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Report No: **34/2010** Public Agenda Item: **Yes**

Title: Commissioning Short Breaks for Children and Young People with Physical and Learning Disabilities

Wards Affected: All Wards in Torbay

To: Health Scrutiny Board On: Thursday 18th February

Key Decision: **No**

Change to Budget: **No** Change to Policy Framework: **No**

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1. What we are trying to achieve and the impact on our customers

Following the launch of the Aiming High for Disabled Children change programme, Torbay Council and Torbay Care Trust commissioned a 'Short Breaks Review' in 2007 to look at current services, patterns of usage and future demand. The review was undertaken via a series of consultations with parents, carers and service providers. The Integrated Joint Agency Children's Disability Service and Torbay Care Trust has been working with parents and carers to develop a menu of short break options to include family to family care and befriending networks. A 'listening and design event' was held on 11th September 2009 to explore the appropriateness of the medical model of care currently being provided and to consider how short break services can be shaped for the future considering the growing need for services and the changing nature of provision.

The John Parkes Unit is an eight-bedded respite unit based at Torbay Hospital Annexe site which caters for children with complex care needs; that have physical disabilities and/or learning disabilities and/or life-limiting conditions. It is commissioned by Torbay Care Trust and NHS Devon from South Devon Healthcare Foundation Trust. Torbay Care Trust is the lead commissioner of the Unit.

A working party was set up with parents and carers, healthcare and social workers to focus on the types of services needed for children with complex health needs. Exploring how services can be developed to benefit the maximum number of families; as well as become financially fit for future. It is essential that service redesign builds on that undertaken by the Integrated Children's Disability Team to form a major component of the short breaks work and governance structures.

The working party has met three times since October to identify what services are needed as part of a menu of short breaks options for children with complex health needs.

A draft service specification will be developed by the end of February which will be reviewed by the parents who use the Unit, before it goes out to wider consultation. The Parents Participation Forum will be assisting us in consulting with a wide range of parents and carers of children with disabilities and special educational needs.

Aiming High for Disabled Children

The transformation of short break services is a key component of the Aiming High for Disabled Children (AHDC) change programme. This element seeks to transform the quality, quantity and range of short breaks provision available for children and young people with physical and learning disabilities. The vision behind the programme is for "all families with disabled children to have the support they need to live ordinary family lives, as a matter of course." (DCSF/ DoH 2008).

Key themes that emerged from the Torbay Short Breaks review were:

- inequity and inconsistency in service provision
- services have historically been based around facilities rather than children's needs
- a need to reduce reliance on overnight services, that have been depended upon as day services are limited
- services should be child-focused and cost effective
- a wish for children and young people with physical and learning disabilities to be able to access the types of activities that non disabled children can access e.g. swimming and brownies
- a need for a range of residential provision options

Developing a menu of options

Following these findings, the Integrated Joint Agency Children's Disability Service (IJACDS) has begun to develop a menu of short break options with the help of parents and carers. A Short Breaks Transformation Officer has been appointed to take forward the transformation process, and Lead Professionals have been working with families to develop individual care plans that include short break arrangements.

New provisions to be offered include:

- family to family care
- a contract care scheme to enable care to be provided in the child's or carers home
- the extension of day care facilities and procurement of additional family-based short breaks
- A Fair Access to Carers Breaks, direct payments scheme to enable families to directly purchase the short breaks that they need.

The Short Breaks Transformation Officer has been working with colleagues in statutory and voluntary sectors to raise awareness of the short breaks work and to encourage them to enable disabled children to access the types of universal activities and diversions that other children take part in, such as attending clubs and societies, using play facilities and accessing sport.

A Short Breaks Steering Group has been established to drive the Aiming High work forward. It is made up of 50% participation from parents and carers, a Councillor and representatives from special schools, inclusion, health and social care. Its remit is to oversee the work programme around short breaks and to monitor the Aiming High money that has been awarded to Torbay to increase opportunities for disabled children and young people. A 'Short Breaks Fayre' for children, young people, parents and carers was organised under the auspices of the Short Breaks Steering Group 15th and 16th of January 2010 which showcased a number of activities and providers of short breaks.

