



Integrated Joint Agency Disability Services

Short Breaks Review

CHILDREN WITH LEARNING DIFFICULTIES
AND DISABILITIES

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ACKNOWLEDGEMENTS

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1 INTRODUCTION

As part of Torbay's strategy for children with learning difficulties and disabilities, Torbay Council and Torbay Care Trust agreed in early 2007 for a review of children's short breaks services to be undertaken. There was recognition that a range of service provision already exists but historically little was known of the full extent of usage and demand on these services which was shared across different agencies. There was also a need to establish baseline activity, spend and value for money which would provide a predictor of future demand on the service. As a result, this report identifies the needs of the local population, current use and provisions of short breaks, and provides information about what is wanted and needed in Torbay in the future.

This report details the findings of the first stage of the review in order to inform both the Children's Trust Executive and the commissioning process, which will be the next stage in the review process. Views of parents and carers were sought as part of the review and further consultation will continue to take place as the service is developed. For example, a number of events are planned for February 2008 to inform and consult with stakeholders on the overall multi agency strategy for children and young people with learning disabilities and disabilities, findings from this review and the introduction of the Fair Access to Carers Breaks Services.

2 DEFINITIONS

The definition of disability for the review is:

“Children with profound disabilities, severe and moderate learning difficulties, autism / Aspergers Syndrome and children with life threatening or life limiting illnesses”

Children and young people are defined as

Aged 0 – 18 years for social care needs

Aged 0 – 19 years for health care needs

The definition of short break / respite for this review is:

“One or more sessions of care or support that enables disabled or vulnerable children to spend time away from the person(s) who provide them with regular and substantial care, which 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.”

This definition was used by the independent consultants commissioned to initially scope key areas of process and risk in 2006. The definition is taken from the “Review of Short Breaks in the South West of England for Disabled Children and Adults with Learning Disabilities” by Carol Robinson from SWALD (South West Learning Disability Network) March 2003.

3 STATISTICS

National

National prevalence of disability indicates that 7% of all children are disabled and that there has been a 2% increase year on year since 1980. However this is in the widest context of the Disability Discrimination Act definition. This rise is due to a number of factors, for example, increased survival of pre-term babies and children following severe trauma or illness, increasing prevalence of impairment amongst children, and improved diagnosis. There is also a longer life span for children with severe disabilities including those with complex medical needs (e.g. the need for ongoing ventilation).

Local

Using the national prevalence figures above, approximately 1600 children in Torbay can be defined as disabled potentially rising to 1770 in 5 years, using the wider definition. 7% of these 1600 are severely disabled, a figure of 114 potentially rising to 124 in 5 years. Due to these relatively small numbers it is difficult to predict the exact numbers of children and young people who will have a disability or the severity of disability in the future. However we can use previous patterns of respite care to predict the type of services required and where gaps in service provision exist.

4 CURRENT ACTIVITY

Using the definition for this review, currently:

- 115 children in Torbay receive a short break service
- 30 of these children receive direct payments to pay for their services
- 48 children receive overnight respite

Number of children by age	
Age of child	No of children
0-5	18
6-10	35
11-13	21
14	9
15	10
16	10
17	11
18	1

Activity detail: overnight stays

Of the 48 children who receive overnight respite, it should be noted that some these children use more than one resource for the overnight stays.

Service	Current number of users	Known children likely to access provision in the future	Bed nights (care planned)	Children whose needs could be met by alternative provision	Notes
JPU	16	4	656	16 out of 20 (at least 577 bed nights)	Emergency use July 05 to Dec 07 = 49 nights total
Robins	17	0	476	5 (at least)	3 users turn 18 in 2008, 1 x 16 year old, 4 x 15 year olds, 2 are holiday use only
F2F	11	10-12		0	10 – 15 awaiting service
Other residential respite	1	1	72	2	High cost placement
Over night care in the home	10	Data not available	Data not available	Data not available	One particularly high cost package of care in place

JPU – John Parkes Unit

F2F – Family to Family

5 NEEDS

The following two tables summarise the needs of children with disabilities and their families currently receiving short breaks taken from the definitions and assessment processes used currently by social care and health care providers. Children may have more than one need. Children with communication and behavioural difficulties may include those diagnosed with autistic spectrum disorder.

