# Leicester City Learning Disability Social Care and Health Short Break Strategy 2009 to 2012



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#### 1. Foreword

'The best short break gives a break to the carer AND gives a break to the person who needs support and care. The best short breaks benefit everyone.'- A Guide to Short Breaks, Paradigm

The Leicester City Short Breaks Strategy for social care and health is a three year plan to develop short breaks that are safe, meet the needs of people who use services, provide them with new opportunities, are sustainable, and are services that Leicester can be proud of.

'One Leicester' is our ambitious strategy that forms the foundation for the changes that the Council, and its partners, want to see in Leicester over the next twenty-five years. This strategy supports the 'One Leicester' value; better support for carers.

#### One Leicester - Better support for carers

"We will provide better support, advice and information to the many carers in Leicester, recognising the valuable role they play in supporting older and vulnerable people."

To do this we will make sure we involve our users of services, and their families, in the journey as equal partners in shaping our future short break service models. We would like to thank all those who were, and continue to be involved in planning, designing and monitoring our new services. Special thanks go to the families and people with learning disabilities who have given up valuable time to co produce and implement this short break strategy from the very beginning.

Quote

Councillor Rory Palmer
Cabinet Lead - Adults and Communities

Quote

Vikki Taylor

Director Strategy and Market Management, NHS

**Leicester City** 

Quote

Stephanie Chapman, Chair - Carers Action Group Leicester City Learning Disability Partnership Board

'Carers and people with learning disabilities both need a break. We need to make sure we get it right, especially for people who can't speak up for themselves'

We Think - Self Advocates Leicester City Learning Disability Partnership Board



## 2. Easy Read Summary

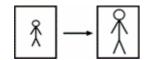
## Leicester City Learning Disabilities Short Breaks Big Plan

OUR SHORT BREAKS	Short breaks used to be called respite care. The name was changed because we wanted everyone to think differently about how people with learning disabilities had time away from their families.
POLICY Y)  RISK RISK RISK RISK RISK RISK RISK RIS	Lots of big plans and reports say that the way people with learning disabilities and their families have breaks from each other needs to change.
0.00	Valuing People Now and the National Carers Strategy also say things should change.
	This is the Leicester City Learning Disability Short Breaks Big Plan. The plan will last for 3 years.
	The Law says health services and councils should work together to meet the needs of carers.
1/100	People with learning disabilities, family carers and staff from Leicestershire and Rutland County Councils and NHS Health Services helped us to write this big plan.
දරිට	In Leicester City we know that:
Leicester City Council	The number of younger people with learning disabilities is growing.
NHS Leicester City	There are more younger people with high support needs.
	There are more younger people with learning disabilities who come from

Black or Asian families and some new communities. Many people with learning disabilities live with older family carers. Only 1 person out of every 3 people who live with their family uses short break services. We need to make sure that there are enough short breaks for everyone. We need to make sure short breaks meet everyone's needs. At the moment people get their short breaks from either social services or health services: Most people have their short break in a residential home. Some people have a health short break in a health home Some people stay with another family. Some people have someone come to the house to sit with them, or take them out. Some people have to move away from where they live to get a short break. Some people have a flexible short break. This means they do different things in the community People with learning disabilities and family carers have been helping us to think about the Big Plan. Health and social services staff from

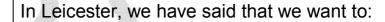
	Leicester, Leicestershire and Rutland asked lots of people what they wanted from short breaks.
	These are some of the things people have said are important:
	<ul> <li>Short breaks should be fun and enjoyable</li> </ul>
	<ul> <li>There should be opportunities to do new and different things</li> </ul>
•••	They should be easy to get, especially in an emergency
	<ul> <li>They should be available anytime, day or night</li> </ul>
	There should be more choice about breaks
	People would like holiday type breaks
	The Big Plan says that:
	Health services and social services will work together to provide short breaks
1/1000	<ul> <li>Emergency short breaks will be available 24 hours a day and 7 days a week</li> </ul>
	<ul> <li>Short break services will be Person Centred</li> </ul>
	Short breaks should meet the needs of people with learning disabilities as well as their carers
	Short breaks will meet peoples cultural needs







- Short breaks for people who challenge services will be better
- People's health needs will be met wherever they are staying
- Short breaks for young people will work together with short breaks for adults, so there will be less change when people turn 18
- There will be easy information about short breaks
- The rules about how people get short breaks will be the same
- Some people might have to pay towards the cost of their short break
- The rules will be easier to understand.



