



PPF EVENT, THE GRAND HOTEL, TORQUAY

Thursday 17th March 2011

BACKGROUND

The PPF Steering Group organised the event as a vehicle for professionals within Children's Services and Torbay Care Trust to consult with parents/carers, and for parents to have the opportunity to discuss with professionals the problems they and their children are experiencing.

In addition, Adrian Wells from Adrian Wells Consulting has been commissioned by TCT to look into the issue of the recycling of equipment provided for children and young people with disabilities, and he wished to seek the views of parents on this.

The PPF also invited three 'exhibitors' to promote their organisations to PPF members at the event, and a representative from DeCiDe (Children's disability register) to recruit any families who were not already signed up to the register.

For full list of professionals who attended, see Appendix 1

FORMAT OF THE EVENT

It was decided to invite professionals to the morning session to hear views and concerns from parents, whilst the afternoon session would be an opportunity for PPF members to meet each other and to shape the future of the PPF

It was felt that a 'speed dating' format for the morning session would be an efficient but fun way to enable parents to have time with each of the professionals, and would ensure that everyone would have a chance to have their say, without having to speak out in front of a large group.

For the complete agenda for the event, see Appendix 2.

THE NUMBERS

ATTENDANCE

Professionals	13
Parent/Carers	30
Children's Society	1

RECRUITMENT

New PPF members enrolled	5
New DeCiDe members enrolled	1

EVALUATION FORMS – SUMMARY

(See appendices 3 & 4)

WHAT WORKED

100% of the professionals who attended and 100% of parents who responded, said 'yes' to the question : "WOULD YOU COME TO A SIMILAR EVENT IN THE FUTURE?"

70% of professionals, and 33% of parents who voted, said 'Speed Dating' was excellent, whilst 30% and 52% respectively said it was good.

50% of professionals who voted said 'Feedback on Speed Dating' was excellent, and 50% said it was good. Parents who voted rated 'Feedback on Speed Dating' as excellent - 48%, and good - 42%

61% of professionals who voted, and 91% of parents, rated the 'Stands' as excellent or good.

59% of parents voted PPF Torbay as excellent; 36% as good and 5% as satisfactory. Overall 85% of professionals and 52% of parents rated the event as excellent.

WHAT DIDN'T WORK

One parent and four professionals disliked the room, and two parents and one professional felt there was not enough time for each 'date'.

We were constrained by having to book the room before final numbers were known, and to allow all parents/carers to visit all the professionals, there was only enough time for each 'date' to last ten minutes.

The only sessions that scored badly on the evaluation forms were 'Pre-Event Info ... ' which 9% of parent/carers voted as unsatisfactory, and 4% of parent/carers voted as poor, and 'The Venue' where again 4% of parents voted unsatisfactory.

No professional voted any session lower than satisfactory (17% voted satisfactory for 'The Venue')

WHAT WE WOULD DO DIFFERENTLY NEXT TIME

We would select a venue that could comfortably accommodate the number of consultation tables required, and would consider having a separate room for introduction and feedback sessions, so avoiding manic re-arrangement of furniture throughout the day!

One parent/carer and one professional said they would like to see an Inclusion Officer at a future event, four parents would like Occupational Therapy to be represented, and two parents would like to see a Speech and Language representative. More professionals attending would mean more time needed for the 'speed dating' session.

FLIP CHARTS - SUMMARY

(See appendices 5 – 12 inc)

Information is a commonly recurring theme – parents commented on the lack of it; professionals on the difficulty of getting it disseminated to parents. Complaints about lack of parental choice and lack of suitable provision were also reported by professionals. Children without a diagnosis, those in mainstream and those with LDD are ‘being forgotten’ and ‘missing out’ in many areas

WHAT NEXT ?

The intention of the PPF Steering Group is to hold a similar event, in a more suitable venue, within three months. We would also extend an invitation to professionals in the inclusion service, occupational therapy and speech and language.

