



# Take-A-Break

**A Review of the Northern Health  
& Social Care Trust's Short  
Break provision to adults with a  
learning disability and their  
carers**

This Review has only been possible through active engagement with people with a learning disability, their carers, service providers and their local representatives who reside in the Northern Health and Social Care Trust area.

**August 2016**

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## Take-A-Break - Executive Summary

### Background

The Northern Health and Social Care Trust has completed a review of its short break (respite) provision for adults with a learning disability. The aim of this review was to engage with service users, carers and staff to inform a Trust strategy for short break provision to improve choice and accessibility and ensure the appropriate targeting of resources to those who are most in need.

### Short Breaks

Many people with a learning disability reside at their family home living with family carers. Although family carers identify rewarding and positive aspects to their caring role, there is also much evidence of negative impacts on the carer's physical and emotional wellbeing. This can include negative impact on family life, lack of sleep, resentment, stress and depression, and back pain from moving and handling.

For many carers Short Break services are an essential element of support, providing them with much needed respite from their caring duties. Without access to Short Breaks they would be unable to continue in their caring roles.

### Demand for Short Breaks

The number of people with a learning disability is increasing across the UK, as people with a learning disability, including those with complex health needs and challenging behaviours, live longer. Additionally fewer people are now living in institutional care and consequently the demand for short break services continues to rise in response to need.

The Equal Lives Report (2005) indicates that respite services need to be developed in a manner that moves away from an over reliance on inflexible residential provision to the provision of a menu of short break services that include home based support, community based activity, family placements and residential options.

The report by the Patient Client Council on Respite (Short Breaks), (2011) indicated that parents, carers and families of people with a learning disability felt that access to respite is essential. Carers said that respite, when they do access it, is provided to a good quality. Carers from the Northern Trust felt that respite services should be improved through greater availability, more flexibility and more local respite facilities.

### NHSCT Short Break Service provision

The Trust provides a variety of Short Break Service to some 520 adults with a learning disability whose needs can broadly fall into three categories;

- People with Challenging Behaviour (n=130).
- People with Complex Health Needs (n=167).
- People with General Needs (n=223).

These needs are met through a range of services principally statutory bed based services, independent sector booked bed based services and family based short breaks through our Share the Care service.

### **Analysis of Service Use**

An analysis of service use is undertaken within the Review and it is clear from this that the current service reflects an evolving development of Short Break provision and a number of key conclusions are drawn:

- There is a wide range of need being met and consequently scope for clearer prioritisation of need against the needs of clients and the complexity of carer needs.
- There is a high level of utilisation and growing demand for the short break provision available and this will continue.
- There is an inequitable access to Short Break provision across the Trust geography.
- There is not a strong correlation between resource intensity of provision and complexity of needs met
- Further investment in short break services is essential to meet increasing demands and provide choice in appropriate localised responses to meet levels of assessed need

### **Stakeholder Engagement Processes**

Central to completing the review was a comprehensive, externally facilitated programme of stakeholder engagement. This took place with four key stakeholder groups;

- People with Learning Disabilities
- Family Carers
- Public Representatives
- Service Provider

Service users provided feedback on the elements needed for a perfect service including more flexibility, closer to home and more things to do. Family carers described how they valued access to short breaks though wanted them to be more flexible and accessible to meet their needs as a family. Some carers valued the option to explore and experience more innovative options, others focussed on enhancing access to more traditional types of short breaks service.

### **Review Recommendations**

The Review's 24 recommendations are set to ensure best practice and the better targeting of resources and will modify the way in which short breaks are commissioned, developed and supported. In summary,

- The Trust will bring to the attention of the DHSSPS and Commissioner(s) the increasing requirement for short break services to reflect the increasing needs of our population

- The Trust will promote choice through both the development of innovative voluntary sector short break providers and encouraging the uptake of self- directed support/ direct payments for short breaks. These can be used by carers/people with a learning disability to improve choice and flexibility eg to obtain home based support, overnight breaks and for the person to go on holiday.
- The Trust will develop a reference group inclusive of people with learning disability and their carers to help explore the development of innovative short break services delivered through community partnership approaches.
- Services will be prioritised to those in most need through the implementation of an operational policy firmly based on a person centred approach and carer's assessed needs.
- Statutory bed based services will develop towards providing short break services for those with pervasive challenging behaviours. The fitness for purpose of the buildings and the training and support needs of staff should be reviewed to facilitate the needs of these service users.
- The Independent sector will be commissioned to provide alternatives for people with complex health care needs that require nursing home care or care in specialist residential settings. These need to be longer term commissioning arrangements to allow for stability and continuity in the delivery of services to these very vulnerable people.
- The 'Share the Care' service will be developed throughout the Trust for those with less complex needs providing more flexibility and choice for families.
- The Trust will resource short break services to facilitate day activities as an alternative to people having to attend their day care centre while on a short break.

## Public Consultation

Take-A-Break has involved engagement with a broad range of stakeholders. It's implementation sees a change in how short break services are delivered in the Trust which will impact upon how some individuals and their carers access these services. This will require further engagement through a period of public consultation on the recommendations contained within the Review.