- Make it easier for people to stay with another family as a short break
- Have a service that can provide emergency short breaks
- Make sure that people from all of our different communities can have short breaks that meet their needs
- Make sure that people can still have their health looked after, no matter where they go for their short break
- Help people to use direct payments or individual budgets to have more choice and control over their breaks. At the





moment direct payments cannot be used to pay for health tasks There is no new money to do all the things we want to do. We need to use the money we have in a better way, to help carers and people with learning disabilities have better lives. For example, using Shared Lives (where you stay with another family) costs less than staying in a residential home. We can make better use of our money if we do more of this. We can work with services in the community, like leisure centres, to make sure they can meet the needs of people with learning disabilities. People can also ask for money from places like the Independent Living Fund (ILF). This money can be used to pay for the care support to help people do different things, like go on holiday. There will be an action plan that says how we will make the plan happen, when it needs to be done by, and who will do it.

The Learning Disability Partnership Board

and the Commissioning Board will get reports telling them if the actions are

Staff from health and from social care,

will report this to the Partnership Board.

carers and people with learning disabilities will check if the actions are happening. They

happening.

#### 3. Executive Summary

#### 1 Introduction

'A carer spends a significant proportion of their life providing unpaid support to family or potentially friends.' – National Carers Strategy - Carers at the heart of 21st-century families and communities

We know, from what adults with learning disabilities and family carers have told us that short breaks help to support family carers and help people living with their families to get a break and have better lives. Both national and local research and consultation shows that many people are not getting either the quality, or the right amount of short breaks to meet their needs.

National studies have shown that there are increased levels of stress, ill health and mental health problems in those people who undertake a caring role. The lack of adequate short breaks can lead to a later need for more intensive and costly support over a longer time. Investment in good short breaks is both responsible and cost effective in the longer term.

We believe that it is important to both consider a carer's outside interests, for example work, study or leisure, when carrying out an assessment and to try to find better joint working between the council and health service to ensure support for carers is delivered coherently. This duty is set out in legislation in The Carers Act – 2004. This has been acknowledged in the National Carers Strategy by the Government committing £150 million in new funding, allocated to the Primary Care Trusts, to work with Councils in order to double support for respite care by 2010.

Leicester City, Leicestershire and Rutland Learning Disability Partnership Boards, along with the Councils and Primary Care Trusts have carried out a complete review of their strategy and approach for offering and providing short breaks because we know what is currently provided is not adequate and does not meet the needs of all our diverse communities.

This strategy sets out our commissioning plans for the provision of health and social care short breaks for adults with learning disabilities and their family carers for whom Leicester City Council has a statutory responsibility to support.

#### 2 Strategic context

The Leicester City Learning Disability Short Breaks Strategy and delivery plan has been produced in partnership with key stakeholders to reflect the priorities in 'Valuing People Now', 'the 'National Carers Strategy' and a range of related legislative and policy documents as set out in Section 4 of the full strategy.

#### 3 Approach

We believe carers should have the opportunities and space they need to participate in activities outside their caring role and they should be free to have an identity that is separate from that of the people they support.

People with learning disabilities should have the opportunities and space they need to enhance their independence, participation in community activities and form relationships and friendships outside of their circle of care.

This strategy recognises the ongoing challenges in identifying and commissioning short breaks that are safe and value for money in a market that has limited capacity and has not been fully explored or developed.

