



Northern Health
and Social Care Trust



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REFORM AND MODERNISATION PROGRAMME



**Take-A-Break:
Consultation on the
outcome of our review of
short breaks for adults
with a learning disability
and their carers (05/09/16
to 31/01/17)**

Consultation Feedback Report

Introduction

We are proud of the progress we have made over the last 10 years to enable people with a learning disability to lead fulfilling lives with the same rights as anyone else. We want to build on this and continue to support people to become more independent and involved in their communities whilst at the same time supporting carers and families.

We know that for many carers, short break (respite) services are an essential element of support as well as providing adults with learning disabilities with opportunities to meet new people and enjoy new experiences. We have carried out a review of our short breaks service and we have now consulted on the outcome of this review and how we propose to provide short breaks in the future. This report should be read in conjunction with the consultation document, *Take-A-Break: Consultation on the outcome of our review of short breaks for adults with a learning disability and their carers* available at www.northerntrust.hscni.net or by contacting the Trust's Equality Unit on 028 2766 1377 or at equality.unit@northerntrust.hscni.net.

This report describes the background to the consultation and gives a summary of the feedback we received as a result of the period of public consultation and our response to this feedback, including what the next steps are.

Our consultation process

It is important to note that during our review we engaged with people who use our short break services, their carers, a number of public representatives and the independent service providers who provide services on our behalf. We held a stakeholder event with a number of voluntary and independent organisations, short break providers, and service user representatives and carers groups. We also held a workshop for service users and six engagement meetings with family and carers. The feedback we received shaped the recommendations we have made.

On 5 September 2016 we commenced a public consultation on the outcome of our review of short breaks for adults with a learning disability and their carers. We planned to close the consultation 28 November 2016 but extended it until 31 January 2017 to allow time for face to face engagement with service users and carers.

To raise awareness of the consultation process over 1,500 groups, organisations and individuals listed in the Trust’s Consultation Database received an email or letter informing them of the consultation arrangements. Consultees were also informed of the extension to the consultation period and reminded of the closing date. Consultation documents were made available on the Trust’s website (i.e. available to the public) and intranet (i.e. available to Trust staff). The consultation document and questionnaire were available on the website in an easy read format. Information about the consultation process was disseminated to all the carers known to the Trust.

A total of 38 written responses (see Appendix 1) were received during the formal 21 week consultation period.

To ensure effective engagement with carers and services users the Trust engaged Compass Advocacy Network to carrying out a series of independent consultations in the Trust area as follows.

<u>Venue</u>	<u>Town</u>	<u>Participants</u>	<u>Locality/Region</u>	<u>Date</u>
CAN Main Office	Ballymoney	Families/Carers	Causeway	16/01/17
Valley Leisure Centre	Newtownabbey	Families/Carers	East Antrim	17/01/17
Cookstown Leisure Centre	Cookstown	Families/Carers	Mid Ulster	18/01/17
Seven Towers Leisure Centre	Ballymena	Service Users	NHSCT	27/01/17

A total of 40 service users and carers participated in this targeted consultation process. A report detailing the feedback from these meetings can be found on the Trust’s website at www.northerntrust.hscni.net. A summary of the key issues raised is on page 13.

This document summarises the feedback we received during the consultation, our response, the final criteria proposed to support the evaluation of homes and the proposed next steps and timeline.

Promoting equality and good relations

The Trust is committed to promoting equality of opportunity, good relations and human rights in all aspects of our work. A preliminary equality screening of the proposed criteria was carried out. We believe that these proposals will have a minor impact on service users. The screening outcome was consulted on at the same time as the Trust consulted on its proposals

What we heard during consultation

Ensuring the people who need the most support get the help that they need first

All of the respondents agreed that the people who need the most support should get the help that they need first and that we should be person centered and look at the needs of the person with a learning disability and their families or carers.

