

Notes of Children's Short Breaks Working Party**Tuesday 8th December 2009, 10.00-12.30am at Lincombe Hill Hall, Torquay**

1	Attendees Apologies		<p>Sharon Matson (SM), Annette Benny (AB), Rosa Marshall (RM), Sue Thompson (ST), Gina Skipwith (GS), Jayne Cooper (JC), Clive Sainsbury (CS), Mel Lane (ML), Paula Macmenamin (PM), Simon Boustead (SB), Kirstin Payne (KP), Julia Melluish (JM), Claire Harding (CH), Keri Barzotelli (KB), Charlotte Stephens (CS), Ann Skipwith (AS), Rebecca Harty (RH)</p> <p>Apologies Elizabeth Payne, Julia Cox, Beryl Perrin, Ann Williams</p>
2	Short Breaks Update	Sharon Matson	<p>SM provided an introduction and welcome to the meeting. She explained that today would be an opportunity to finish the work that we started on 01/10/09.</p> <p>SM talked about a draft proposal for a change to JPU service. South Devon Healthcare Foundation Trust have looked at the usage of the John Parkes Unit over the past 11 months in order to understand trends in demand so that it can be adequately staffed. As families have opted for alternative short break care, the occupancy of the Unit has reduced over the past few months. The unit had had to close regularly due to staff shortages or no children attending the Unit. Often nurses are relocated from Louisa Cary ward, however the ward is already short staffed due to a large amount of maternity leave. In order to maintain standards it is proposed that for a trial period the Unit could close on Sunday and Monday nights, closing at 5.00pm on Sunday and reopening on Tuesday at 1.00pm. Parents will still be given a choice in the short break, with the flexibility of booking into the other 5 nights of the week in advance. The consolidation of bed nights would improve utilisation across the week and enable the staffing of the Unit to be planned to an acceptable level with one trained nurse a 2 HCAs/ shift.</p> <p>JM raised the point that at the first meeting in September- parents had explored the idea of a bank of nurses specifically for the JPU. JM wanted to know what had happened to this idea. JC explained that this has not been explored in depth, there is currently a shortage of paediatric nurses available to staff let alone the Unit. JM felt that lots of ideas had already been put forward by parents but they weren't being progressed and questioned the value of their contribution. SM explained that some ideas might run, others may not due to a range of factors e.g. lone working, health and safety, cost. JM suggested that the group should at least have an update on progress against the suggestions or an explanation of why these ideas might not work.</p> <p>ACTION: RH to provide a grid of suggestions/ actions and an update on progress against each for circulation.</p> <p>It has been difficult to staff the Unit when bookings have not been placed in advance. Some parents book 3 months in advance- at least a week was thought to be an acceptable notice period.</p> <p>There was a concern that if the draft proposal was put in place, where would children go if they needed emergency respite on the days that the Unit is closed? Under these circumstances it was felt that it would not be acceptable for them to be admitted to Louisa Cary ward which offers acute care.</p> <p>ACTION: RH to discuss the emergency respite issues with GS, CH, Elizabeth Payne and Julia Cox</p> <p>It was discussed that on most nights the 8 beds at the Unit are operating on 40-50% capacity- so there would be space to deal with emergencies on the</p>

			<p>nights that the Unit is open.</p> <p>Questions were asked as to the admission criteria for the Unit. It was explained that an acuity scoring system is used to determine needs. Devon has introduced a health assessment system- which determines an overall eligibility score for individuals. It is important to remember that Devon is ahead of Torbay in terms of assessment and criteria; Torbay is still in the preparatory phase.</p> <p>ACTION: a paper regarding the proposal will be circulated to parents once it has been through SDHFT's internal governance process.</p> <p>CS, a Devon parent, explained that her child, Bella, has been assessed but has not met the criteria for the JPU. Devon parents have received a letter from Devon Children's Services which states that beyond 31st December they will not have access to the JPU. SM explained that the aim of the meeting is to discuss options for Torbay, Devon has their own process and she was not aware of all the facts pertaining to Devon communications with parents. CS felt that the group should not ignore the impact that the reduction in Devon's usage will have on the viability of the Unit as a whole.</p> <p>AB stated that it is difficult for us to manage choice and risk as we do not yet know what the scale of the problem may be, we all have talked about making JPU a choice as part of a menu of short breaks, however we need to know what the demand for the Unit as part of the menu should be.</p> <p>Many parents receive direct payments, which enable them to purchase the services they choose. Any services need to provide the elements that parents want and also need to be affordable.</p>
3	Developing the vision/ Your Ideal World	Annette Benny	See attached flipchart notes
4	Next steps		<ul style="list-style-type: none"> • RH to write up notes, collate actions into a table and share. Paper regarding the reduction in opening times at the JPU to be shared with the working party • SM to meet with Devon colleagues to discuss the Devon position • RH to work with Elizabeth Payne, JC and CH to contact the parents who used to use the Unit to discuss why they no longer use it? • RH to develop options that can be tested with a wider group of parents- this could be a questionnaire at the Short Breaks Fair on 15th and 16th January- as part of a JPU interactive stand? Parents forum/ Short Breaks Steering Group- RH/JM to discuss <ul style="list-style-type: none"> ○ Options could be: <ul style="list-style-type: none"> § All singing, all dancing multi-agency centre § Residential Unit § Partnership development • RH to share draft options with ST, CS, JM,CH, KB, PM by email (comments to be back to RH by 5th January 2010) • RH to arrange another meeting so that we may consider outcomes from the Fair- the group will meet again <p>Monday 1st February 10.00am-12.00pm venue to be confirmed</p>