Given the number of parent comments on Transport and Children’s NHS Service (nappies!), we may consider holding a mini-event on just these areas.

We aim to circulate feedback on action points from professionals who attended this event, within one month.

We plan to use the findings of this event to shape our agenda for the rest of the year

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 additional needs, and their families, and build on the close working relationship developing between the PPF and the Local Authority and TCT.

PROFESSIONALS ATTENDING

Name	Organisation
<u>Consulting (9)</u>	
Louise Blakemore	Family Information Service
Julia Cox	Project Manager, AHDC
Rebecca Harty	Commissioning Manager, TCT
Tony Jordan	Group Manager: School Organisation
Marianne Lewis	Pupil & Parent Liaison Officer
Ryan Merchant	Transitions Project Lead
Kirsty Stafford	IPS Volunteer
Adrian Wells	Adrian Wells Consulting
Christine Whitehead	Operations Manager, SEN
<u>Stands (4)</u>	
Sian Couldwell	Bronshill
Natalie Pink	Bronshill
Debbie Roache	DeCiDe
Andrea Whiscombe	Percy Palm 4 Parents
<u>Facilitating (1)</u>	
Bekki Redshaw	The Children's Society

PPF Event – Cavendish Room, The Grand Hotel, Torquay, Thursday 17th March 2011

- 9.45am** **Coffee and Registration**
- 10.10am** **Welcome and Housekeeping**
- Ice Breaker**
- Round Robin Introductions** – Professionals please use this time to say whether you are attending the event to listen to parents’ views/comments regarding the service you are representing, or if there is a specific topic you wish to consult with parents on today
- 10.25am** **“Speed Dating!” – An overview** of how the event will run, to ensure every parent has a voice and every professional has the opportunity to consult
- 10.30am** **Start the Speed Dating** - Professionals each allocated a table with flip chart and pens. Groups of two or three parents visit each professional in turn. Individual professionals to record concerns/queries on flip chart.
- 11.45am** **Feedback** by professionals of information you have gathered from the Speed Dating session together with any resulting action points to take away with you.
- 12.30pm** **Lunch**
- Further opportunity to continue any conversations
 - Professionals to complete Event Evaluation Forms please
 - Parents able to visit stands by: DeCiDe, Percy Palm for Parents and Bronhills
- 1.30pm** **Goodbye and Thanks** to the professionals who have attended
- PPF Torbay** – where we’ve come from, where we are, where we are going 2011.....
- 2.45pm** **Event Evaluation and Close**

EVALUATION FORMS Page 1– Professionals (NUMBER OF FORMS RETURNED : 13/13)

	<u>Excellent</u>	<u>Good</u>	<u>Satisfactory</u>	<u>Unsatisfactory</u> <u>Poor</u>	<u>No Vote</u>
Pre-Event Information & Organisation	4	8			1
Ice Breaker	6	5			2
Introduction	7	5			1
Speed Dating	7	3			3
Feedback on Speed Dating	5	5			3
Stands (DeCide, PP4P, Bronshill)	3	5			5
PPF Torbay	8	3			2
The Venue	5	5	2		1
Overall Evaluation of Event	11	2			0

EVALUATION FORMS Page 2 – Professionals(NUMBER OF FORMS RETURNED : 13/13)**WAS THERE ANYTHING ABOUT THE EVENT YOU PARTICULARLY ENJOYED?**

- Meeting Parents face to face
- Speed dating was a great tool to enable me to get ideas, opinions and experiences from parents/carers, which I can follow up on
- Icebreaker and friendly atmosphere
- The icebreaker
- The chance to talk to all parents
- Speed dating was an effective way to meet service users
- Very informal atmosphere
- The speed dating - really great to talk to so many parents
- As ever, working with users is a pleasure
- The whole day was very enjoyable - everyone very friendly and welcomed me
- Very useful to get feedback from parents + ideas
- No response x 2

WAS THERE ANYTHING ABOUT THE EVENT YOU REALLY HATED?

