



Briefing Report No: **230/2009**

Public Agenda Item: **Yes**

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

Wards Affected: All wards

To: e Health Scrutiny Board On: 29 October 2009

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## 1. Key points and Summary

As part of Torbay's strategy for children with learning difficulties and disabilities, Torbay Council and Torbay Care Trust commissioned a review of short breaks services in 2007. It was recognised that a range of service provision already existed, but historically little was known of the full extent of usage and demand on these services across different agencies. The review was undertaken via a series of consultations with parents, carers and service providers.

The review identified inequity and inconsistency in allocation of breaks, a limited range of choice of residential and day care options. It also highlighted that a large percentage of spend goes on meeting the needs of a small number of children with high levels of need. The review recommended an expansion of short break options to provide a wider choice of placement and method of delivery (e.g. direct payments), including the introduction of a fairer assessment process to offer short breaks in an equitable way. There are currently 180 families in the Bay receiving short break services, this number is predicted to rise to 210 in 2010/11 as more children and families become eligible to receive short break services.

Following the review, 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 alternatives such as family to family care and befriending networks. A 'listening and design event' was held on 11<sup>th</sup> September 2009 for the parents and carers of children that use the John Parkes Unit to revisit the findings of the short breaks review and to capture their views.

This report outlines the findings of the event on 11<sup>th</sup> September, subsequent working party and the timeline for the future.

## 2. Introduction

2.1 Following the launch of the Aiming High for Disabled Children change program, 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 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).

2.2 The definition of short break/respite for the review was:

"One or more sessions of care or support that enable disabled or vulnerable children to spend time away from the person(s) who provide them with regular and substantial care; that is beneficial for the child/ carers. This includes the provision of short periods of day, evening and weekend activities, as well as overnight stays. Such breaks can be provided in the individual's home or another setting, but no break should exceed one month of continuous care", (Review of Short Breaks in the South West of England for Disabled Children and Adults with Learning Disabilities, Robinson, SWALD, 2003)

2.3 Key themes that emerged from the Torbay 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

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, as part of the IJACDS, to take forward the transformation process, and care managers and social workers 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, although it is proving difficult to recruit individuals who have accessible accommodation to take on this work and no carers have yet been appointed.
- the extension of day care facilities and procurement of additional family-based short breaks purchased through a tendering process to determine most effective/ cost efficient night/ bed day cost. Torbay Council has worked with Plymouth Council to purchase placements from 'Action for Children'.

The Short Breaks Transformation Officer has been working with colleagues in statutory and voluntary sectors to raise their 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 which would provide them with a stimulating short break, activities could include: attending clubs and societies, using play facilities and accessing sport.

A Fair Access to Carers Breaks, direct payments scheme has been introduced in Torbay and Devon, which enables families to directly purchase the short breaks that they need. Devon implemented the scheme a year ahead of Torbay. The Devon experience shows that families using this system are choosing to access more flexible family to family support for short breaks rather than traditional overnight options as these tend to be less expensive.

2.4 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.

The respite facilities at the John Parkes Unit are based on a medical model. Each shift is run by one trained nurse, with medical backup from the acute hospital, should it be required. If there is a medical emergency children are taken via ambulance to the acute trust as the unit has no facilities to support emergency care. There are currently around 10 children in Torbay receiving respite at the unit and 6 in Devon, at a total cost of 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, plus overhead and staffing costs. Devon Children's Trust is ahead of Torbay in the short breaks transformation process and 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, if Devon do not sustain their element of the block contract.

Torbay Care Trust and partners invited parents and carers of children using the unit from Torbay to a 'Listening and Design event' on 11<sup>th</sup> 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. There is a gap in provision locally for a range of short breaks services for children with complex needs. NHS Devon and representatives from Devon Children's Trust also attended the meeting along with Devon parents

Parents and carers were concerned about the purpose of the meeting and were keen to express their support for the Unit. They were under the impression that an announcement would be made to the effect that the Unit would be closing. Parents shared their thoughts about the Unit with the wider group and explained why this service was so important to them (see appendix 1. for notes).

Following this feedback, Torbay Care Trust pledged that the respite beds at the John Parkes Unit will remain open and agreed to set up a working party with parents and carers, healthcare and social workers to enable the John Parkes Unit to evolve into a service which is able to benefit the maximum number of families; as well as become financially viable. It is essential that this service redesign builds on that undertaken by the Integrated Children's Disability Team to form a major component of the short

breaks work.

The working party met on 01/10/09 to begin the process of identifying the needs of children, parents and carers. The group began to consider 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. It is essential to link this process into the wider short breaks work and Torbay Care Trust and partners will work with parents and carers over the coming months to develop this vision. We hope to have greater clarity in early 2010 as to the service specification required and would be pleased to update Health Overview and Scrutiny Committee as often as advised. It is essential to take parents and carers through this visioning process, it would be wrong for us to predict the needs of children, parents and carers without this engagement work.

**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)

**Documents available in members' rooms N/A**

## **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**