There was recognition that the Trust has limited resources available to provide short breaks and that this may result in prioritisation based on need but there was some concern that this would result in people who are 'less needy' not getting short breaks. It was suggested that the Trust should refer to 'targeting' services as the term 'prioritisation' would result in 'eligibility and access thresholds'.

It was felt that all families need support and that some families (due to the complexities of the disabled persons condition) have few if any other forms of support from family or friends due to the difficult nature of care and count more and more on trained carers in a 'respite unit'.

It was suggested that building based respite should be used for clients who display challenging behaviours or other complex needs but it was felt that that alternative options for others are currently limited. It was suggested that the Share the Care model should be expanded to offer more service users and their families greater input into how, who and where their care is delivered.

Trust response

The principle of prioritising resources to those who need the most support is central to the Take-A-Break review, alongside the commitment to person centred services. The development of an operational policy that will incorporate fair and transparent access criteria is essential to ensuring the effective targeting of resources to those in greatest need.

Take A Break envisages that we will develop alternative options for short breaks to include establishing the Share the Care service across the Trust area.

Carers needs

All of the respondents agreed that carers needs should be fully assessed to make sure that the Trust can provide the right type of short breaks. It was suggested that the uptake of direct payments and carers assessments should be improved regionally by setting and monitoring targets. It was also felt that a full assessment of carers needs can only be properly undertaken in the 'absence of a blanket cap on the maximum number of permitted short breaks', thereby ensuring that provision is in keeping with the needs led and person centred approach. There was concern that without the right advocacy and support many carers will not have their needs assessed and unless there is adequate assessment and monitoring of unmet need it is difficult to appropriately prioritise.

It was felt that only a robust assessment of carers needs can inform the type of short breaks required and that regular contact with a social worker is important, particularly as needs can change. It was stated that resources should be available to meet identified needs and concern that carers will be 'worse off' if money is not available.

There was concern that some families rely on the short breaks provided by the Trust and that many carers are getting older. There was some frustration felt by some carers that short breaks are not being prioritized for people with challenging behavior. It was highlighted that in research 8 out of 10 family carers indicated that they don't get the short breaks they require and are at 'breaking point'.

Trust response

The uptake of direct payments and carers assessments are monitored and reported on regionally through the DoH Commissioning Plan Direction Targets & Standards. The Trust is promoting carers assessments through staff training and the provision of information for service users and carers.

Take-A-Break identifies the assessment of the needs of carers as being essential to ensuring the prioritisation of short breaks to those who need the most support. The Trust is committed to prioritising its services for those in greatest need including people with challenging behaviours and their carers.

There is no 'blanket cap' on the maximum number of permitted short breaks' for an individual however the availability of short breaks is based on assessed need and the capacity available within commissioned services.

The Trust is currently considering how to enhance the availability of advocacy services to people with learning disability and their carers. The Trust reports on Short Break services, including service pressures and unmet need, to the HSCB each year through the Delegated Statutory Functions report.

Providing better information on types of short breaks

Respondents agreed that the Trust should make sure that it provides better information about the types of short breaks available, particularly as carers have different needs. It was suggested that "information is key to giving people choices" and Trusts should ensure that all families in their area are also informed about and offered the opportunity to access Direct Payments and Carers Assessments.

It was felt that there is limited information available and some respondents stated that they had never been informed of anything other than 'regular respite'. Carers requested more information on what to do in an emergency situation.

Trust response

The Trust will work with service users and carers to develop information, in accessible formats, on the options available for short breaks.

Self-directed support

Only one of the respondents felt it was not a good idea to encourage people to choose self-directed support. While the majority felt encouraging self-directed support is a good idea and easier access to Direct Payments for short breaks is required. It was also suggested that people should be informed of the different type of support available rather than being encouraged to choose self-directed support.

One respondent emphasised that when individuals do choose Self Directed Support, the Trust must take appropriate action to make sure that arrangements are in place to facilitate managed budgets so that service users/carers can spend their personal budget on the services they choose.