Leicester City commissioners in Partnership with Leicestershire and Rutland County Councils, Leicestershire Partnership NHS Trust, service providers, carers and adults with learning disabilities aim to address this by developing:

- Clear information about short breaks, their availability, eligibility and costs
- Models of service that are good quality, safe and offer more choice and flexibility
- Emergency short break provision that is adequate and responsive
- Capacity of all short break services to meet the needs of Leicester's different communities and people with high support needs
- Community health services that can support people wherever they receive their break
- Individual Budgets and Direct Payments to promote choice and control
- Creative and innovative person centred approaches to short breaks

#### 4 Issues in Leicester

About a third of all people living with family members currently access short break (or respite) services and an increasing number of family members are elderly and may themselves require increased care and support. This has significant implications for both the needs of the carer and long term planning for the future support needs of individuals that currently live with elderly relatives.

Currently approximately 40% of people living with family carers are from Black and Minority Ethnic (BME) communities and it is anticipated that this number will rise, as younger people from BME communities become adults. Leicester has a higher than national average of younger people from the South Asian Community who will transfer to adult services.

Leicester also has a higher than national average of people with learning disabilities with high support needs and again the number of young people with complex health and social care needs who will transfer to adult services is also increasing.

#### 5 Current position and financial sustainability

Short break services in Leicester City are provided in accordance with the criteria of "fair access to care", this means people have a baseline assessment of whether or not they are identified as having a learning disability and their level of need from this. The current access criterion for social care services in Leicester is that a person must have an assessed IQ of 70 or lower plus a critical or substantial need. However this criterion may not be the same for people accessing health short breaks or short breaks from our neighbour Local Authorities.

During 2008/09, 17% of all adults with a learning disability who were known to the Council received one or more short break services from a City Council 'in house service', the health service, independent homes and a flexible community based short break service.

Figures show an overall increase in number of respite days provided over the last three years, but with the number of stays per service user reducing and the length of stay of episodes increasing.

Leicester City gross projected expenditure for 2009/10 for learning disabilities short breaks shows the significant increases in expenditure since 2007/08.

Learning City Council Learning Disability Short Break Expenditure			
2007/08	2008/09	2009/10 (forecast)	
585,686	748,679	758,972	
NHS Leicester Cit	y Learning Disability Sh	ort Breaks Budget	
1,294,762	1,324,541	1,347,058	
Total Leicester City Learning Disability Short Break Expenditure			
£1,880,448	£2,073,220	£2,106,030	

The increased expenditure on services must be considered and this means new services that meet personalisation values will be critical in achieving both positive outcomes for people with learning disabilities and family carers and to deliver quality short breaks within limited resources.

Currently around 80% of service users receiving short breaks also receive day care services. There needs to be an improved variety of services offering greater choice and flexibility, including breaks at home, the provision of equipment or adaptations to facilitate respite, access to mainstream and community based activities, befriending groups and the expansion of 'Shared Lives' services and self directed support.

#### 6 Governance: Measuring progress and implementation

A Strategic Implementation Group, which will report to the Learning Disability Partnership Board and the Commissioning Board, will be established to monitor the progress and development of the strategy and the Delivery Plan. The Group will set outcome measures and receive regular progress reports as well as help to identify resources and overcome problems.

#### 7 What the strategy and the delivery plan will do

In order to achieve the new ways of working a number of task and finish groups will be set up to lead on and implement key areas of work within the delivery. The groups will work on the 'here and now' and what we need to develop for the future. Task groups will look at:

- Eligibility, Assessments and Pathways
- People with Complex Health Needs
- People who Challenge
- People with complex physical needs
- People from BME Communities
- Community based short breaks
- Building based short breaks
- Emergency Breaks
- Sitting, Befriending and Home Care Redesign
- Self Directed Support
- National and Local Best practice models
- An Approved Provider Framework (Guide)
- Finance and data collection/sharing
- Information
- Support, advocacy and brokerage for people with learning disabilities and carers

#### 8 Acknowledgments

The Learning Disability Strategic Commissioning Service in Leicester has produced this strategy in partnership with:

- Adults with learning disabilities and family carers,
- Leicester City Learning Disability Partnership Board,
- Children and Young People Services,
- NHS Leicester City,
- Leicestershire Partnership NHS Trust,
- Leicestershire County Council
- Rutland County Council

#### Leicester City Learning Disability Short Breaks Strategy

#### 1. Aims

Family carers are often lifelong carers retaining responsibility for caring and decision making beyond childhood. Adults with learning disabilities are generally not given the opportunity to share the same life experiences as the rest of society. Our aim is to deliver short break services that reflect the needs of carers and the needs of the people they care for.