## Implementation - Strategic Development Plan

The Trust will establish project structures to drive forward the implementation of the Take a Break Review

A strategic development plan is identified which will provide focus for the Project Board and sets out the strategic milestones to be achieved over a 5 year period. An engagement approach with service users their families and stakeholders will continue for the life of this project

## Take-A-Break Review

### 1 Background to the Review

The Northern Health and Social Care Trust (NHSCT) in response to the Transforming Your Care Review (TYC) established a strategic review of short break (respite) services available to adults with a learning disability.

The review commenced with the development of a project plan and structures including the appointment of an Independent Expert, Professor Roy McConkey, to lead on the critical stakeholder engagement processes. An important aspect of the review was the development of a database containing information on the profile of carers both using and requiring short break services as well as profiling the needs and characteristics of the people with a learning disability using short break services. The Review Team, Terms of Reference and Methodology for the Review is set out in Annex 1.

This review describes the services currently available to service users and the carers with a learning disability and based on its recommendations describes a Strategic Development Plan for the period 2016 to 2021 – Annex 2.

The aim of the Review is to:

- improve the quality and appropriateness of short break services,
- ensure fairness and equity in the allocation of services and to assist in the development and improvement of Short breaks,
- improve service utilisation by extending choice,
- ensure the most effective use of the resources aligned to short breaks, and
- work within existing and emerging policy frameworks linked to local priorities.

### 2 Short Break Services

The term Short Breaks is used in preference to the term Respite as the latter suggests solely the relief of a burden; whereas, the provision of short breaks conveys a positive experience which is of benefit both to the carer and the person for whom they care.

Most people with a learning disability reside at home with the support of family, formal support services and other informal social support systems. Through these supports people can remain at home for as long as possible, delaying and preventing the need for entry into long term care. Although carers identify rewarding and positive aspects to their caring role, there is also much evidence of negative impacts on the carer's physical and emotional wellbeing. This can include negative impact on family life, lack of sleep, resentment, stress and depression, and back pain from moving and handling.

A break from caring can enhance a carer's physical and emotional wellbeing, enabling them to continue in their caring role. Supporting carers to take a break allows them to have time to themselves and to have a life of their own alongside caring.

For many carers Short Break services are therefore an essential element of support,

providing them with much needed respite from their caring duties. Without access to Short Breaks they would be unable to continue in their caring roles.

### 3 Demand for Short Break Services

The number of people with a learning disability is increasing across the UK and globally. Demographic projections suggest that the numbers of people with learning disabilities will continue to increase at both ends of the age spectrum due to better survival rates in premature babies, improvements in health care and general increases in standards of living. Adult Learning Disability Services covers a wide age span from 18 to 80+ years and as life expectancy increases the number of adult with a learning disability will grow.

In addition the number of individuals with a learning disability with complex needs, including co-morbid health problems and behaviors perceived as challenging, is increasing across the UK (A third of people with severe and profound learning disabilities also have an associated autism spectrum disorder). People with learning disabilities often experience health and social problems associated with ageing, earlier than the general population and there is increasing incidence of dementia within some groups.

Accompanying this growth in the life expectancy is an increase in the population of carers, including an increasing number of ageing carers, and of new carers who will be caring for their loved ones for longer. McConkey (2005) found that 34% of adults living with family carers in Northern Ireland were accessing some form of overnight short break; this was comparable to the proportions accessing some form of short break elsewhere. McConkey also noted that many carers either needed increased number of breaks or were not yet accessing breaks.

Short Breaks are central to sustaining care in the community and preventing admissions into long-term care and associated costs. A comparative analysis undertaken within the Trust across the time periods 12/13 to 14/15 showed a 6% increase in the hours of respite provided to meet assessed needs. This was predominantly in bed based services for people with more complex needs. The requirement for short break services will continue to increase and needs to be recognized within DHSSPS and Commissioner priorities. The increase in need also requires service provision to be more innovative and adopt proven best practice in terms of service delivery. Partnership approaches are essential in working more closely with other statutory agencies, independent providers and with service users and carers to ensure we optimize our health and well-being potential, and use our resources effectively.

### 4 Policy and Strategic Context

Within Transforming Your Care Review (2011) DHSSPS(NI)([www.dhsspsni.gov.uk/tyc.htm](http://www.dhsspsni.gov.uk/tyc.htm)) (TYC) a central goal for people with learning disabilities is for them to be supported to live in their own homes. This requires the continuing commitment and dedication of carers. Feedback provided to the TYC Review indicates that achieving this objective will require particular focus and specifically highlights short breaks provision as a key area for reform. TYC also indicated that whilst short breaks provision has increased in recent years, service users and carers believe that more remains to be done to meet current needs.

The Bamford Review of Mental Health and Learning Disability, Equal Lives (2005) Report ([www.dhsspsni.gov.uk/learning-disability-report](http://www.dhsspsni.gov.uk/learning-disability-report)) indicates that respite services need to be developed in a manner that moves away from an over reliance on inflexible residential provision to the provision of a menu of short break services that include home based support, community based activity, family placements and residential options. Services are frequently accommodation based. Whilst these are important more flexibility in the home or local day placement should be explored. Respite care provision is not always age appropriate, eg respite provided for younger adults with a learning disability in nursing homes primarily for older people, and new models need to be created.