- No x 4
- Not enough time to talk to individuals
- Not really
- Disliked room - was too small and too hot
- Room a bit small
- The room could have been bigger
- Room a little cramped, but understand why
- No response x 3

ARE THERE ANY OTHER SERVICES YOU WOULD HAVE LIKE TO HAVE SEEN REPRESENTED AT THE EVENT?

- Schools?
- Inclusion Service
- None that spring to mind
- Heads of Service at Torbay children's Services
- Adult Commissioning
- No
- No response x 7

WOULD YOU COME TO A SIMILAR EVENT IN THE FUTURE?

- Yes x 12
- Yes please
- No response - nil

EVALUATION FORMS Page 1 – Parent/carers (NUMBER OF FORMS RETURNED : 22/30)

	<u>Excellent</u>	<u>Good</u>	<u>Satisfactory</u>	<u>Unsatisfactory</u> <u>Poor</u>	<u>No Vote</u>
Pre-Event Information & Organisation	13	5		2 1*	1
Ice Breaker	6	11			5
Introduction	9	8	1		4
Speed Dating	7	11	3		1
Feedback on Speed Dating	10	9	2		1
Stands (DeCide, PP4P, Bronshill)	9	11	2		
PPF Torbay	13	8	1		
The Venue	8	12	1	1 0	
Overall Evaluation of Event	11	9	1		1

*The parent who voted 'Pre-Event Info' as poor, commented on the form : "Learnt about event via phone call from PPF 2 days before event"

EVALUATION FORMS Page 2 – Parent/carers (NUMBER OF FORMS RETURNED : 21/30)

WAS THERE ANYTHING ABOUT THE EVENT YOU PARTICULARLY ENJOYED?

- See the service providers (name to face)
- Excellent, professional event
- Opportunity to meet a range of professionals
- Atmosphere was great. Involvement from all parties was well thought out
- Nice to hear feedback
- Professional visits
- Meeting the professionals face to face
- 'Speed dating' a great idea. 10 minutes not quite enough, though. Would liked (sic) to have learned more about Connexions in particular
- Parent conversation (lunchtime)
- Speed dating
- Opportunity to talk to professionals face to face. Opportunity to meet other PPF parents
- Meeting the professionals and putting a face to them
- All
- Feedback
- Range of services which attended
- Having the chance to meet with various professionals and having an opportunity to have our say
- All good professionals, very friendly + supportive
- Information provided by Debbie Roache (DeCiDe) and meeting some very nice individuals
- Relieved to see people I already knew
- No response x 3

WAS THERE ANYTHING ABOUT THE EVENT YOU REALLY HATED?

- No x 10
- The venue size made it very difficult to hear conversation during 'speed dating', due to close proximity of stations
- Not enough time with individuals/speed dating
- Not enough time at individual tables
- Hard having a toddler present lunchtime too long to occupy
- Not too impressed with lunch, requested plain sandwiches! Sorry. *
- No response x 7

ARE THERE ANY OTHER SERVICES YOU WOULD HAVE LIKE TO HAVE SEEN REPRESENTED AT THE EVENT?

- No x 3
- Respite care options
- Deputy Director of Children's Services
- OT
- Maybe OT services
- OT S and L
- Inclusion Officer
- More info about sibling's groups
- House adaptations
- OT, speech and language, learning disability nurse, house adaptations
- Direct payments
- Safety in the home/garden
- No response x 8

WOULD YOU COME TO A SIMILAR EVENT IN THE FUTURE?

- Yes x 20
- No response x 2

(*This parent had not responded to our invitation, therefore her catering requirements had not been noted)

FLIP CHART TRANSCRIPTION – LOUISE BLAKEMORE, FIS

Family Information Service – Feedback from PPF event

Parents comments:

Despite extensive distribution of marketing leaflets, poster campaigns and meetings with key people in the IJACDS and other services to encourage parents they work with to use the FIS (particularly the brokerage service), most parents at the event stated that they hadn't heard of the FIS or seen any of our marketing. Only one of the parents present had actually used the service.

