT NEXT ?

The PPF will conduct another survey in June 2012, to review parents' experience of the Continence Service

The PPF will continue to promote the Continence Service to its members and will circulate the Service Leaflet as soon as it is available

The next PPF event will be held in January 2012, and will incorporate themes suggested by parent/carers, and we will liaise with the guest speakers re the content of their presentation to make sure it is in line with our aims for the day

We will promote our next event more vigorously in order to reach parents who are not PPF members

We will explain parking arrangements on the invitation, and also promote the crèche which will be available to all children, not just the under fives. We will also arrange to have the crèche in a separate room to the Event

We will have a much later closing date on the invitations to ensure parents have as long as possible to reply

* * * *

The PPF would like to thank all parents and those in a professional role who attended the event. We hope that this event and report will have a positive impact on developing good quality, relevant services for children and young people with special needs, and their families, and build on the close working relationship developing between the PPF and the Local Authority and Torbay Care Trust

PROFESSIONALS ATTENDING

Name	Organisation
<u>Professionals (9)</u>	
Elizabeth Payne	Service Manager, CIS
Jenny Faulkner	Councillor
Carrie Williams	Paediatric Nurse Specialist
Leah Wutschik	Keyworker, Children's Learning Disability Team
Sue Thompson	Day Care Services, CIS
Beverley Burgess	Community Nursery Nurse
Mandy Cowell	Surestart
Kiri Green	Children's Occupational Therapist, CIS
Jacqui Ginley	Community Care Worker, CIS
<u>Stands (2)</u>	
Debbie Roache	DeCiDe
Louise Blakemore	Family Information Service



Torbay PPF Continenence Event

Grand Hotel – 3rd November 2011

AGENDA

- | | |
|--------------------|--|
| From 9.30am | Registration and Coffee |
| 10.00am | Welcome and Housekeeping |
| 10.05am | PPF Introduction – Julia Melliush, PPF Chair |
| 10.20am | New Continenence Service and Pathway – Claire Lindsay,
Senior Specialist Paediatric Bladder and Bowel Care Nurse |
| 11.10am | Coffee Break |
| 11.30am | Continenence Aids and Adaptions – Louise Smith, Children’s
Occupational Therapy Team Leader |
| 11.50am | Your Chance to have Your Say – on a post it! |
| 12.15pm | Lunch |
| 12.50pm | Family Information Service – Charlotte Partridge, Service
Manager |
| 1.00pm | Responses to “Your Say” and any other Q&A’s – Carrie
Williams, Specialist Paediatric Bladder & Bowel Care Nurse |
| 2.00pm | Event Feedback Forms Completed |
| 2.10pm | Thank you and Close |

STATISTICS/RESULTS OF PARENT/CARER FEEDBACK

(NUMBER OF FORMS RETURNED 26/31)*one couple left earlier than expected as they felt the event was not for them but they did speak to the incontinence nurse for a referral.

Graduated Responses

Statistics

PPF Event Management

62 % rated as excellent, 35 % rated as good, 4 % left this question blank and no one answered average, satisfactory or poor.

PPF Intro & Welcome

65 % rated as excellent, 27 % rated as good, 8 % left this question blank and no one answered average, satisfactory or poor.

Professional Presentations/info etc

46 % rated as excellent, 38 % rated as good, 12 % left this question blank, 4% rated poor and no one answered average, satisfactory.

Your opportunity to have your say

54 % rated as excellent, 42 % rated as good, 4 % left this question blank and no one answered average, satisfactory or poor.

How well were the event aims met

62 % rated as excellent, 19 % rated as good, 4 % rated average, 4% rated as satisfactory and 12% left this question blank. No one answered poor.

Your PPF Torbay Steering Group

65 % rated as excellent, 12 % rated as good, 4% rated as satisfactory and 19% left this question blank. No one answered average or poor.

Coffee/Tea

85 % rated as excellent, 8 % rated as good, 4% rated as average and 4% rated as satisfactory. No one answered poor.

Option of Lunch provision

85 % rated as excellent, 8 % rated as good and 8% left this question blank. No one answered average, satisfactory or poor.

Option of childcare

62 % rated as excellent, 12 % rated as good, 4% average, 15% blank and 8% answered n/a. No one answered satisfactory or poor.

The venue (facilities, access & disabled friendly etc

69 % rated as excellent, 27 % rated as good and 4% average. No one answered satisfactory or poor.

Venue room size

77 % rated as excellent, 15 % rated as good, 4% average and 4% blank. No one answered satisfactory or poor.

Overall evaluation of event

62 % rated as excellent, 27 % rated as good and 12% blank. No one answered average, satisfactory or poor.

Conclusion

Many of the results here indicate a high satisfaction rate with a large proportion of excellent and good with a small range/no range of average, satisfactory or poor. However, Some questions provided more variety in range and some were left blank e.g. how well were the event aims met, Your PPF Torbay Steering Group, Childcare, Overall evaluation of event etc. The possible conclusion here is that some people may have felt that the question(s) did not relate to them or they had their own aims/agenda and it was what how well those were met that they commented on.

Only one result scored under half (excellent 46%) and also provided a range of response levels. This was Professional Presentations/info etc. It was also the only answer that was scored as poor (4%). The possible reason for this maybe, that the information did not satisfy the expectations of a small amount of parents/carers. On a separate part of the questions, where specification was required, some parents had put good information or very good information. In contrast a parent had commented that there was "too much information about guidelines and pathways" However it was not the same questionnaire.

The PPF are not able to dictate fully to a professional with regards to their presentation. We can only give guidance of what we and parents/carers expect and the professional(s) would respond and present information based on that.