The report by the Patient Client Council on 'Respite (Short Breaks)', (2011) ([www.patientclientcouncil.hscni.net](http://www.patientclientcouncil.hscni.net)) indicated that parents, carers and families of people with a learning disability felt that access to respite is essential. Carers said that short breaks, when they access them, are provided to a good quality. Carers from the Northern Trust felt that respite services should be improved through greater availability, more flexibility and more local respite facilities.

'Caring for Carers' ([www.dhsspsni.gov.uk/ec-caring-for-carers](http://www.dhsspsni.gov.uk/ec-caring-for-carers)) in recognising the huge contribution of carers recommends that Trusts must act positively to support carers so that they can continue to care for as long as they wish, and are able to do so, without jeopardising their own health and well-being, financial security, or reducing their expectations of a reasonable quality of life.

The Learning Disability Service Framework (<https://www.dhsspsni.gov.uk/publications/learning-disability-service-framework-documents>). Standard 29 states that : All Health and Social Care staff should identify carers (whether they are parents, family members, siblings or friends) at the earliest opportunity to work in partnership with them and to ensure that they have effective support as needed.

## 5 NHSCT Short Break Service provision

The Trust provides a variety of Short Break Service options to people with learning disabilities. These include:

### Statutory Bed based services

- a. Ellis Court, a six bedded residential unit in Carrickfergus.
- b. Hollybank, a five bedded residential unit in Magherafelt. One bed is partly ring-fenced to support clients with assessment and treatment requirements.

### Independent sector booked bed based services

- a. Booked beds in nursing home and residential home settings providing care particularly for those with complex health care needs
- b. Two beds in, a residential setting in Coleraine specialising in management of service users with highly challenging behaviours. One of these beds is partly ring-fenced for



use in the event of emergency community situations, primarily to avoid admissions to Muckamore Abbey Hospital.

### **Family based short breaks – Share the Care**

The Trust's Share the Care service arranges breaks through volunteer carers ranging from day sitting to overnight to weekends and longer. It relies on the recruitment, training and matching of volunteers to service users who require family based respite. It is currently operating in the Causeway and Ballymena sectors and, to a more limited extent, in Mid Ulster. It requires to be developed as an option in the east Antrim sector. The scheme operates either as a sitting service in the client's own home or as a stay over in the volunteer's home.

### **Alternative arrangements**

A range of alternative arrangements are also available to provide choice and flexibility. These include direct payment allocations, independent living fund, use of complex needs funding to address specific needs, specialist arrangements within the Trust for specific individuals including third party bespoke arrangements specifically where there is significant risk of placement or family /carer breakdown.

Service users may avail of more than one type of short break provision and some can get services across the range of provision described.

In addition to the Short Breaks provision described above the Trust also provides a comprehensive range of day services in Adult Centres (788 service users) and day opportunities (560 service users) which are essential to supporting carers throughout the year providing them with short day time breaks and providing service users with a wide range of vocational, educational, leisure and social activities. Day services provision have expanded and developed over recent years in response to demand.

## **6 Profile of Service Users and Carers**

Understanding the needs of Service Users and Carers and the types and extent of Short Breaks they require is essential to the completion of the Strategic Review. A database was established using 2012/13 as the benchmark and validated up to 2014/15. Information was collected from the community learning disability teams, team managers and short break service managers. Information was collected on:

- the needs of service users ,
- the amount of service provision,
- the allocation of short breaks,
- the types of short breaks,
- the location where breaks are provided, and
- the costs associated with providing short breaks within current models of practice.

### **Analysis of needs of service users**

In the period analysed there were a total of 520 people with a learning disability availing of respite short breaks.

The needs of Service Users will vary from individual to individual, however for the purpose of Short Break provision three categories of need are identified as follows:

- People with Challenging Behaviour: this group comprises people with a severe learning disability and moderate to severe challenging and/or self-injurious behaviours or emotional disturbance frequently associated with autism (n=130);
- People with Complex Health Needs : this group comprises people with severe and profound learning disability and physical and sensory health care needs eg epilepsy, hearing impairment, physical impairment, severe impairment in communication skills, visual impairment, physical disability and complex health needs including tracheostomy, peg tube feeding etc, (n=167),
- Service Users with General Needs: this group comprises people with moderate to severe learning disability who have some need for supervision or support but who do not have particularly challenging behaviour or complex health needs (n=223).

Using these categories of need Table 1 below shows the number of individuals by age band accessing short break services within the Trust.

**Table 1 - The number and percentage of Service Users by need and by Age band:**

Ageband	Challenging Behaviour		Complex Health needs		General needs		Total LD population receiving respite		Total LD population receiving services	
	Num	%	Num	%	Num	%	Num	%	Num	%
18-29	53	26	59	29	89	44	201	39	632	30
30-39	31	26	37	31	53	44	121	23	347	16
40-49	25	33	24	31	28	36	77	15	382	18
50-59	14	18	30	38	32	41	79	15	394	19
60+	7	16	17	39	20	46	44	8	362	17
<b>Total</b>	<b>130</b>	<b>25</b>	<b>167</b>	<b>32</b>	<b>223</b>	<b>43</b>	<b>520</b>	<b>100</b>	<b>2117</b>	<b>100</b>

This table demonstrates that almost 1/4 of people known to community learning disability services are in receipt of short break services. The majority of users of short breaks are aged between 18 and 39. These service users represent 62% of those receiving short breaks whilst comprising 46% of the Trust's Learning Disability service user population. Whilst this may reflect higher proportions of older adults with a learning disability in care, and consequently not requiring short breaks, there is also a trend of increasing numbers of younger people with more complex needs requiring short breaks transitioning through to adult services. These people will continue to need these services as they and their carers grow older.

