

**Notes of Children's Short Breaks Working Party****Monday 1<sup>st</sup> February 2010, 10.00am-12.00pm at Lincombe Hill Hall, Torquay**

1	<b>Attendees</b>		Sharon Matson (SM), Annette Benny (AB), Rosa Marshall (RM), Sue Thompson (ST), Clive Sainsbury (CS), Mel Lane (ML), Simon Boustead (SB), Kirstin Payne (KP), Julia Melliush (JM), Claire Harding (CH), Keri Barzotelli (KB), Ann Skipwith (AS), Heather Parker (HP), Rob Baker (RB); Tania Baker (TB), Julia Cox (JC), Debra Mountford (DM), Rebecca Harty (RH)
	<b>Apologies</b>		<b>Apologies</b> Elizabeth Payne, Gina Skipwith (GS), Paula Macmenamin (PM), Jayne Cooper (JC),
2	<b>Welcome</b>	<b>Sharon Matson</b>	<p>SM provided an introduction and welcome to the meeting. She explained that today would be the last time that the working party would meet as a group and in future this work stream will merge with the work undertaken by the Short Breaks Steering Group to ensure good respite care across the piece.</p> <p>The Steering group is made up of 50% parents and carers as well as representatives from the Council, Care Trust and Torbay Hospital. Councillor Jenny Faulkner sits on this group, JM also attends the group as a parent representative. The groups remit is to drive the Aiming High for Disabled Children programme for the Bay.</p>
3	<b>Feedback from the Short Breaks Fayre and Former users</b>	<b>Rebecca Harty</b>	<p>RH reported on the Short Breaks Fayre which took place on 15<sup>th</sup> and 16<sup>th</sup> January. It was very successful and had been organised by JC and DM with a lot of help from JM and KB. There was good representation from providers and interest groups, but there were not so many visitors.</p> <p>Following the last working party meeting a leaflet was produced to try and gauge what services people valued and whether they would use service provided by the JPU. Feedback from only 13 people was captured on the day (more feedback has since been provided by the working party and this has been incorporated into the results circulated with the minutes). RH and Jayne Cooper, Matron for Child Health, set up a table over the two days of the fayre to try to capture feedback.</p> <p>The feedback clearly show demand for overnight provision as well as day care, holiday schemes and day trips. More feedback is required in order to understand demand for services and to develop a service specification. CH had asked lead professionals within the Integrated Joint Agency Disability Service to collect feedback from former users of the JPU. This is incorporated into the feedback sheet.</p> <p>JM expressed disappointment that the JPU had not had a table at the Short Breaks Fayre. Staff at the Unit were preparing for the fayre and then gave notice two days before that they would not have a JPU table. Other parents agreed and felt that this was underhand. SM explained that a decision had been taken at Chief Executive Level that the Unit would not have a JPU table as the South Devon Healthcare Foundation Trust (Torbay Hospital) is not in a position to provide clarity as to what the future offer of the Unit will be. Parents felt that this was a poor decision and that it sent out a poor message to users as to the hospital's commitment to the Unit.</p> <p>JM and KB felt that the parents were only getting part of the picture around the JPU and decisions were being made outside of the meetings. A discussion followed about the closure of the Unit on the day that the Health Overview and Scrutiny Committee visited the Unit. A response was sent to councillors from RH which some parents felt was insufficient.</p>

		<p>SM explained that the group is coming together in good faith to try to work in partnership with parents and carers to reshape the service.</p> <p>TB shared her experience of JPU with the meeting. She feels that the family are being pushed into family to family care, it has been said by lead professionals working with the family that the JPU is not in her son's interest and is detrimental to him. RB stated that they don't feel that the family to family lady has helped or been able to answer any of their questions. They are happy with the service at the JPU and don't see any other possible service available, there isn't enough family to family care.</p> <p><b>ACTION: CH to follow up on TB and RB'S concerns around family to family care</b></p> <p><b>ACTION: RH/JC to do some concentrated work around market development</b></p> <p>A discussion followed around how the JPU can be viable and accessible for more children. The Unit is also used for acutely ill children for convalescence and when Louisa Cary is full. It will be important to understand the contract and funding around the non-respite admissions.</p>
4	<b>Future and next steps</b>	<p>A clear specification for respite services in the Bay will be developed by JC by the end of February. It will describe the service model of care that we are looking to buy. It could be that other providers than SDHFT (Torbay Hospital) can provide the services outlined in the specification. They could be provided by Torbay Care Trust or a 3<sup>rd</sup> sector organisation. AB talked about an example in North Bristol run by Barnardo's.</p> <p>SDHFT cannot currently deliver the service within the financial envelope that is provided. SM explained that the financial position within the NHS is tight, in Torbay significant savings have to be found every year for the next 6 years. It is crucial that we do this work so that we can buy the services we want for the best value for money for the children and young people of Torbay.</p> <p>If the JPU stands still, it is likely that it won't be financially viable if Devon do not fund their half of the contract. We could broaden the criteria for the Unit so it could become a health and social care venture for children with less complex needs for example ST's inclusion activities could be run from there? It might be that we need 3 beds instead of 8, play facilities, day respite, palliative care and a range of activities, basing the integrated disability service there. Could one of the 'special schools' provide respite?</p> <p>There will be lots of issues to work through, such as the implications for staffing, the costs- this might drop if the Unit were not run by an acute hospital trust.</p> <p>A discussion followed around the indicative allocations for Fair Access to Carers Breaks. Children with high medical needs have been given indicative allocations (IA'S) that would mean that they would be able to purchase very little care if they received a direct payment. RH explained that these have not been finalised and clarified that these would come from the Integrated Joint Agency Children's Disability Team. Work is ongoing over the next few months to finalise what the IA's will be.</p> <p>SM clarified that NHS Devon has not given notice on the Unit, 6 months notice is required. SM repeated her pledge to maintain respite care at the JPU for the foreseeable and explained the nature of the contracting process with SDHFT and NHS Devon as a whole for the acute contract, that she will</p>

		<p>be shortly entering contract negotiations- the JPU will be considered as a part of the whole. SM reiterated that she will be honest with parents and keep them informed at each step.</p> <p><b>ACTION: JC to write up the service specification by the end of February 2010. This will be on the agenda for the Short Breaks Steering Group meeting on 9<sup>th</sup> March. The parents and carers who have made up the working party will act as an expert reference group/ focus group and will have the opportunity to comment on the specification before it goes out to wider consultation via the Parents Participation Forum. Parents and carers will receive travel and childcare expenses for participating in the reference/ focus group.</b></p> <p><b>ACTION: Parallel conversations will have to happen with SDHFT and potential other providers. Before the service will be taken through a procurement process.</b></p> <p><b>ACTION: RH is tasked with developing a project plan once the specification has been developed.</b></p> <p><b>ACTION: The Parent Participation Forum is about to do a mailing to all parents on the disability and SEN registers. JM offered to send out the market research leaflet with the mailing so that we can capture more views. RH and JM to liaise.</b></p> <p>SM thanked everyone for their time and contribution to the work so far.</p>
--	--	---