Developing the vision/ Your Ideal World- Flipchart notes (notes from 01/10/09)

The group started to look at what short breaks mean to them:

- Overnight rest/ time out for parents- especially when child is very young
- Time out and activity/ stimulation for the child as they get older
- Somewhere to meet my child's needs (physio, sensory room)
- Access to doctors and clinical staff, often other medical tests happen whilst my child is in JPU- it is handy to have all of this happen at once
- ML would like to access overnight respite-she can access day care, but would choose overnight respite so she could have a night's sleep. Overnight is not available at JPU for ML's son as the Unit can't manage her son who requires ventilation- can staff on the Unit be trained to do this?
- The group considered needs in terms of ages: Transitional- preschool-early support

1. Early support 0-5 year olds

- the importance and role of the key worker (someone who knows what services are available)- EP is taking forward work around this
- Families tend to get information about services and from their early support key worker.
- Key workers can help parents to navigate the system, help with benefits and form filling, access to JPU and all the appointments
- There is a criteria for access to a key worker due to capacity issues, the funding from central government for this service has run out and the local authority has taken on the function of managing this service (EP will liaise with the PCT about this). It is the intention of the Integrated Disability Service that key workers should be available for all children with special needs, not just those with complex needs
- EP suggested that good information is available in Torbay through the MyBay website and the Family Information Service. There will also be a Short Breaks Fair in January, like a wedding Fair, which will enable parents and carers to meet with providers of services to see what is available. The Children's Resource Directory also provides a good source of information for parents
- An information and marketing part-time post is being developed as part of the Short Breaks work, this post will help to improve the accessibility of information for parents and carers
- ST discussed some of the universal activities that children and young people are able to access through the inclusion service. Some of the parents present did not know about the choices available, ST to contact the families separately
- Parents wanted a responsive service to help now
- Continuous service rather than taking it away when my child is 5
- In a crisis, I need help to be able to access the support my child needs- it is really important to have an emergency plan (Carers legislation requires that one is in place for every carer).

Developing the vision/ Your Ideal World- Flipchart notes (notes from 08/12/09)

2. 5-12 year olds

- Respite should be about the child, their parents and siblings
- It is important for the child to have a good time:
 - activities should be of good quality
 - should enable the child to get some fresh air
 - should involve interaction
 - hydro access

- sensory toys (big toys that they can't necessarily access at home)
- days out e.g. beach, zoo or choices
- accessing activities that other children access
- keep my child safe
- provide school holiday and weekend cover
- staff that are trained to play with the children- could Mayfield classroom assistants, trainee nursery nurses, staff from other local provisions/ charities run activities from the JPU
- activities should be planned around the child
- I need access to someone who knows most about my child and family e.g. a central point of contact e.g. key worker/ professional
- JM stated that she thought the group was formed to save JPU, not develop alternative options. Clive Sainsbury (CS) responded that this group should be about saving services for children with complex needs not a specific provision. AB reiterated that the point of this exercise is to determine what aspects are valued/ required by parents so that the Care Trust can commission the right level of service and so that providers can identify what it is that they are able to deliver.
- Keri Barzotelli (KB) asked if the referral criteria will change- as she is aware of parents that might like to use the Unit, but their children haven't fitted the criteria. AB stated that this could change, we don't know as we need to work up what the service model would be.

3. **13-19 year olds**

- Young teens area
- Computer access
- Supporting young people to develop independence
- Remember learning ability/ age appropriateness
- Supporting transition
- Workers who can work with teens- youth workers

For all ages:

- All agreed that it is important to consider needs for different age bands (0-5, 5-12, 13-19) though it is crucial that there is flexibility in age bands as learning ability will vary- consideration should be given to the child's individual need rather than actual age (age appropriateness and learning ability). It is also important to remember issues of transition.
- The group looked at the notes on 0-5s from 01/10/09 and tick
- Transport is an issue
- Workforce: need to be trained/ have the right skills to provide a good time/ fun experience for children as well as meet their additional needs
- Short breaks need to provide time out/ rest for parents and for the child
- Services need to be responsive to help in a crisis
- Help is needed at all stages to navigate 'the system'
- Help is needed with form filling understanding benefits
- My choice needs to be a real choice
- Services needs to be continuous
- Need access to clinical staff
- Somewhere to meet my child's health, developmental and social needs
- Family passport record needs to be updated regularly and kept with the family

The future- We're looking for a setting that is:

- More inclusive

- Mixed social care and healthcare staff working together
- Convalescence (step down and also palliative care) Vs Short Break
- More children accessing, more things going on- 'a buzzing atmosphere'
- Affordable to use
- Can respite be calculated in terms of hours rather than cost?

To throw into the mix:

- Individual packages of support that are commissioned on a case by case basis
- Carers are often in family homes to help families to get through the day