Over 40% of the Service Users receiving short breaks do not have a high level of complex needs and are classified as General Needs. The numbers in this classification are fairly consistent as a percentage across the age ranges. The proportion of those with complex

health needs increase over the age bands whilst those with challenging behaviours decreases.

Table 2 below looks at which of the Short Break services people in the various categories of need accessed.

**Table 2 - Where short breaks are provided by Numbers of Service Users and Category of Need**

	Statutory Residential - Ellis Court	Statutory Residential - Hollybank	Ad Hoc – Residential Home	IS Nursing Home	IS Specialist Residential	Share the Care - Causeway	Share The Care Antrim & Mid Ulster	Direct Payments	Independent Living Fund
<b>Challenging Behaviour</b>	42 36.8%	38 37.6%	3 4.6%	0	9 47.4%	17 11.3%	21 20.6%	10 18.9%	6 20.7%
<b>Complex Health Needs</b>	48 42.1%	29 28.7%	33 50.8%	25 100%	10 52.6%	43 28.7%	12 11.8%	27 50.9%	17 58.6%
<b>General Needs</b>	24 21.1%	34 33.7%	29 44.6%	0	0	90 60.0%	69 67.6%	16 30.2%	6 20.7%
<b>Total</b>	<b>114</b>	<b>101</b>	<b>65</b>	<b>25</b>	<b>19</b>	<b>150</b>	<b>102</b>	<b>53</b>	<b>29</b>

In total 520 service users accessed 658 places across the various types of services. This means that a number of services users accessed more than one type of short break service. Further analysis indicates that 143 service users were in receipt of mixed packages (27%). The remaining 377 service users were in receipt of one service option only (73%).

People with General Needs predominantly get their needs met in the Share the Care Services and to a lesser extent in the two statutory residential facilities and the independent sector (IS) residential home.

Complex health care needs are met across a wide range of service types possibly reflecting that within this population there is a broad spectrum of needs. With the exception of the two specifically commissioned bed based services all other services meet an assorted mix of needs.

Whilst all three services are shown as accepting people with Challenging Behaviours service users with severe challenging behaviours tend to use the IS Specialist Residential service and Hollybank statutory service whereas Ellis Court provides a service to those with more mild to moderate challenging behaviours.

Those with the most complex health needs tend to receive short breaks through nursing home provision, Independent Living Fund and Direct payments.

### Profile of Carers Needs

In looking at the characteristics of carers the following classification was developed to reflect the different circumstance which would impact upon a carer's ability to undertake a caring role.

- Lone carers
- Carers over 65 years of age
- Carers with other dependents
- Carer has own health needs

The information in Table 3 has been produced from the available carer data. Please note that carers may fall into more than one category:

**Table 3 - Breakdown of Carer Characteristics**

Characteristic	Yes		No	
	Number	Percentage	Number	Percentage
<b>Carer aged over 65</b>	183	34.7	345	65.3
<b>Carer supports more than one service user</b>	178	33.7	350	66.3
<b>Lone carer</b>	173	32.8	355	67.2
<b>Carer has own health needs</b>	249	47.2	279	52.8

Note: Missing data is assumed to be a negative.

From table 3 it is apparent that:

- Approximately 1 in 3 carers are over 65
- 1 in 3 are caring for more than one person
- 1 in 3 are a lone carer i.e. they have no additional support living with them
- Approximately 50% of all carers have their own health care needs.

As short breaks aim to provide a service to support carers it is important that resources are targeted effectively to meet the individual circumstances of carers. As noted carers may have more than one of these characteristics.

Table 4 below groups the characteristics of carers and provides an element of a framework for determining priorities for allocation of short break services.

**Table 4 - Carers Complexity of Needs Matrix**

		Carer Under 65		Carer over 65	
		More than one carer helping	Lone Carer	More than one carer helping	Lone Carer
Carer has no known Health Needs	Cares for one person	104	36	29	9
	Cares for more than one person	53	14	8	3
Carer has known Health Needs	Cares for one person	31	23	42	56
	Cares for more than one person	44	17	22	14

Table 4: Distribution of characteristics amongst carers

Note: Some data is missing so this represents 505 Service Users and not all 528

One Characteristic		Three Characteristics	
Two Characteristics		Four Characteristics	

The colour of the box reflects the number of characteristics relevant to the carer. Some 104 carers (20%) have none of these characteristics, thus four out of five carers share one or more of them. At the other end of the scale 14 carers (3%) have all four characteristics.

While not a sole determinant for allocating resources this information enables an overview of how resources are currently utilised and if there is a need to refocus usage. Carers were allocated 2 points each for being a lone carer, caring for multiple service users and having their own health needs. If the carer was over 65, they were allocated a further point recognising that whilst being older is not a barrier to caring it can make the caring role more challenging. The sum of the four categories scored spans from 0 to 7 indicating Carer Complexity. These scores can then be mapped to the Category of Need of the person cared for. This is set out in Table 5 below.