Child's needs			
Epilepsy	13	Reflux	2*
Visual impairment	9	Gastrostomy	3*
Hearing impairment	6	Wheelchair user	17*
Communication difficulties	23	Safety issues – no awareness of danger	
Behavioural difficulties	15	Social isolation	19
Life threatening / limiting illnesses	5*	Emergency care	21
Physical disability	18	Specialist handling	2
Learning disability	27	Specialist equipment	13
Severe brain injury	1	Vulnerability	15
Medication	16*	Use of oxygen and ventilation equipment	1*
Feeding difficulties	8*	Suction	1*
Postural difficulties	18*	Mental health issues	1*
Shunt	1*	IV fluids and nutritional needs	
Co-ordination difficulties	3*	Asthma	1*

* At least

The following are listed in recognition that short breaks are also provided to meet families' needs, although due to data issues, no figures are available at this time.

Family's needs	
Emotional coping	No wider family support
Physical coping	Single parent
Child protection concerns	Housing issues re access
Eating disorder	Safety issues
Marital issues	Unable to use public transport
Siblings needs	Health needs
Financial issues	Sibling needs- behaviour
No transport	Mental health issues
Learning difficulties	

6 FINANCE

There a number of commissioning arrangements currently in place including a block contract with one provider and a contract for number of bed nights with another making direct comparisons difficult and misleading. Therefore, we are establishing a unit cost methodology jointly between the council and the Care Trust will enable comparisons to be made across providers and types of provision.

Total current projected spend on respite and short breaks services is £1,198,600 for 2007-08 in total, (£681,300 from Torbay Children's Services and £517,300 from TCT).

Type	Service	Number of users	Budget (including grants)	Projected spend
Overnight respite	JPU	15	£378,000	£378,000
	Other residential respite	1	£215,000	£181,000
	Robins	17		£34,000
	Over night care in home or carer's home (direct payments)	10	£191,500	(£152,000)
	Family 2 Family	11	£20,000	(£7,200)
Day care	Playscheme and Saturday Club	54	£114,600	£114,600
	Independent sector day care	22	£1,100	£50,000
	Day care by sessional workers & direct payments	22	£9,000	£59,000
	Befriending by sessional workers & direct payments	39		£52,000
	Independent sector day care in home	22	£65,000	£38,000

A number of observations can be made from this initial budget analysis:

- a predicted overspend within day care services which could be an indicator of the high demand from families for daytime respite/short breaks.
- an underspend predicted within the F2F and over night care in the home which is mainly due to the challenges and difficulties of recruiting adequate carers.

Additional funding has been identified to provide an increase in the provision of respite services in Torbay. This funding will be extra funding from the Comprehensive Spending Review detailed in "Aiming High for Disabled Children" to add to already existing revenue streams. Additional funding allocated to the NHS is still being confirmed to work with local authorities to increase the range of short breaks available for children with complex care needs.

	2009-10 allocation	2010-11 allocation	2011-12 allocation
Torbay Local Authority	£138,484	£419,649	£419,649

7 KEY FINDINGS

Strengths of current services

A small sample of service users who have been involved in the review to date have expressed satisfaction of their current provision and the flexibility in what is provided.

However, there is a limited range of choice especially as alternatives to residential care.

Service	Summary of Current Short Break/ Respite Service
Family to family	Provides a successful flexible provision although there are challenges recruiting carers to meet demand – service judged as good in a recent Ofsted inspection of Fostering Services. The development of this service will also be addressed as part of the Accommodation Strategy.
Playscheme and Saturday Club	Are highly successful, judged by Ofsted to demonstrate good outcomes and are well thought of by children and families. Takes children up to 17 years old although a gap in appropriate provision for 16-21 year olds has been identified.
Horizons and Baytree	Horizons is suitable for some but is not wheelchair accessible. Baytree can cater for the needs of some 17+ year old young people.
Robins	Provide a good service for children with challenging behaviour and is well thought of by families. Had a good CSCI report.
The bank of sessional workers	have a wide range of skills to meet the needs of children in a wide range of settings
John Parkes Unit	has access to medical and nursing input and support when this level of care is needed

Weaknesses to address

- There is a disproportional usage of traditional residential / tier 4 provision. As a result, a large percentage of spend goes on meeting the needs of a low number of children with high levels of need. In order to expand the provision to the larger number of children who need services, whilst continuing to meet the needs of the existing children, Torbay needs to expand other respite options to provide much wider choice of placement and method of delivery (e.g. direct payments). This includes the introduction of a fairer assessment process that offers short breaks in an equitable way.
- To address the inequitable allocation of short break/ respite provision and availability of resources, the fair access to carers break (FACB) services tool is being implemented during 2008-09. In order to develop a range of provision, a matrix will be developed using indicative allocations to match against need and with provision.
- Although still only in the early stages of implementation a number of issues have been identified that could impact from the introduction of FACB:
- A greater number of disabled children could be classed as eligible for short break services than as is the current situation.