Parents felt that the FIS postcards don't have enough information on them and therefore don't sell the service. However, it was explained to the parents that at the beginning of this year we began updating all of our leaflets (one in particular at the request of the IJACDS) for this reason and that the new leaflets, which have been with the design team and should be available in the next couple of weeks, will explain more clearly about the role of the FIS.

As parents at the event weren't aware of what the FIS offers, much of the discussion was around how and where we should advertise the service. It was felt that though many of the practitioners are aware of our service, they are not passing on this information to parents. Most of the places for advertising that were suggested are places where we have already routinely advertised in the long term including, but not exhaustive to, schools, GP surgeries, health visitors and libraries. A lot of parents felt that they would be more likely to access the service if one of the professionals they speak to referred them or recommended the service rather than the parents having to pick up a leaflet and find out what the service is themselves, which is what the FIS are aiming to achieve through our regular outreach sessions and drop-ins and by engaging services such as children's centres and the IJACDS.

The consensus was that there is inconsistency across schools in Torbay and that some of them have promoted the FIS to parents and others hadn't. Parents agreed that encouraging more schools to include FIS leaflets in book bags would be helpful and that attending events at more of the schools would help make more parents aware of what the FIS can offer them. This is already the case at Kings Ash primary School, where the FIS attends a regular drop-in session and the FIS has been present at various parents evenings and school-run events at other schools. Several parents suggested that contacting the PTA directly to try to get stands at school events such as summer fetes etc might be more effective than contacting the schools main office as it is usually the PTA who organise these types of event.

Other suggestions included contacting school nurses and school sencos and sending leaflets to the hospital (John Parkes Unit) and Children's Community Nursing Team.

The FIS has offered to attend meetings of the PPF on more than one occasion but have been informed that this was not appropriate as the forum already has a full agenda and events such as this are now in place for us to speak to members of the PPF in person. The offer still stands and we are more than happy to attend meetings or meet parents to talk to them about what the FIS can offer. Hopefully, this event will have gone some way to improving knowledge of the service among parents.

Actions:

Contact schools:

- Request contact details for PTA chair/secretary
- Send another request for FIS leaflets to be sent out in bookbags to all parents

Send posters to Torplay to be displayed – sent 17.03.11

Contact Kathie Johnston to request FIS leaflets are put in all Bookstart packs – email sent 17.03.11 unfortunately leaflets can't be included in these packs

FLIP CHART TRANSCRIPTION – JULIA COX, Aiming High Programme Manager

PPF Event – Notes

Consultation Topic:-

- Parent/Carer Participation
- Short Breaks & Direct Payments
- Disabled Children's Access to Childcare

Parent Comments/Issues:-

- More life skills/independence training options
- Better information re Short Breaks Access (eligibility/access/pathways)
- Better trained Childminders – e.g. O2, peg feeding, moving & handling
- More Information packs to more families
- More services/options/groups for siblings
- Gaps in provision of support for children with complex needs
- Lack of named workers for families (key workers)
- More education for School Nurses around what is available for families with disabled children
- A menu of services that families can buy with Direct Payments
- Is Aiming High for Disabled Children going to continue?

Julia's Action Points:-

- Organise more Information Station Points – By May 2011
- Send out Information Packs to families who requested them at event – March 2011
- Speak to PPF about putting Info Pack details in bulletins so parents can ring and order their copy – March 2011
- Look into recruiting more young male befrienders – May 2011

Julia Cox – Aiming High Programme Manager, 17th March 2011

FLIP CHART TRANSCRIPTION – REBECCA HARTY, Commissioning Manager, TCT

CONSULTATION TOPIC: Torbay Care trust Children's NHS services

PARENTS COMMENTS

Children's Community Nursing Team

Discharge Post operative support is lacking

Family had to attend A&E to get Mickey button put in- why can't the team do this?

