

**Notes from the Listening and Design Event with families
at the John Parkes Unit
Friday 11th September 2009**

Attendance from: Sharon Matson, Acting Director of Commissioning, Torbay Care Trust; Annette Benny, Acting Assistant Director of Commissioning; Torbay Care Trust; Lynne Leyshon, Divisional General Manager Women, Children, Diagnostics and Therapies, SDHFT; John Shaw, Strategic Commissioner for Children with Additional Needs, Devon County Council; Beryl Perrin, Commissioning Officer, Aiming High for Disabled Children; Barbara Jones, Contracts Manager, Devon PCT; Denis Onley, Further Response Manager, Devon PCT; Keith Thompson, Executive Head Specialist Service, Torbay Council; Peter Taylor, Contracts Manager, Torbay Council; Julia Cox, Short Breaks Lead, Torbay Council; Dr Clive Sainsbury, Consultant Paediatrician SDHFT; Jayne Cooper, Matron; Child Health SDHFT, Rebecca Harty, Commissioning Manager, Torbay Care Trust; Julie Porteous, Senior Social Worker; Judy Arnold, Social Worker; Su Irmiger, Occupational Therapist; Rachel Sheils, Social Worker; Gill Harris, Family To Family Social Worker; Sarah David; CCW; Jan Wickens, CCW: Children's Integrated Disability Service

Sharon Matson welcomed the participants and introduced staff from Torbay Care Trust, NHS Devon, South Devon Healthcare Foundation Trust and Devon and Torbay Children's Services to the families present and clarified that the aim of the meeting was to discuss the future commissioning arrangements for short break services.

It was agreed that notes would be taken and these would be sent to all participants.

Issues:

Some families received very short notice of the meeting which meant that it was inconvenient for them to rearrange work and other commitments so that they could attend. Some families found out about the meeting via the media as they did not receive invitation letters. There was a feeling that the PCT had been underhand in sending out invitation letters in school holidays when parents cannot discuss matters. SM apologised for the mistakes made with the distribution of invitations and assured families that there is no 'hidden agenda'.

Structure of the NHS: SM explained that as Director of Commissioning she is responsible for purchasing health and social care services to meet the needs of the Torbay population, e.g. services from Torbay Hospital, Nursing Homes, District Nursing, Dentists and GPs. SM and her team are responsible for ensuring that services are safe, friendly, clean, easy to get to and clinically sound.

There are two organisations involved in the purchase of the John Parkes Unit- Torbay Care Trust and Devon Primary Care Trust (PCT); the Unit belongs to South Devon Healthcare Foundation Trust (Torbay Hospital).

It was asked why the press were not invited to the meeting. SM explained that Torbay Care Trust and Devon PCT wanted to have the opportunity to talk to families in a closed meeting about the services they receive. There would be opportunities for the press to talk to families after the meeting.

The feeling within the room was that there had been lots of mixed messages about the meeting and its purpose. Some families had been told by their Care Managers that they will need to use alternative services as the JPU is closing. SM explained that the JPU would not be closing. SM explained that there is a formal process of a 12 week public consultation that the PCT's must undertake if any major change is proposed. At the moment there are no proposals to consult on –

the meeting is the first step in developing these, and it is not clear that a consultation would be required.

Devon PCT have been consulting with parents and carers since 2007 which resulted in the development of an 'Integrated Commissioning Strategy for Short Breaks and Shared Care for Children with Additional Needs'. The Strategy aims to provide care in different settings and closer to home, which will steer purchasing decisions around short breaks. Families have been provided with individual budgets to purchase breaks in a different way so that they can access more respite- choose from a menu of options.

Issues were raised by individual Devon families around the amount of care they receive- these were to be addressed separately with Devon PCT/ Children's Trust.

There was some discussion around NHS provision and social care provision. It was explained that health and social care have separate resources. It is important that these are looked as a 'whole pot' to make sure that the widest provision is available to meet the needs and to develop individual care plans with care managers for each child. The Short Breaks Review showed that there are fewer options available than parents would like.

SM felt that it was important to see this meeting as a 'fresh start', an opportunity to review the Short Breaks work, as only one parent in the room had been part of the Torbay Short Breaks Review.

Costs: SM explained that the John Parkes Unit is expensive to run- it costs £880.00 night; there are currently 20 users accessing the unit. These costs cover overheads, staffing and equipment. Torbay Hospital cannot run the Unit at a loss. In comparison, other providers such as Robins cost approximately £470.00/ 24 hour period and £320.00 for overnight care (after school and back to school the next morning). However they clearly provide a different service to the JPU.