- Devon's pilot showed that families were opting for direct payments to put together their own creative packages of support, and that a number of families receiving overnight institutional care were opting for family based or non institutional breaks as their indicative allocation could then provide effectively more breaks.

Provision specification

Provisions will need to meet the following specification:

- Wheelchair accessible environments
- Accessible by public transport
- Within a reasonable distance to Torbay (approx. 20 mile radius) to reduce travel time and costs
- Access to equipment for health care, postural management and moving and handling
- Trained in a range of healthcare needs or ability to be trained
- Trained in manual handling and principles of postural care
- Ability to administer medication and clinical procedures
- Trained in behavioural management techniques
- Ability to liaise with other services and staff about physical and behavioural management programmes to ensure consistency across services
- Ability to meet a range of health care needs
- Ability to manage behavioural issues
- Ability to communicate across a range of skills
- Provision of safe environment: both physically safe and has 'safe' carers i.e. CRB checked
- Provision of social contact and play and leisure activities
- Ability to deal with ages ranging from 5 to 19
- Ability to match needs and abilities to maximise opportunities for children
- Ability to provide a range of day care and over night services in a flexible way
- Ability to deal with emergency access (Low demand – 2-5 per year) and crisis response
- Positive and proactive attitude to inclusion
- Understanding of the needs of children with disabilities and their families
- Understanding of equality and diversity
- Understanding of child protection and safeguarding procedures

The above criteria will be addressed by a multi agency framework in the commissioning of future provision.

Options for further consideration

Recognised need to develop a wider range of services which promote equality and diversity including better choice and one which expands the offer of respite to a greater number of families. Parents,

carers and staff involved in the review have suggested the following options for service provision which need further consideration

- Increased family based respite
- Increased child minding
- Contract care (salaried foster carers) for physical and behavioural disabilities (would need adaptation to home)
- Outreach workers to take children out
- Day and night nursing home based respite
- Respite bungalow attached to local special school
- Day care or 'Playscheme' for those with high level physical disabilities with complex medical needs building on the principles of the Karma group offered by the Playscheme.
- Increased 'Inclusion' service over a greater age range and to support those with 1:1 needs – community based activities
- Children's disability centre with integrated disability services staff based there and that has 2 respite beds for high level medical need.
- Single provision that meets physical, behavioural, medical and social needs.
- A single provision that offers a full range of overnight breaks, day care and outreach to provide support in children's homes and in the community
- Expand choice through the continued use of Direct Payments

8 NEXT STEPS - PLANNING AND DELIVERY OF SERVICE

A matrix listing service specification criteria against proposed provision (Appendix 1) suggests the following priority list for development:

- Respite bungalow at local special school
- Contract Carer(s)
- Enhancing Playscheme and Saturday Club
- Extending Day and Night nursing respite
- An integrated disability service with respite bed facilities to cater for children with high medical needs

It is recognised that a small number of children and young people will have exceptional needs requiring flexible support.

New investment to develop and provide wider choice and volume of service is needed to:

- increase social work time to recruit and support an increase in the numbers of F2F carers
- review contract carers salaries
- increase social work time to recruit and retain contract carers
- recruit direct payments worker to administer the predicted increase in payments
- recruit fair access to carers breaks project worker to help families use their indicative allocation in a creative way using community resources as well as the menu of Torbay Children's Services resources (Could include direct payments role as above)

As part of stakeholder consultation a provider forum will be established to:

- build upon existing strengths
- help develop the local market
- develop options for creative and flexible solutions
- develop a wide range of options outside of institutional care arrangements
- develop a continuum of support options
- ensure that any tendering needs to be able to be flexible and fluid to meet the likely changing demand with the implementation of FACBS and anticipated increased use of direct payments
- link in with regional commissioning groups and neighbouring authorities and PCTs strategies

Existing providers will be scored against the matrix specifications listed in appendix 1.

A commitment is made to continue with existing contracts for a further 12 months (April 2008-March 2009) whilst service specification is agreed, market engaged and tendering of contracts.

The development of the service specification must take in to consideration the statements listed in appendix 2 and agreed by the Project Steering Board.