As part of this work stream, a Parents Participation Forum has been established for the parents and carers of children with physical and learning disabilities and also a Children's Disability Council. In order to maintain independence, both groups are facilitated by Children's Rights and have clear aims

and objectives as groups and provide a powerful resource for the Council and Care Trust to work alongside.

John Parkes Unit and working party

As a result of the changes to the way that respite care is provided, there are currently around 11 children in Torbay receiving respite at the John Parkes Unit. NHS Devon is further ahead than Torbay in re-specifying short break services. The Unit costs approximately £800,000 a year to run on a block contract basis. The pricing structure for this is based on a national tariff for respite, which is inclusive of overhead and staffing costs. Given the declining numbers of Devon users, it is not clear how NHS Devon would wish to commission the Unit in the future. Torbay Care Trust could not fund the Unit alone in its current form and costing.

A 'Listening and Design' event was organised for September 11th 2009 to discuss the situation with parents and carers who use the Unit and to capture their thoughts and ideas as to a way forward for Torbay children. As a result, a 'Short Breaks Working Party for Children with Complex Health Needs' was formed comprising parents who use the unit, Lead Professionals and staff from the Council, Torbay Hospital and Torbay Care Trust. The working party met in October and December to begin the process of identifying the service needs of children, parents and carers. The group considered what short breaks mean to them and the services they would like to access, splitting needs into those of the 0-5 year olds, 5 years and over, and transition arrangements for children moving onto adult services (see Appendix 1 for meeting notes).

The working party suggested that a market research exercise could be undertaken at the Short Breaks Fayre to try to understand demand for services and to find out whether parents receiving an individual budget would use their budgets to purchase services at the John Parkes Unit. A leaflet was produced and feedback from 18 users was captured (see Appendix 1 for feedback and leaflet). In order to gain a wider view, the Parents Participation Forum has offered to send out the leaflet with their forthcoming mailings to capture a feedback from a greater number of parents and carers.

The working party met for the final time on 01/02/10 to discuss the feedback from the Fayre and to develop next steps. For the future, this work stream will merge with the Short Breaks Steering Group structure to ensure joined-up respite care and short breaks in the Bay (see Appendix 1 for meeting notes).