Action: - It is not something that we can alter for next time as we request the information etc from the professional based on the totalled comments and requests of the parents or carers regarding arranging a specific event. However perhaps next time we can ask the professional for a brief outline of their presentation and work with them to help alter this.

Marketing Feedback**Statistics** **Statistics have been rounded to whole numbers for ease of reporting.*

PPF Mail shot 54%, Other 14%, School (mailshot) 9%, Key Worker 9%, Sure Start/Childcare worker 9%, CDC 6%

No one ticked Continence service, Health Visitor SENCo School Nurse OT/Physio Website/forum.

Conclusion

It is clear from these statistics that over half of the marketing was directly from our mailshot (PPF). It is positive that, Other, accounted for 14%, and that when asked to specify the source, we had results of SG Member, deputy head of Curledge street school, family member, unspecified email and behaviour nurse. However, it is very disappointing that no-one ticked Continence Service, Health Visitor, SENCo or School Nurse, as these are the professionals that have a large role to play in this area of our children's health and should be advising parents/carers on who and where they can access help.

Action: - We need to find out from these groups what happened in regard to their promotion of the event to determine how this can be rectified for any future events to ensure more parents are aware/can attend.

We also need to ensure that the other groups that scored a percentage are increased upon next time e.g school mail shot & others scoring (9%) and CDC (6%).

What Type of school/Setting is you child in?

Statistics **Statistics have been rounded to whole numbers for ease of reporting.*

54% of the parents children attended a special needs school, 35% of the parents children attended a mainstream school, 4% of the parents children are educated at home, 0% of the parents children attended a mainstream school with an enhanced provision for a special need(s). 8% of parents children left this blank or n/a.

Conclusion

Over half of the parents attending the event have children that attend a special needs school (some named them: - 4 Mayfield, 2 Coombe Pafford & 1 Bidwell Brook).

We still have a large group of parents whose children do not attend a special school but are still in need of information and help (some named them: -2 Queensway, 1 Holy Angels, Curledge Street & SDC).

Action: - We need to establish ways to ensure that the groups that scored low percentages are recruited or made aware of the PPF to try and increase attendance at any PPF events and help/inform as many parents/carers as we can.

One good thing

Proff. Reps/Stands 32%, Social Aspect 21%, Lunch 14%, Format of the day 14%, Venue 11%, Childcare Provision 4%, blank 4%. Parking, Times, Other all scored 0%

Parents/carers comments relating to these subject areas

Proff stands. "Very good information", "good information".

Social aspect "meeting others always an advantage.... Information swapping between talks & information always valuable" "Good to recognise other parents have the same issues as us",

Lunch "excellent choice" "fantastic food" "lovely room & Lunch",

Venue (see last comment)

Childcare Provision "couldn't have attended at all"

One poor thing

Parking 54%, Blank 31%, Other 8%, Proff. Reps/Stands 4%, Social Aspect 4%, Lunch 0%, Format of the day, Venue, Childcare Provision, Times all scored 0%

Parents/carers comments relating to these subject areas

Parking "Couldn't find any didn't know where to park" "Had to move the car after 3 Hours" "Not very many parking spaces" "Had to park in Solsbro road-quite a long way away" "Limited"

Blank a high percentage (31%) here were blank either because they were not filled in or because people specified/commented that they couldn't think of anything or nothing was poor.

Other "Dividing into little groups helps with intro's, networking, improves questioning"

Professional Reps/Stands Too much info about guidelines & pathways (This parents had ticked parking here but commented about this area)

Social aspect "didn't get the chance to meet with other parents"

Conclusion

Many parents/carers seemed unhappy with regard to the parking. Whilst it is inevitable in any situation that people will usually display some dis-satisfaction with regard to parking facilities it usually arises because sometimes people are unaware or what is actually available/cost/how long etc or do not know how far away the parking is.

One parent/carer made a comment with regard to dividing into groups. The layout planned on this occasion had everyone in small groups seated at round tables. We did not specifically divide into groups as the room/table layout had ensured this already.

Action(s): - We could suggest/send out information, with the poster/invite, regarding nearby parking facilities as many parents either took ages to park and had to walk a way to the venue (some with children) and others didn't know where to park. We could possibly enquire regarding any parking scheme that the Grand hotel, or others, may have or perhaps we could arrange a parking facility that parents/carers and professionals could park in all day. This would not solve the problem of limited parking or closeness but more people would be aware of what was available and how long they would need to ensure they arrive on time for the start of an event. It may encourage more people to come to an event if they are aware in advance of the parking that is nearby especially if they have not long lived in Torbay or are new to the area.

Future event suggestions that parents/carers felt important to them^{*categories grouped in to similar heading}

Speech and language/communication 3 suggestions, OT Day (equipment/provision) 2, Meet and greet parents/kids/fun day, Sleep, Behaviour & Physio all received 1 suggestion each.

Would you come again to a similar event in the future

100% of the parents/carers answered yes

Were the time slots convenient for you

100% of the parents/carers answered yes

Website Suggestions^{*categories grouped in to similar heading}

Activities/Events (social things to do in hols school time etc, what's on, events inc PPF sports programme pcc) - 7

Useful phone numbers professionals etc who's who - 5

Info on accessible/disabled venues especially playtime venue for children with special needs - 3

Equipment recycling/swapping (incontinence product etc) - 2

Useful links (including forms) - 3

Equipment available from OT service, funding how and where to go for something, list of services available, support groups, referral paths each had - 1

CW 03/11/2011