Children's community nursing – help with IV antibiotics – nurses currently won't help at home – big impact on the whole family.

Children who don't fit any criteria – children in mainstream school don't seem to have the same access to services

Nonexistent emotional support (for living with their condition) for children in mainstream schools, children facing own mortality, long waits for psychology and inappropriate interventions

Want continuity of nurse – same person so family can get to know them.

Continence

Nappies: why can't I have both nappies & continence pads – nappies aren't any good overnight- they leak

Why do we have to have 3 months supply of nappies- storage issues in family homes

Positive response from parents to idea of direct payments & monthly orders for continence products

Nappies – reassessment seems very difficult to get new sizes or quantities

Why can't we phone Tena directly – it is such a hassle to get the nappies we need

Ordering pads /nappies – have to do this 2 weeks before – delivery dates count weekends
“computer says no”

Would like advice & guidance: toileting – for children with SEN/LD/Phys Dis

Knowledge about continence alarms, Mum had to research these herself- why is it so difficult to get help?

Swim Nappies- can we have these?

Would like clear contacts and pathway for the new continence service

Speech and Language Therapy

Particularly for children and young people with Downs Syndrome

Child Development Centre

Offers a low class nursery – therapeutic input poor, why can't children be seen in their own nursery?

Relationship with portage – needs to be more joined up

ADHD

ADHD prescriptions Dr Imong does do them– Dr Dibble doesn't – why?

Autistic Spectrum Conditions

Why do we have to travel to Newton Abbot- can we have assessment in Torbay?

Respite

Gap in service for children with autism, behavior, learning disability “complex needs” require - specialist support

BECKYS ACTION PLAN

1. Ask PPF to help with consultation on Child Development Centre and Children's Community Nursing services and pathway development
2. Continence:
 - Test new pathway to see that it makes sense with parents
 - Plan public launch of the new continence service in the summer
3. Discuss and plan with IJACDS how to meet gaps in respite for children with autism
4. Feedback all the comments to the Paediatric Clinical Commissioning Group and relevant pathway working parties

FLIP CHART TRANSCRIPTION – TONY JORDAN, Grp Manager : School Organisation

MY TOPICS: personalisation of transport and general feedback about the service

Comments from parents

My child's school has asked me to provide transport for my child to attend an off site activity during the school day

When I need to attend school to see the teachers about my child, the transport team do not let me hitch a lift on my child's transport to school.

The vehicle provided for my child isn't suitable because it is too high off the ground and the transport team do not allow the driver and escort to use a portable step because they say it is dangerous to carry on the vehicle

Escorts should be allowed to offer better personal care e.g. wiping children's noses

The transport team sometimes under-estimate the effect of a change of vehicle. When it changes there should be a new risk assessment. I'm not sure that the new vehicle is suited to my child's wheelchair.

I do not think I have been asked to update the risk assessment even though my child's condition has changed.

I am not sure that drivers, escorts and the transport team understand enough about my child's needs and so simple errors are made that could be avoided (child with autism).

The journey times are too long for some children.

Changes to transport should be planned jointly with parents.

It would be a good idea to share the child's "My Life" book with escorts.

The retractable step on the vehicle has never worked very well and doesn't seem to have been sorted out.

Why can't my child's special car seat be transferred from school transport to holiday transport (the seat is provided by the transport team; the holiday travel is arranged by Children's Disability Service. The seat remains with the school transport operator during the holiday) ?

The severe weather arrangements are not flexible enough - if the transport cannot get up my steep hill, I can meet it at the junction with the main road. This would be better than cancelling the transport.

Why do some escorts and drivers telephone to say that they are delayed whilst others hardly communicate at all ?

Today's Action Points Feedback to the transport team on these issues and reflect on how the service can be improved. How can we use PPF to help us to develop and test our systems for providing transport

Parked Issues I made a note of 5 issues about specific children to investigate.