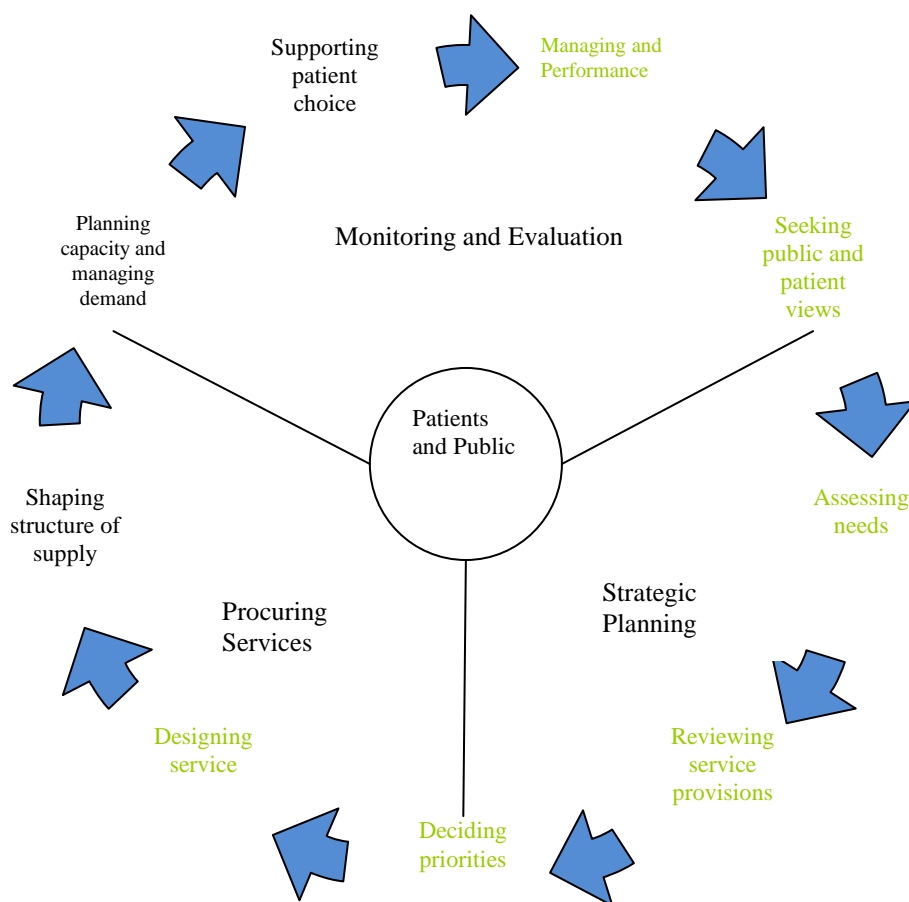
The future

A draft service specification will be developed by the end of February which will include all the elements of service that the working party and users have said are important. The parents who have taken part in the working party have been invited to be part of a focus group to comment on the draft before it goes out to wider consultation with the help of the Parent Participation Forum.

2. Recommendation(s) for decision

A service specification will be developed using the outputs from the workshops in October and December, by the end of February, and will be subject to wider consultation to enable us to gauge demand for services. The Parents Participation Forum will be assisting us in consulting with a wide range of parents and carers of children with disabilities and special educational needs using the above mentioned leaflet and other methods to be agreed with them. This feedback will shape the service specification.

The diagram of the World Class Commissioning Cycle demonstrates the process that we are undertaking. The [six] sections coloured green show the elements of the cycle that we have completed the remaining elements are those that we will be working towards over the coming months.



We would ask for guidance from the Health Overview and Scrutiny on the sequencing of the consultation process, it is our intention that the service specification is developed with the help of parents who have attended the working party meeting, as an expert panel of users. We would then like to consult with a wider range of parents and carers on the specification before undertaking a tendering and procurement process.

3. Key points and reasons for recommendations

- The Aiming High Disabled Children change programme advocates the extension of short breaks opportunities to a wider number of children with physical and learning disabilities
- As a result of the Short Breaks Reviews undertaken by Devon and Torbay it is necessary to review current provision to ensure that services are designed to meet users current and future needs and that they provide value for money
- There is uncertainty as to whether NHS Devon wishes to commission the John Parkes Unit. No Devon children are currently accessing the Unit, but NHS Devon has not given South Devon Healthcare Foundation Trust notice to decommission its element of the block contract
- The introduction of the Fair Access to Carers Breaks Scheme will mean that parents and carers will have control over how they spend their direct payment
- Parents and carers who are users of the John Parkes Unit are working with us to develop a service specification to meet the short break needs of a range of children, not just those who are medically complex.
- We are seeking guidance from the Health Overview and Scrutiny Committee on the timeframes and process for consultation. We anticipate that a draft service specification will be developed for the end of February. We would like to test the draft with the Short Breaks Steering Group and with our panel of users before taking this out to wider consultation.

For more detailed information on this proposal please refer to the supporting information attached.

Name of Head of Business Unit: Sharon Matson

Title of Head of Business Unit: Acting Director of Commissioning, Torbay Care Trust

Appendices

Appendix 1

Notes of the Listening and Design Event at the JPU (11/09/09)

Notes of the working party (01/10/09)

Notes of the Working Party (08/12/09)

Notes of the Working Party (01/02/10)

To Follow

Short Breaks Leaflet

Feedback from market research exercise, 15 and 16 January 2010

Background Papers:

The following documents/files were used to compile this report:

- **'Short Breaks Review', Integrated Joint Agency Children's Disability Service, 2008**
- **Children's Disability Strategy, Children's Services, Torbay Care Trust and Torbay Council, 2008**
- **'Aiming High for Disabled Children', Department for Children, Schools and Families/Department of Health, 2008**
- **'Healthy Lives, Brighter Futures'- the strategy for Children and Young People's Health, 2009**