**Table 5 - Carer Complexity by Category of Client need.**

Category of Client Need	Carer Complexity of Need								Total Service Users
	0	1	2	3	4	5	6	7	
Challenging Behaviour	26	8	30	18	15	26	3	4	130
Complex Health	38	11	35	22	19	28	7	7	167
General Needs	55	9	57	18	47	27	7	3	223
<b>Grand Total</b>	<b>119</b>	<b>28</b>	<b>122</b>	<b>58</b>	<b>81</b>	<b>81</b>	<b>17</b>	<b>14</b>	<b>520</b>

The table links the distribution of the carer's complexity of need with the needs of the service user receiving short break services. This shows that over 10% (55 of 520) of the service users who receive short breaks have low complexity and their carers also have low complexity. This indicates that there may be scope for improved prioritisation of services against the needs of service users and the complexity of carer needs.

## 7 Short Break Provision and Cost

The total hours of short breaks provided across the various provisions equates to 288,934 including an estimate for direct payment hours. Table 6 below indicates the types of respite provision, hours available and % Utilisation.

**Table 6 - Trust Short Break Provision**

Respite provision	Total hours provided	Total hours available	% Utilisation
Statutory Bed Based	90,010	95,424	94
Contracted Nursing Home	15,000	17,520	86
Contracted Residential Home	10,680	14,592	73
Share the Care	75,058	NA	NA
Ad hoc respite	50,153	NA	NA
Specialist in Trust provision (TC)	1,296	NA	NA
Direct payments	46,737 est	NA	NA
ILF	NK		
<b>Total</b>	<b>288,934</b>		

This illustrates that the two statutory residential facilities in Magherafelt and Carrickfergus provided the largest number of respite hours in the Trust. This is followed by the Share the

Care Scheme, despite its limited availability across the Trust. The majority of the ad hoc provision was from a single provider of residential respite.

Table 7 sets out the hours of Short Breaks provided to clients broken down by their Trust locality of origin. It also shows the overall % of Learning Disabled clients from that locality.

**Table 7 Short Breaks provided to clients broken down by their Trust locality of origin**

Trust Locality	Hours of Short Break Provided	% of Hours Provided	% of L D Population
Causeway Locality	92,626	38	27
Ballymena & Antrim	47,689	19	26
Mid Ulster	36,052	15	18
East Antrim	68,851	28	30
Total	245,218*	100	

\* For a % of service users no postcode was available on the database to identify locality.

This illustrates an inequity of access with proportionally increased access to short break provision in the Causeway locality than in others. This reflects the longer standing Share the Care Scheme availability in that locality. Conversely the lesser provision in the Ballymena and Antrim area may reflect the lack of local provision in that locality acting as a barrier to accessing short breaks.

### Short Break Cost

Short break provision for people with a learning disability cost in 14/15 some £2.137m across the various types of provision in the Trust.

Analysis of the hourly cost of the different types of provision on the basis of hours available indicates a significant range of costs from £2-50 per hour paid as expenses paid to Share the Care volunteer host carers to £12-84 per hour as the cost of statutory bed based provision.

Overall the analysis showed a significant variance in average costs across the various types of provision. It illustrated that the Share the Care Scheme and Ad Hoc respite provisions are the least expensive and these predominantly, though not exclusively, cater for people with general needs.

At the other end of the scale the Statutory Bed Based and the IS Specialist Residential Home are the most expensive. These facilities support a significant population of people with Challenging Behaviours and Complex Health needs however the two statutory homes also support a population of people with General Needs.

The contracted Specialist Nursing Home whose hourly costs falls in the middle supports exclusively people with complex health needs. Direct Payment would generally be used on an Ad Hoc basis in a crisis situation or for sitting type services. They are likely to be a similar population to those using Share the Care.

## 8 Summary of Analysis of Service Use

It is clear from the analysis of the current service that it reflects an evolving development of Short Break provision and a number of key conclusions can be drawn:

- There is a wide range of need being met and consequently scope for clearer prioritisation of need against the needs of clients and the complexity of carer needs.
- There is a high level of utilisation and growing demand for the short break provision available and this will continue.
- There is an inequitable access to Short Break provision across the Trust geography.
- There is not a strong correlation between resource intensity of provision and complexity of needs met
- Further investment in short break services is essential to meet increasing demands and provide choice in appropriate localised responses to meet levels of assessed need

## 9 Stakeholder Engagement Processes

Central to completing the review was a comprehensive, externally facilitated programme of stakeholder engagement. This took place with four key stakeholder groups;

- People with Learning Disabilities
- Family Carers
- Public Representatives
- Service Provider

For the purposes of this report Headline Messages are illustrated for each engagement event and (full reports are available in Annex 1).



## Messages from People with a Learning Disability

A practical exercise was undertaken with service users where everyone got to place bricks in building the perfect services. This is direct feedback on the elements needed for the perfect service:

- More friends at respite
- More things to do
- Flexibility
- Proper disabled access
- Mini breaks
- Good staff
- More family settings not homes or care homes
- Closer to home
- Better quality service for complex needs
- Accessible information
- More money for Share the Care carers

## Messages from Family Carers

The engagement exercise told us how much family carers valued access to short breaks though wanted them to be more flexible and accessible to meet their needs as a family. Whilst some carers valued the option to explore and experience more innovative options others focussed on enhancing access to more traditional types of short breaks service.