FLIP CHART TRANSCRIPTION – MARIANNE LEWIS – Pupil & Parent Liaison Officer

Feedback from PPF event regarding Parent Partnership Services

Marianne Lewis (PPS staff)

and Kirsty Stafford (Independent Parental Support – PPS volunteer)

Consultation topics:

Generic checklists
Publicity of the service

Parent comments:

Looking for a secondary provision and discussing checklists: checklists currently available for visiting schools, annual review meetings and general other meetings ...all these are useful but not currently available on the website

Awareness of the PPS service and other information they can provide: how to raise general awareness of services, circulating information appropriately, 'grass roots' level awareness raising via consultation caravan in town centres and other community events welcomed and positive reaction to trial of checklists for transition to secondary, visiting schools and yr5 annual review to be sent out to parents alongside the EP yr5 assessment report

Suggestion for schools to be encouraged to send relevant PPS checklists out to parents

Suggestion for further checklists to be devised for post 16

Parked issues:

How does anyone get to know about parent partnership services?

More suggestions welcomed about ways to effectively promote Parent Partnership Services and what it does.

More checklists to be devised ...parents suggestions welcomed about other topics for checklists.

Marianne's Action Points:

To send out by email electronic versions of checklists currently being trailed to parents who left their email addresses

To complete devising all relevant checklists for secondary transfer and get them sent out alongside yr5 EP assessment reports this year as a trial

To draft a checklist for post 16 provision and then share it with PPF for comments

FLIP CHART TRANSCRIPTION – RYAN MERCHANT, Transitions Project Lead

Parent Comments

- Issues around primary to secondary school transitions – very different experiences
- Accessibility of mainstream schools for disabled young people and the part parents/carer anxiety plays
- Too few special school places
- The actual use of information gained at school reviews (“is it just locked in a draw and ignored”)
- Children educated in mainstream and specialist placements out of Torbay being forgotten or ‘missing out’.
- Lack of information in relation to education and LDD – including school and local authority responsibilities
- The different experiences of young people and their families with recognisably similar difficulties
- Transition process issues post-16.

Action Points

- Continued development of Person Centred Approaches in schools in Torbay
Exploration of Primary to Secondary Transitions and identify how I can become involved

FLIP CHART TRANSCRIPTION – ADRIAN WELLS, Adrian Wells Consulting

Consultation Topic: Recycling of Disability Equipment	
Parents Comments	
Choice: New/Secondhand/Refurbished Ownership Tasters of equipment before buy/supply <u>System needs to be easy</u> <u>Pedro's!</u> <u>Information: Clarity of where/who to return to</u> Marketplace/Trading Opportunity/Library <u>Support to make (or not to make) decisions</u> <u>Unused equipment: poor/inaccurate explanation of use?</u> Design and aesthetics <u>Safety and support</u> <u>Wheelchairs!</u> <u>Local Feedback</u>	Parked Issues: Reviews User Input
Adrian's Action Points:	
<u>Write report for NHS South West</u> Copy of report to Torbay PPF and Torbay Children and Young People's Group	

FLIP CHART TRANSCRIPTION – CHRISTINE WHITEHEAD, Operations Manager, SEN

Consultation Topic : Statementing processes - the future

: Admissions to Special Schools/ Enhanced Provisions

: Parent Partnership

Parent Comments

The challenge of ensuring all appropriate children are on the DECIDE register to support future service planning.

Transitions remain a concern particularly around Y6 – Y , into post 16 and post 19 provisions.

The issue of children having to go through repeated assessments.

Discussions around the SEN Green Paper particularly the plan to replace the current statements by an 'Education, Health and Care' plan from birth to 25.

Very positive comments about Mayfield and the fact that pupils can stay until * therefore avoiding a change of school.

(* ? should read “ ... stay until 19 ...”)

Actions

Julia to liaise with PPF to produce a pack giving details of DECIDE which could be included in the letter sent by SEN to parents following the annual review. Julia then to discuss with CW