#### 2. Objectives

We want to make it easier for carers to get the information and short break services they need when they need them, promote independence for carers and the person being cared for and make short breaks a valuable and enjoyable experience for both the adult with the learning disability and the family carers:

- Develop clear information about short breaks, their availability, eligibility and costs that will enable families to exercise their rights and make informed choices
- Develop person centred models of service that are good quality, safe and offer more choice and flexibility ensuring that the needs of families and the person with a learning disability are met
- Ensure emergency short break provision is adequate and responsive in order to safeguard the person with a learning disability
- Increase the capacity of all short break services to meet the needs of Leicester's different communities and people with high support needs in order to maintain the health and well being of individuals and their families
- Develop specialist community health services that can support people with their health needs in whatever form of short term break service they choose to use
- Promote the use of Individual Budgets and Direct Payments so that people can choose how and where they receive their short break
- Develop advocacy, support and brokerage services with the right skills and knowledge to help both carers and people with learning disabilities who choose a Direct Payment or Individual Budget
- Support providers, commissioners and people using the services to develop creative new approaches to short breaks to give people opportunities to experience and learn new things

## 3. What the strategy will deliver

Where we are now	What the strategy will deliver
Strategy	Clarity about what is a short break
Understanding of local issues and needs	Services that meet the needs of our diverse communities
Proposed new ways of working	Better planned and coordinated services
	Commission and procure new models of services to provide more choice
Models of Service Independent sector building based breaks	Flexible community based health and social care short breaks
Health building based breaks	Specific emergency short break services
Shared Lives (Adult Placement)	Expansion of Shared Lives Service
Community Opportunities (Day Services)	Refocus and redesign of building based short breaks
Direct payments	Home based support in and outside of the family home
	Holidays with staff support
	Hotel type building based or sitting services
Information Information is not available in easy read	Easy Read information about short breaks
format	Person centred assessments and reviews with clear outcomes
Carers and people with learning disabilities often do not always understand their assessment	Clear understanding of what short breaks are available
Not enough information about what is available	Clear eligibility criteria so families know if they are entitled to a short break
Eligibility and charging criteria is different in social care and health	Clear information about charges for short breaks and the way this is worked out
Self Directed Support	30% of all people receiving short break services exercising
A limited amount of people using self directed support to purchase flexible respite	their choice and control via Direct Payments and Individual Budgets
Limited choice and capacity of service	Services designed to meet the needs of customers
provision	Shaping the market to create innovative opportunities for people to learn and experience new things
Health	Redesign of health short breaks in line with Personalisation
Building based health short break provision	Define the difference between specialist healthcare support and healthcare that can be provided in social care settings,
	then commission accordingly
	Community based health services that support people wherever they have a break
	Health support available as and when necessary
Equality and Diversity	Some specialist services
Limited short break provision and expertise for people who challenge services	Experienced well trained staff who can meet specific needs wherever the short break is provided
Services that do not necessarily meet the cultural needs of our communities	An expansion of the Shared Lives Service and home based short breaks

#### 4. Partnership approach

Making sure we have good, safe, sustainable short break services that meet the needs of adults with learning disabilities and their family carers is a key priority for a range of agencies and the people who use our services, including Leicester City Council, NHS Leicester City, Leicestershire Partnership NHS Trust, Leicestershire and Rutland County Councils, adults with learning disabilities and family carers.