- The availability of short breaks did not meet the needs of carers: they wanted more breaks.
- Carers received more breaks when they were with children's services. They had experienced a reduction in services when transferring to adult services.
- If families relinquish care of their relative, it would cost the Trust a great deal more to care for the person.
- New referrals for short breaks have long waiting times before a service is provided.
- As carers get older they require more breaks. Their informal supports (such as their parents) are no longer available to them or their own health begins to fail
- Carers deserve a break although some may not want to avail of formal short break services. They use it reluctantly.
- The criteria for allocating short breaks are not explicit. Less needy families appear to receive the same as more needy ones.
- Carers are fearful that the Trust is looking to reduce services and instances were cited when this had happened individuals recently. The case for more services is not being heard.
- The style and pattern of breaks needs to be individualised to suit the carer and the person they support.
- Bed-based services are more reliable; less prone to cancellation at short notice. On the whole, carers were satisfied with the services they received from Trust and other providers.
- Local services are preferable: easier to maintain contact with carers; person knows the locality.
- Carers were unaware of, or had not received a recent Carers Assessment.

## Messages from Public Representatives.

Public representative were supportive of the Trust looking at the issue of short breaks and were aware of how important access to these services are for families and carers.

- The review of short breaks was welcomed by all public representatives
- Support will be available from public representatives to the Trust during the process of the review.
- Assurances were sought regarding existing resources these will not or should not impede development in terms of service provision and funding.
- Consensus that the need to re-engineer some services was required to make better use of resources.
- Concern was shown regarding those who live in rural communities.
- Concern was shown regarding those with complex health needs.
- Proactive communication of this type was welcomed by representatives.
- Public representatives to be kept advised and informed of progress.

## Perceptions of a Service Provider

One independent sector service provider shared with the Trust their perceptions of the priorities for action.

- Should be a commissioning priority
- Clear criteria and guidance needed
- Emergency provision must be considered

## 10 Conclusions

There is increasing need for short breaks reflecting both demographic changes and social change with many more people with a learning disability, and particularly those with complex needs, being supported in the community. With the increasing numbers of people accessing current services capacity is becoming inadequate and oversubscribed to meet

assessed need. Increased demand coupled with a static capacity means the amount of short breaks offered to each person reduces over time.

Service users who may not require the level of support and care provided in bed based services have historically been referred to these units in the absence of alternatives. Bed based short break services are the most heavily resourced and consequently should be targeted at those with the most specialist needs. The profile of people attending bed based services should be reviewed to make the most effective use of these resources through their specialising in meeting the particular needs of either people with complex health needs **or** those with challenging behaviours. Statutory bed based services should develop to specialise in meeting the needs of those with challenging behaviours, with people who have complex health care needs getting their needs met in specially commissioned independent sector nursing and residential care beds.

The environment in statutory facilities at Hollybank and Ellis Court need redesign and modification at a minimum in order to meet the needs of complex individuals with challenging behaviours.

The Share the Care Scheme within the Trust is highly successful and is well developed in the 'Causeway' area. It offers individually based flexible service and will often better meet the needs of people when a crisis or emergency occurs. Whilst some carers indicated that they were unaware of the service or felt that it could not be relied upon in the same way as bed based service the response from carers who receive this service was very positive and it was deemed by them to be reliable and flexible. Service users were also very positive about their Share the Care experiences. This service should be developed throughout the Trust offering a suitable alternative to residential bed based provision. To help promote this service the rate for covering volunteers expenses should be reviewed.

Service Users emphasized their wish for mini breaks and more things to do. The Trust should more actively promote direct payments and self-directed support options for accessing short breaks which will allow service users and carers to develop their own opportunities and choices for innovative Short Breaks. The Trust should also promote choice and availability in alternative short break options which would meet the aspirations of service users. The Review is aware of successful Short Break service models being delivered elsewhere by voluntary organisations such as HFT (formerly Homefarm Trust) and The Camden Society who are both recognised as centres of excellence in this field. These organisations offer a range of innovative Short Breaks in specialist hotels and guest houses with a wide range of activities. Links are <http://www.thecamdensociety.co.uk/ourservices/shortbreaks>; <http://www.hft.org.uk/Supporting-people/Our-services/Short-breaks/>

The expansion of the Share the Care service and direct payments/self-directed support across the Trust should aim to free up bed based services to meet the needs of those with more complex needs.

Carers and clients were realistic about resources but they argued their need for more flexibility and choice that is locally based and tailored to meet individual's needs. Carers and clients understood that planning and allocation is crucial for bed-based services but want a more transparent approach to the allocation of resources. An explicit resource allocation template for short breaks needs to be developed to ensure fairness and transparency of

access against need. This would form part of an operational policy for short break services (see below)

Carers need reliability and appropriate service provision for people with more complex needs and challenging behaviour and increasingly those with acute mental health and forensic needs. Many carers expressed the concern and the anxiety caused to them by changes in providers particularly for those with complex health needs. This was in particular reference to nursing home care and Trust procurement and contracting processes. There needs to be longer term contractual arrangements for this provision to have consistency of care so that carers can develop confidence in the service provider.