It was suggested that the Trust should consider how individuals who are receipt of a direct payment could be 'grouped together' so that they could 'collectively procure' their short break.

Not everyone understood what self-directed support means and it was emphasized that the Trust should make self-directed support as easy as possible for services user and carers and clear concise information and advice should be available.

It was felt that self-directed support is not suitable for everyone and may only be for people with less complex needs. Again it was suggested 'sufficient funds' would have to be available and have the flexibility to allow for 'creative solutions'. The involvement of carers in deciding how care is delivered was seen as important.

One respondent queried if the provision of self-directed support would be provided by the Trust or procured from other organisations. There was concern that SDS is based at an hourly rate which does not include staff mileage, staff expenses or travel time.

Trust response

Self –directed support is still a relatively new concept within N Ireland and people will become more widely aware of it, and its potential, as uptake increases .

The Trust will continue to develop the its range of short break options and promote the availability of self-directed support as a choice for short breaks for those people who wish to avail of this. The Trust recognises however that this will not be an option suitable for everyone.

The hourly rate for self- directed support is a regional rate for direct payments for personal care determined by the HSCB which takes into account the living wage and employer costs.

Short break services for people with challenging behaviour

All of the respondents agreed that the Trust should develop its short break services for people with challenging behaviours and make sure that staff are properly trained and that short break buildings are the right place for people with challenging behaviours. Alongside this it was felt that the Trust should also consider how short break services for people with challenging behaviours could be met through other innovative short break approaches.

It was felt that services for people with challenging behaviour in the Trust area are limited and those caring for people with challenging behaviour can become isolated and need regular short breaks. It was also suggested that support people with challenging behaviour with the right activities may be more important than ‘buildings’.

It was again emphasised that decisions around how short breaks for people with challenging behaviours are delivered should always include the views of the service user where possible and their family. It was suggested that evidence from Shared Lives schemes in other parts of the UK is that many Shared Lives carers can support people with very challenging behaviours and this could be explored as part of any expansion of “Share the Care”. The safety of the service user and the carer should be paramount in any decisions

but the option of accessing “Share the Care” short breaks should be open to everyone.

Trust response

The Trust will look at other options for providing short breaks for people with challenging behaviour alongside building based provision. This will include considering the potential for developing Share the Care service for people with more complex needs and challenging behaviour. This is now reflected in the final draft for approval of the Take-a-Break review page 19 and an additional recommendation 10 on page 21

Short breaks for people with complex needs

Most of the respondents agreed that it was a good idea for the Trust to pay for people with complex needs to have short breaks in places like Private Nursing Homes or more specialist units. It was suggested that that the issue of ‘respite is of considerable concern’ for families who have an adult with complex needs living at home.

There was some concern that this may not be suitable if the person is young and that any provision must be age appropriate and address the full range of complexity of needs.

Again it was suggested that the right type of support is more important than the ‘right building’ and it is important that people with complex needs are supported by those who understand them and know how to support them.

It was felt that “Share the Care” should be offered as an option to everyone model has demonstrated its capacity to support many service users with very complex needs in schemes in other parts of the UK. This would be subject to availability of suitable carers and the training and support that they receive.

Trust response

The Trust is aware of the challenge involved with placing people for short breaks within nursing homes. Take-A-Break envisages commissioning short break beds within specialist learning disability facilities which are age and needs appropriate.

Share the Care Service

All but one of the respondents agreed that the Trust should develop its Share the Care service with one respondent describing the service as 'exemplary'. It was felt that the expansion of the "Share the Care" service would give people an alternative and allow service users to be cared for in a family environment with the benefits of a trained and approved carer. One respondent however felt they would not be happy to go to a 'stranger's house'.

It was recommended that the Trust should engage with other Trusts to explore the possibility of running a joint recruitment campaign for this service to help to share recruitment costs and reach potential carers.

One respondent noted that the Share the Care Service is not currently available in the Antrim and Newtownabbey area and said they would support its further development. The development of this service across the Trust was supported but it was suggested that there is 'not enough involvement with parents and families'.