Leicester City Learning Disability Partnership Board and the Commissioning Board were charged with overseeing and monitoring the review and development of short break provision. In order to carry out the work a steering group was set up to:

- Understand the core needs of Service Users and Carers
- Review the current Short-Breaks provision
- Develop a Short-Breaks Strategy in partnership with all stakeholders
- Support the development of a cross boundary, quality Short-breaks strategy in partnership with Leicester Partnership NHS Trust, Leicestershire and Rutland Councils
- Develop a broad and imaginative range of quality short break services in order to meet the health and social care needs of adults with learning disabilities and their parents/family carers

The Steering group comprises of representatives from Leicester City Council, NHS Leicester City, Leicestershire Partnership NHS Trust, CLASP the Carers Centre, Ansaar's Asian Carers Project and the Carers Action Group.

#### 5. Key strategic links, policies and guidance

- **5.1** The Short Breaks Strategy has been informed by 'Valuing People Now From progress to transformation, 2009' and a number of supporting key plans, strategies and targets:
  - Human Rights Act, 1998
  - Valuing People A New Strategy for Learning Disability for the 21st Century, 2001
  - The Carers (Equal Opportunities) Act, 2004
  - Our Health Our Care Our Say A new direction for community services, 2006
  - Green Paper on Welfare Reform Department of Work and Pensions, 2006
  - Putting People First A shared vision and commitment to the transformation of Adult Social Care, 2007
  - Paradigm A Guide to Short Breaks, 2007
  - World Class Commissioning Transforming the way the NHS commission health and social care services, 2007
  - Mansell 2 Services for people with learning disabilities whose

- behaviour present a challenge, 2007
- Progression Through Partnership Department for Children, Schools and Families, 2007
- A life like any other, 2007
- Aiming High for Disabled Children Transforming services for disabled children and their families, 2008
- One Leicester Shaping Britain's Sustainable City, 2008
- National Carers Strategy Carers at the heart of 21st century families and communities: a caring system on your side, a life of your own, 2008
- NHS Next Stage Review and 2012 Vision Modernising Leicestershire Partnership NHS Trusts provision and services, 2008
- Healthcare for All An independent inquiry into access to good healthcare services for people with Learning Disabilities, 2008
- Independent Living Strategy Cross government strategy for all disabled people, 2008
- Leicester Carers Strategy Identify the need to support carers to have a break and the opportunity to access employment and learning, 2009
- Six Lives The provision of public services to people with learning disabilities, 2009
- Improving the Health and Wellbeing of People with Learning Disabilities
   World Class Commissioning, 2009
- **5.2** A key priority is to ensure that the strategy and delivery plan link to the National Indicator Set and Leicester's Local Area Agreement upon which the effectiveness of Local Authorities are measured. The key priorities that link to the short break strategy are:
  - NI 119 Self reported measure of peoples overall health and wellbeing
  - NI 133 Timeliness of social care packages following assessment
  - NI 135 Carers receiving needs assessment or review and a specific carer's service, or advice and information
  - NI 136 People supported to live independently through social services
  - NI 139 The extent to which older people receive the support they need to live independently at home
  - NI 140 Fair treatment by local services
  - NI 141 Vulnerable people achieving independent living
  - NI 142 Vulnerable people who are supported to maintain independent living
  - NI 145 Adults with learning disabilities in settled accommodation
  - NI 146 Adults with learning disabilities in employment
- 5.3 The seven key outcomes from "Our Health, Our Care, and Our Say" also provide an approach to measuring the outcomes for people receiving short break services:
  - Improve health and emotional wellbeing
  - Improve quality of life
  - Support adults in making a positive contribution

- Make a commitment to providing greater choice and control
- Ensure freedom from discrimination
- Improve economic wellbeing
- Promote personal dignity

#### 6. Involvement and what people have told us

Carers and people with learning disabilities have been, and continue to be, involved in the review and development of short breaks in Leicester City. This has mostly been done via questionnaires and face-to-face meetings. There are three carer representatives on the City Council Short Breaks Review and Implementation Group.

#### 6.1 Consultation with parents and carers

- Carers Action Group
- Ansaar Asian Carers Project
- Jyoti Group Asian Carers Support Group
- Carers of people using day services
- Carers of people using NHS short breaks

Short breaks are essential in order to help carers maintain both their physical and mental well being, thus enabling them to continue in their caring role.