It was explained that the costs of NHS respite are a fixed national price- an overhead cost in square metres is applied to the cost of an episode of care. If more children used the Unit, the cost could come down.

The future: SM reiterated that Torbay Care Trust is clear that it intends to maintain the respite beds at the JPU.

Discussion followed about the impact on the future of the JPU if Devon ceased to commission respite beds at the Unit.

SM committed to working with parents and carers to redesign the Unit. It was suggested that the children should also be involved- resources from 'Participation Works' were shared.

It was pointed out that some families are eligible for short breaks, but don't access anything. The JPU could be redesigned to include elements such as a summer club or play scheme.

Devon Families and Torbay families separated into two groups to work with the respective PCTs and Children's Trusts to look at the future.

Flipchart notes from JPU meeting 11/09/09- Torbay group

What works well at JPU?

- Provides a break that we need plus the medical care
- Safe and secure
- Security in knowing that they are safe because of the medics on hand
- Support from staff is amazing- accessible and friendly, relationship with staff, I trust them with my child
- Continuity of staff
- Short notice emergency respite- flexible, can help when there is a crisis
- Lifeline to enable me to get on with my life
- Second family- family atmosphere
- They know me and my child individually, we can talk and they understand
- Facilities- sensory room, bathing (wouldn't get these if went to family to family)
- We can concentrate on other children at home- love and look after the kids
- More for children to do here than on Louisa Carey
- Easy physical access- drop off, just off the ring road
- Can do medical assessment here rather than on Louisa Carey
- Specialist care- know the background of the staff
- My son has had physio several times a day from here
- Don't have to bring all the kit as it is all here
- Palliative care- will be cared for in a quiet environment
- Each child is individual- advocate for the child
- If you don't have JPU- you'd be taking away someone's choice

What doesn't work well? (things that could be done better)

- Door!!!!-can this be automatic?
- Staffing- when booked in for respite here, often ends up going to Louisa Carey due to lack of staff (SDHFT haven't reduced the budget)
- Criteria for respite seems to be a lot stricter
- Equipment in unit seems to be reducing and disappearing (water room- because we are a hospital- different regulations for sources of infection)
- I want my son to know who the staff are
- Flexibility in start and finish times
- My son can't have overnight respite (needs VPap)
- Not enough staff
- Historically- Some staff clearly did not want to work here and sometimes I have left JPU anxious as to whether she would get the care in the unit
- More staff to enable children to out on trips
- No bank for JPU staff-could train up a cohort of staff to form a regular bank- would save moving children up to LC and staff down from LC

What else- Blue Sky thinking....

- Need clarity on what the future will be
- Aiming High is about increasing the number of breaks available- more capacity for family-based care
- Could JPU go back to what it was like 7 years ago?- it was a home from home, safe, with staff that stayed
- Can staff be trained to have cannulation and VPAP skills? Overnight respite training?
- Want it to stay like it is
- Never get to see a dietician- they're all part time, can never track them down- could they be based in JPU?
- Consistency of staff

- ? take on running by PCT
- ? groups of children that could come here
- Has the criteria changed- could this be lowered/ different?
- Referral routes have been via paediatricians- can this be de-hospitalised?
- What could the unit be like? Centre of Excellence- so other families would want to use it- why isn't there a waiting list
- What has caused the changes? – the level of service has been maintained, but not grown
- Got some families who get support and others who don't
- Don't want to get rid of something for something else (more provision)
- History (the Haven)
- Don't lose integration (health and social care should work together)
- Could space be rented out for offices- create a 'children's hub'?

How do we take this forward?

- Develop a blog for ideas- Keri B
- Set up a working group within 4 weeks- staff, parents, care trust- need to look at how to engage Devon in this
- Urgent review of children's needs – so there is a full picture of needs for Torbay/ Devon
- Lynne Leyshon to take a paper to her Board- presenting options, commitment to working with Devon
- Charity- have a go at making up the shortfall
- Torbay Care Trust has pledged- JPU in some form or other

Media messages

- Respite beds in JPU will stay open
- Set up a working party through which we will work together on the future of JPU
- Access to JPU- don't want to just fight for us, but for other families in Torbay

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</p> |

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| | | | <p>children with a wide range of disabilities, including challenging behaviour, 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 | AB provided support to start to unpick short breaks- see attached flipchart notes |
| | 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-12.00p.</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).