Trust response

As indicated above the Trust agrees that we should seek to develop Share the Care as an option for those with more complex needs and challenging behaviours. It is our experience that recruitment is best done locally and through local networks of people who are committed to caring for and supporting individuals with a learning disability. The first phase of Take-A-Break implementation includes the roll out of Share the Care in the South Antrim and Newtownabbey area.

Things to do during the day

All of the respondents agreed that the Trust should provide provide short breaks which include things to do during the day. A number of suggestions were made such as cinema, bowling, shopping, drama and arts and crafts. It was felt that this would be beneficial at the weekends

While respondents felt activities were important there was concern that adequate resources would not be available to support this and some respondents indicated that they are content with what is in place at the adult centre. It was felt that the provision of short break services that include day activities so that people will not have to attend their day care centre should not affect or jeopardise regular day care placements and a commitment should be given to individuals and families to state this.

Trust response

Take-A-Break recognises the importance of providing an enjoyable break for the person with a learning disability. It is believed that extending choice and variety in the types of short breaks will contribute positively to this aim.

The provision of short break services that include day activities will not affect or jeopardise regular day care placements.

Working with people with learning disabilities and families to improve services

All of the respondents agreed that we should work with a group of people with learning disabilities and families to improve our short break services.

It was felt that families should be included at all times and service users should be central to the ongoing review and development of the service.

It was suggested that the Trust and the 'reference group' should explore other models of short break provision available in other areas and ask existing

providers to present to the reference group on their respective model - a budget to pilot new initiatives should be established for this purpose.

There was some concern if the Trust had involved families and services users in a previous review and it was felt that the service has not changed.

It was also asked that the Trust should be 'more explicit and proactive' in getting the views of users and carers who have used short breaks. It was suggested that the Trust listen to the views of Share the Care family carers particularly in relation to the support they need to continue to care.

There was a query about who will be in this group and how people will be selected and that a service user/patient forum would be a welcome method of reviewing short break services.

Trust response

The Trust will establish a reference group involving families, service users and include volunteers who provide the Share the Care service. The group will promote oversee and advise the implementation of Take-A-Break and the involvement of the group will be a fundamental and core element of taking the review recommendations forward. We are committed to an open and transparent process of inviting service users and carers to participate in the group.

Informing people who plan services

All of the respondents agreed that the Trust should make sure that people who plan services in Northern Ireland know that there is a need for more short break services. It was suggested that the Department of Health should further develop and expand the provision of flexible short break services regionally.

There was concern that too many people need the service and 'not enough places' are available and it was suggested that more facilities and care is required to meet the huge demand, along with more funding. It was suggested that as funding is always limited 'a strict criteria' should be applied to ensure that those most in need benefit.

It was suggested that planners are already aware of the need for more short breaks and they should be told 'as long as they listen'.

It was felt that service planning and commissioning decisions needed to be supported by improved information systems that record of unmet need and can provide robust evidence.

It was proposed that the "Share the Care" model should be shared with other programmes of care and that there is potential to establish this model in older people to support home from hospital.

Trust response

Take-A-Break recognises that services are under increasing pressure as the population of people with a learning disability continues to grow with a consequent increased need and demand for access to short breaks. The key purpose of the Take-A-Break review is to ensure that services are appropriately targeted and developed against levels of assessed needs.

The Trust will share copy of its final report with Commissioners and the Department of Health to highlight demand for short breaks to meet the growing need of service users and carers.

Further Comments

- Transport should be provided to and from the 'respite' centre.
- 'Units' are covering too wide an area and more should be provided.
- More short breaks should be provided rather than spreading what is available 'thinner'.
- Service which needs to be expanded for younger people
- Day opportunities are of no benefit as the clients have to be transported by parents/ carers to their day time placement.
- The approach to develop short breaks in partnership is very positive

- Agreement with the different aspects to develop to address a range of choices and needs.
- Emphasis on good information and involvement is welcome.