Concern was also raised about having to travel long distances to and from specialist units including the additional costs this entailed in terms of time and money. Transport is not provided by the Trust for residential short breaks services. There is a need to move towards more local provision to better meets the needs of service users within their localities. This will require both realignment of current service provision and targeting of any opportunities provided through future investment.

The Trust should develop an operational policy to assist community learning disability teams in making professional decisions or judgements as to the type and/or allocation of short breaks. This is more important as the strain on resources remains a real part in the decision making process. The development of an operational policy that will incorporate fair access criteria is key to assisting staff in assessing individual needs. It will give them the confidence to negotiate and agree the best way in which services should be allocated Carers must be informed of this process and be better informed about how decisions have been made.

## 11 Recommendations

Based on the analysis of information and the feedback from stakeholders a total of 24 recommendations are made to ensure best practice and the better targeting of resources which will improve the way in which short breaks are commissioned, developed and supported.

### Carers & Service Users

1. Carers and service users will be offered more flexible options for short breaks based on their assessed needs. This may include services that are not provided by Health and Social Care.
2. The Trust will develop a reference group inclusive of people with learning disability and their carers to help explore the development of innovative short break services delivered through community partnership approaches.
3. Improved information will be made available to carers & service users about the types of services that they can access.

4. Eligibility for short break services should be underpinned by a carers assessment. Carers' needs must influence the amount and type of short breaks offered.
5. An operational policy will be drawn up in consultation with service users and carers. This will assist them in understanding the process by which services are allocated.
6. Carers will be made aware of the eligibility criteria set within the operational policy for services at the outset of the assessment process.
7. The needs of carers should be prioritised as follows so that short breaks can be targeted more appropriately:
  - carers over the age of 65;
  - carers who care for someone on their own;
  - carers who have more than one dependant and
  - carers who have medical /health problems that impact on their ability to care,

## Services

8. Bed based services offer the most intensive levels of care and support and must be made available for those who need this most:
  - a. Hollybank, Ellis Court and Woodford Park will develop to meet the needs of those with challenging behaviours.
  - b. For those with complex physical health care needs the Trust should commission care from appropriately registered Nursing and Residential home providers. This will be provided to clients who require residential or nursing care or waking night staff to manage the risks associated with their assessed need. These need to be longer term commissioning arrangements to allow for stability and continuity in the delivery of services to these very vulnerable people.
9. The Share the Care Service will be fully implemented across the Trust. Clients with 'general needs' who are currently availing of bed based should be reviewed and offered more appropriate short break alternatives including Share the Care. This would create additional capacity to meet assessed need for bed based services
10. The current rate for volunteer expenses for Share the Care should be reviewed by the Trust
11. The Trust will explore options for overnight breaks in existing registered provision across the Trust area including older person's services for those who are older or need nursing care.

12. The Trust will promote choice through both the development of innovative voluntary sector short break providers and encouraging the uptake of self- directed support/ direct payments for short breaks. These can be used by carers/people with a learning disability to improve choice and flexibility eg to obtain home based support, overnight breaks and for the person to go on holiday.

## People

13. The Trust will review staffing and skill mix in statutory beds based services to support service users with more challenging behaviours
14. Training and education plans should be developed for staff working in short break services to meet existing and upcoming needs
15. Community Learning disability teams should be provided with training on short break services including on the implementation of the new operational policy.

## Planning and Developing Capacity

16. The Trust will bring to the attention of the DHSSPS and Commissioner(s) the increasing requirement for short break services to reflect the increasing needs of our population
17. Adult learning disability services will develop effective processes for transitions planning with children's disability services in order to predict upcoming need and provide information on the range of services for adult short breaks
18. For new service users and carers, where short break services are an assessed need, the overall support plan will be taken into account before recommended allocation of short breaks for example if day care or other supports are available.
19. Emergency short break plans for those with assessed need should be developed for each individual as part of normal assessment and care planning processes. Consideration should be given to all alternatives rather than purely statutory commissioned care eg another family member is identified who could care for a short period of time.
20. Day activity /services will be provided in bed based services rather than travelling back often long distances to their adult centres. This will provide an opportunity for service users to enjoy new experiences while on a short break and will have more of a holiday feel to them. This will require a small investment within Trust bed based facilities but will enable a more efficient use of resources within current day care and transport arrangements.

21. There should be further integration of day centres and day opportunities services in developing short break options other than overnight breaks.
22. New and existing resource allocation should be overseen by senior staff in the learning disability programme to ensure equity of allocation on the basis of the revised operational policy.
23. A database will be maintained and developed by the Trust to monitor the overall allocation of short breaks and ensuring equity of allocation against needs.

### **Buildings**

24. An estates appraisal will be undertaken of the fitness for purpose of the existing statutory short breaks buildings in Carrickfergus and Magherafelt. This should consider both short term works to achieve fitness for purpose for the changing needs of clients and the best option for longer term service provision



## Annex 1

## Review Team Membership and Terms of Reference

### Membership of the Review Team

Mrs Donna Morgan	Head of Service
Mrs Rosemary Wray	Manager East Antrim Supported Living and Short Break Services
Mrs Arlene Stewart	Manager Hollybank Supported Living and Short Break Services
Mrs Katrina Mc Govern	Team Manager Community Learning Disability Team
Mr Alec Walker	Manager Share the Care Short Break Services
Mr Seamus McKenna	Planning Manager
Mrs Irene Heath	Planning Manager
Mr Patrick Harper	Intern
Professor Roy McConkey	Independent Expert

The Project Team wishes to thank service users, their carers, advocacy and carers groups, Health and Social care staff and public representatives who facilitated this review through participating in the engagement process or in providing relevant information.