APPENDIX 1 - RESPITE SPECIFICATION MATRIX

Trained in behavioural management techniques	3	3	3	3	3	3	3	3	2	2	2	2
Ability to liaise with other services and staff about physical and behavioural mgmt programmes to ensure consistency across services	3	3	3	3	3	3	3	3	2	3	2	2
Ability to meet a range of health care needs	3	3	3	3	3	3	3	3	2	2	2	2
	A single provision that offers a full range of overnight breaks, day care and outreach to provide support in children's homes and in the community	Respite bungalow at local special school	Contract care for physical and behavioural disabilities (would need adaptation to home)	Day and night nursing respite	Single provision that meets physical, behavioural, medical and social needs.	Children's disability centre with integrated disability services staff based there: 2 respite beds for high level medical need.	Day care or 'Playscheme' for those with high level physical disabilities with complex medical needs building on the principles of the Karma group offered by the Playscheme.	Outreach workers to take children out	Expand choice through the continued use of Direct Payments	Increased 'inclusion' service over a greater age range and to support those with 1:1 needs	Increased child minding	Increased home based respite
Ability to manage behavioural issues	3	3	3	3	3	3	3	3	2	2	2	2
Ability to communicate across a range of skills	3	3	3	3	3	3	3	3	2	2	2	2
Provision of safe environment: both physically safe and has 'safe' carers i.e. CRB checked	3	3	3	3	3	3	3	3	1	3	3	3
Provision of social contact and play and leisure activities	3	3	3	2	2	2	3	3	3	3	3	3
Ability to deal with ages ranging from 5 to 18	3	3	3	3	3	3	3	3	3	3	2	3
Ability to match needs and abilities to maximise opportunities for children	3	3	3	3	2	3	3	3	3	3	3	3
Ability to provide a range of day care and over night services in a flexible way	3	3	3	3	2	2	1	2	3	3	3	3
Ability to deal with emergency access (Low demand – 2-5 per year) and crisis response	3	3	3	3	3	3	1	3	3	1	2	1
Positive and proactive attitude to inclusion	3	3	3	3	2	1	3	3	3	3	3	3
Understanding of the needs of children with disabilities and their families	3	3	3	3	3	3	3	3	3	3	3	3
Total (min 19, max 57)	57	57	56	54	53	53	51	51	44	43	43	43

APPENDIX 2 - DEVELOPMENT OF SERVICE SPECIFICATION

The following statements and issues have been highlighted for consideration by commissioners in informing the development of our service specification

<p>Our starting point</p>	<ul style="list-style-type: none"> ■ Numbers of children and young people with learning difficulties and disabilities in Torbay have been increasing rapidly and will continue to do so ■ Our vision is for universal services to meet all but the most complex of needs, with specialist input for those with additional needs. Specialist provision should focus on those with the most challenging behaviour / very complex health needs ■ Resources are limited, with increasing demand. ■ The introduction of FACBS is aimed at ensuring equitable access. Commissioning will take into account changes in demand resulting from the implementation of FACBS. ■ Resources need to be used to develop a wider continuum of support options. ■ Resources will be reviewed as part of the Aiming High spending review.
<p>What might we commission?</p>	<ul style="list-style-type: none"> ■ The review indicates that short term breaks need to be seen in the wider context of a continuum of provision for the full range of needs of children and young people with learning difficulties and disabilities, and carers support. This continuum might include ■ Specialist input to support universal services such as children’s centres and child minding ■ Additional support with Inclusion ■ Day care in the child’s home or provision or a carers home ■ Child activity support such as befriending and other community support ■ Day time breaks in a range of settings ■ Evening breaks – sitting, tea sessions etc ■ Weekend and holiday breaks building upon Saturday club and holiday Playschemes ■ Activity breaks – community activity support ■ Breaks from caring at home – domiciliary care ■ Options for overnight breaks– residential, contract carers, family to family ■ Specialist emergency / crisis overnight breaks

<p>What types of commissioning do we need to think about?</p>	<ul style="list-style-type: none"> ■ Contracts / service level agreements (in-house and external providers) ■ Expand individual choice and control of service through Direct Payments ■ Future: budget holding Lead Professional commissioning and Individualised budgets
<p>What should a specification look like?</p>	<ul style="list-style-type: none"> ■ Details of exactly what outcomes we are aiming for ■ The level of service we expect (i.e. expected numbers of service users and any forecast trends) ■ Range of supports / services ■ Expectations re. service user participations, flexibility of services etc ■ Quality ■ Diversity e.g. continuum of needs, locations, different age groups, cultural diversity ■ Performance measures
<p>What should our commissioning process be?</p>	<ul style="list-style-type: none"> ■ Commissioning board. ■ Ensure service user involvement and direction ■ The Children Trust Executive will monitor and review the development of the commissioning of short breaks and respite provision.

APPENDIX 3 - GLOSSARY

CSCI	Commission for Social Care Inspection
DDA	Disability Discrimination Act
FACB	Fair Access to Carers Breaks
F2F	Family to Family
JPU	John Parkes Unit
SWALD	South West Learning Disability Network
TCT	Torbay Care Trust

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