Trust response

The Trust does not routinely provide transport from respite or short break centres but we will continue to work with partners to identify local solutions to help with individual transport issues as these are raised.

The Trust is committed to developing a range of short break services included the development of our Share the Care service.

Take-A-Break envisages the development of local services to ensure that people with challenging behaviour do not have to travel so far to access short break services.

Summary of key issues raised during independent consultation meeting with service users and carers

- Adequate resources are required to support the review recommendations
- Some participants felt they had not been involved in or aware of the Review
- Concern that health services and education are not 'marrying up'
- Don't want a one size fits all service, people want choice
- Lack of provision during holiday periods
- Quality of life is important for families
- Communication between Trust and service users/carers can sometimes be poor
- Regular contact with social worker important
- Not all 'respite' can be planned
- Share the Care is not available everywhere and not enough information available on where it is available
- Services users indicated they would 'like to stay in someone's house' but some said they would like it for a few hours rather than an overnight stay.

- Concerns that children/adults with challenging behaviour will not be able to access Share the Care if they have challenging behaviour
- Share the Care is good idea but some concerns about safety of adults/young people
- Homes who take part in share the care are not always adapted for physical disabilities
- View that share the care more appropriate for younger people
- Not everyone aware of self-directed support
- View that self-directed support is 'not for everyone'
- Concern about responsibilities associated self-directed support
- Some people have to travel quite a distance for 'respite'
- Transport to 'respite' has been lost/cut
- Query why existing facilities are not being developed
- View expressed that some families are not turning up 'respite'
- Concern that while there is continuing demand for 'respite', beds in Ellis Court were removed due to 'cuts' and offices created for social services
- Activities are available at building based respite which is positive
- View that some people need more help than others for example at meal times and with transport
- Self-directed support described this as 'do it yourself'
- Suggestion that an 'approved list' should be provided to people for self-directed support

Trust response

The Trust seeks to accommodate people's wishes but it is difficult to facilitate the demand for short breaks over holiday periods. The Trust will work to increase the range of short breaks that can be accessed during holiday periods through the Share the Care model.

It is important to note that the beds reduced in Ellis Court were residential beds reprovided in Abbots Court as supported living tenancies. The number of respite beds in Ellis Court was not reduced.

The Trust will consider the potential for developing Share the Care for people with more complex needs and challenging behaviours.

Written responses were received from the following.

Louise Skelly, Patient Client Council
Iris Smyth, Individual
Frances Bradley, Individual
Sean Oboyle, Individual
Leah Junkin, Individual
Alison Keenan, Antrim & Newtownabbey Council
Paddy and Tony OKane, Individuals
Eunice O'Neil, Individual
Claire Knox, Individual
Mary McEldowney, Individual
Jack Johnston, Individual
Keith Buchanan, MLA NI Assembly for Mid Ulster
Patricia Donaghy, Individual
Lauren Walls, Parenting NI
Lauren McMew, Individual
Scott Hawthorne, Individual
Daphane McClelland, Individual
Mark Gregg, Individual
Aaron Cahoon, Individual
Ian Reid, Individual
Tim Parr, Positive Futures
Eileen Thomson, The Cedar Foundation
Frank Johnston, Shared Lives Plus
Eithne Darragh, Health & Social Care Board
Meta McAleese, Individual
Geraldine McGurk, MENCAP
Nigel Hampton, Enable
Fidelma Ohagan, Law Centre
Linda McKendry, Compass Advocacy Network
Philip Parkinson, Individual
Jimmy Moore, Individual
Katie Davidson, Individual
Stefan Clarke, Individual
Hayley Allen, Individual
Adam Martin, Individual

We want to thank everyone who took the time to be part of this consultation, either through attending one of the consultation meetings or by writing or filling in a consultation form.

Alternative formats

This document can be made available, upon request, in other formats including Braille, large print, computer disk, audio tape or in another language for anyone not fluent in English. For alternative formats please contact:

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