### Terms of reference

- To develop a Trust Strategy and Operational Policy for short break provision for people with a learning disability and their carers
- To develop a comprehensive database profiling carers and service users
- To engage with local political representatives
- To engage with all stake-holders
- To engage with family /carers
- To engage with people with a learning disability who use services.
- To identify inter-relationships with other Trust programmes and services
- To revise and develop the operational plans for the range of provision of short breaks

### Methodology

The methodology adopted for this review was designed to gather the views of people with a learning disability and their carers as well as staff and services responsible for delivering short break services.

The methods used included:

- A presentation to local representatives across all political parties provided background information on the Trust's intention to carry out the review.
- A database was created by the Project Team and Strategic Planning and Modernisation department. The database was populated and validated by Community Learning Disability teams. This information informed the project team of the current

provision of services, the profiles of carers, the needs of the individuals being cared for, the types of care provision and the locality in which services have developed and been offered and the cost of provision. This has assisted in benchmarking services within the Trust. It is intended that this database is kept live and could also be used also by Children's services.

- A stakeholder event was held to which invitations were given to voluntary and private agencies, Trust short break providers, service user representatives and carers groups with a specific interest in short break provision
- A workshop for service users was held about the current service of short break provision and opportunities. They are afforded to share and discuss their views. The workshop was hosted by Compass Advocacy group and had a semi-structured approach using a list of specific questions designed by the expert .

There will be six engagement meetings for family carers. The purpose was to explore their experiences and perspectives on the development of future short break provision within the Trust. Each of the sessions had a semi-structured approach using a list of specific questions and they were facilitated by Roy McConkey .

## Annex 2



## Take- A- Break Implementation - Strategic Development Plan

### Introduction

The Mental Health, Learning Disability and Community Wellbeing Directorate will establish a new project board and develop a Strategic Development Plan to take forward recommendations identified in the Take a Break Review

The strategic plan will provide focus for the Project Board and will outline the strategic milestones to be achieved over a 5 year period.

An engagement approach with service users their families and stakeholders will continue for the life of this project

Learning disability services will engage with children's services transitions planning with children's disability services in order to predict upcoming need.

A database should be maintained to monitor the overall allocation of short breaks and ensuring equity of allocation against needs and based on operational policy.

Self -directed support will be developing and broadening choice

New and reuse of existing resource will be overseen by senior staff in the learning disability to ensure equity of allocation on the basis of the operational policy

Strategic milestones To be achieved 2016/17
<p>Presentation of Take a Break Review to NHSC Trust Board</p> <p>Public Consultation process and review of strategy</p> <p>Approval of final strategy by NHSC Trust Board</p> <p>Project Board and Project team and sub groups to be set up</p> <p>Establish reference group</p> <p>Engagement with Commissioners/DHSSPS re Service Need</p> <p>Agree and classify recommendations into short medium and long term and set up work streams</p> <p>Project Plan to agreed and finalised</p> <p>For those with complex physical health care needs the Trust will tender and commission care from appropriately registered Nursing and Residential home providers</p> <p>Operational Policy to be agreed</p>

Programme of training to be developed and implemented for staff using the operational policy

#### **Strategic milestones To be achieved 2017/18**

Implementation of operational policy

Development of share the care services in Mid Ulster and East Antrim through focused recruitment campaign

Estates appraisal of the fitness for purpose of the existing statutory short breaks buildings in Carrickfergus and Magherafelt.

Complete a scoping process in partnership with community partners develop a definitive menu of services that can be offered as an alternative to bed based service

Identify and assess service users and their families who will benefit from immediate alternative to bed based services

Training needs analysis to be completed and training designed to meet the needs of those with complex challenging behaviour

Engage with learning disability teams regarding yearly transitioning process

Reinstate the database and maintain

#### **Strategic milestones To be achieved 2018/19**

Programme of focused assessment of those who may benefit from alternative forms of respite using the operational criteria not identified already

Complete a commissioning process regarding alternative services if required

Develop a model of day centres and day opportunities with short break services to create options other than overnight breaks

Plan following appraisal recommendations regarding the development of Ellis Court and Hollybank

Matching process for share the care and service users

Management of change programme for service users moving from share the care

Programme of training to be implemented in identified services

#### **Strategic milestones To be achieved 2019/20**

Implement a model of day centres and day opportunities with short break services to create options other than overnight breaks

To further promote self- directed support direct payments for short breaks.

Review and update menu of services through continuing engagement with stakeholders

Oversee planned refurbishment of Ellis Court and Hollybank

Continue the management of change process for service users and family carers

**Strategic milestones To be achieved 2020/2021 +**

Engage with service users and families regarding progress and formal review of services

Review the operational policy

Review the choice services available

Review the commissioning process and develop further if required

Analyse data collected through database

Project Board stood down