

Notes of Children's Short Breaks Working Party**Thursday 1st October 2009, 9.30-11.30am at Living Coasts, Torquay**

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| 1 | Attendees Apologies | | <p>Sharon Matson, Annette Benny, Rosa Marshall, Sue Thompson, Elizabeth Payne, Gina Skipwith, Jayne Cooper, Clive Sainsbury, Mel Lane, Paula Macmenamin, Simon Boustead, Kirstin Payne, Jill Payne</p> <p>Apologies Julia Hunt, June Palmer, Julia Cox, Theresa Wills, Claire Harding, Judy Arnold</p> |
| 2 | Thoughts, feelings and worries following 11/09/09 | Sharon Matson | <p>Sharon Matson provided an introduction and welcome to the meeting. She reiterated that following the Listening and Design event with parents and carers on 11/09/09 that the Care Trust is keen to explore what we can do jointly with Torbay Council to develop the John Parkes Unit into a resource so that many families can access, building on the prowess of the Child Development Centre.</p> <p>SM hoped that the working party would provide a forum to develop a vision and that those present could work together within an environment of trust. SM also stressed the importance of remembering that there are other families in the Bay who could benefit from this work and at some point the group may need to reform to bring other parents in.</p> <p>SM recapped on the meeting of 11/09/09, stating that she was pleased with the outcome of the meeting as it provided the Care Trust and partners with a clear steer going forward. SM asked those present to share their thoughts and reflections:</p> <ul style="list-style-type: none"> • I went into the meeting feeling very negative and came out feeling positive- this can only happen if we all work together and take a positive approach. We do need to just get on with it. • It is important to remember the staff at the Unit- the staff are very worried about what will happen in the future. • I felt apprehensive- it would be great to work together- to reinvigorate this wonderful resource • It was good to have parents at the event to express themselves, there are huge gaps in communications between Torbay and Devon <p>SM stated that the messages are still mixed from Devon. There is a definite need for us to change the Unit in some way to make this financially viable and to make the Unit into something better.</p> <p>EP reflected that the Short Breaks Review that was undertaken two years ago by the Council and the Care Trust, had identified a need for a JPU-type provision. Some new services for short breaks have been developed, however there isn't a range of choice for children with complex needs. EP informed parents that there is a short breaks steering group that they could join which is a group that drives all of the short breaks work forward. RH suggested that this group could be a sub-group of the steering group.</p> |
| 3 | Short Breaks presentation | Rebecca Harty | <p>RH delivered a short presentation (attached) about the Aiming High for Disabled Children Strategy and short breaks transformation work.</p> <p>EP explained that family to family (F2F) care is available locally and is run from within Torbay Integrated Joint Agency Children's Disability Service. The F2F scheme is constantly marketing and recruiting new family based carers, who all go through a rigorous training and vetting process prior to being accepted to the scheme. Carers are offered continuous support and training. Currently the F2F service offers short break (respite) support to children with a wide range of disabilities, including challenging behaviour,</p> |

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| | | | <p>learning disabilities and complex physical disabilities and associated health needs</p> <p>Torbay would also like to offer contract care, where the local authority would have a contract with carers who would deliver x nights care in their home or the family's home. It is difficult to recruit contract carers who have homes that are accessible. Contract carers would also need suitable equipment and kit in order to care for complex children. Contract carers could be trained nurses, who would be able to deliver the same kind of care and medical support that parents do. SM suggested that one option could be that the JPU is adapted to provide a couple of adapted flats that would enable contract carers to offer a service from the Unit?</p> |
| 4 | Developing the vision | Annette Benny | <p>AB provided support to start to unpick short breaks- see attached flipchart notes</p> |
| | Next steps | | <p>RH to share the notes from the meeting with all parents and carers who attended the meeting on 11/09/09 and to ask for their comments and suggestions.</p> <p>Next meeting to look at the needs of the over 5's. RH to arrange a meeting for early November and then for early January. The venue worked well- the timing needs to be tweaked to 10.00am-12.00pm.</p> |

Developing the vision- Flipchart notes:

1. 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?
2. The group considered needs in terms of ages:

Transitional- preschool-early support
3. **Early support 0-5 yrs**
 - 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).