Carers value a short break as an opportunity to have a complete break from their caring responsibilities. It is also an opportunity for carers to spend quality time with other family members and do ordinary things like go shopping or visit friends.

However it is vital for them to know their loved one is safe and being well cared for, this is particularly the case for people with high support need and those that challenge services.

Carers consider a meaningful short break to be for at least 48 hours. There should be clear protocol in place for when things go wrong. Carers should not be expected to cut short their break.

There is an urgent need for flexible emergency short breaks services that can respond quickly and efficiently.

Supported holiday short breaks for the person with a learning disability would also be welcome.

Of those carers who currently access short break services satisfaction rates are significantly higher for White British carers.

Some of the reasons carers do not access short breaks are:

- There is insufficient information about what short breaks are, what is available, how to go about arranging a short break and eligibility
- BME carers in particular look to their friends and family for support
- Carers try and manage for as long as possible as they do not want to be seen as shirking responsibility
- The person with a learning disability refusing to go anywhere overnight.

When asked to give their preference in relation to current short break provison the order in which carers rated the importance of short break services was:

1st - buildings based 2nd - home based 3rd - Shared Lives

This was then further broken down into preferences between white and BME carers, showing that both groups rated building based services as very important, but the Shared Lives service and in particular home based services were given a higher rating by carers from BME communities.

#### 6.2 Consultation with adults with learning disabilities

- We Think Self advocates with learning disabilities
- Bright Lights Self advocates with learning disabilities
- Ansaar Culturally appropriate services for adults with learning disabilities
- People who use day services

It is important for people with learning disabilities to get an enjoyable break from their families. It is just as important for parents and carers to have a break from caring. However people would like to have a choice about where they go for a break.

People with learning disabilities would like to be able to go on holiday on their own or with a group of friends. They enjoy going on trips and visiting new places. Short breaks should include helping people to make new friends, do different things and learn new skills. Short breaks can also be a way of helping people with learning disabilities to prepare for supported living.

Direct payments could be used to pay for different short breaks, for example accessing services at weekends and in the evenings or paying for support to use ordinary community services such as the leisure centre.

Some of the reasons people with learning disabilities may not access short breaks are:

- There is not enough information about what short breaks are and what sort of break people can have
- People miss their families
- The support is not always good

 People with learning disabilities do not have enough choice and control over short breaks

#### 6.3 Consultation with children and young people and their families

Consultation carried out by Children's and Young Peoples Services shows that whilst some building based short break availability is important, young people and their families want access to a range of community activities and options.

These include after school, weekend and non-term time activities as well as holidays as a family. One example being explored is the possibility of purchasing two motor homes for families to go on short holidays. The family would stay in one motor home and the support in the other.

#### 6.4 Summary of key messages

Short breaks are important to both carers and people with learning disabilities. In developing a model of service some of the key messages that need addressing are:

- Information Families and people with learning disabilities, care managers and social workers all need up to date, accessible information about short breaks options and how to access and arrange short breaks
- Transparency Families and staff should have a clear understanding of assessment, eligibility criteria and paying for services
- Training Staff need regular training to help them in their roles and to understand the needs of the diverse communities in Leicester
- Emergency Short Breaks Families need assurance that their loved one will be taken care of in case of illness or in a crisis
- Shared Lives Service (Adult Placement) Expansion of the service and recruitment of paid carers from different communities
- Menu There needs to be a range of services and options available to suit individual needs
- People with high support needs People need to be safe and happy in a suitable environment with the right support and equipment
- Funding clarity about benefit entitlement and rules around the use of ILF
- Personalised budgets clarity about how individual budgets and direct payments can be used in social care and in health

#### 7. Current provision and issues

Local intelligence together with prevalence rates for learning disabilities suggest that approximately 6000 adults with learning disabilities live in Leicester City:

- Around 1600 people receive support or are known to Health and/or Social Care services. Around 700 of these individuals live with their families in the family home.
- Around 900 people are known to Adult Social Care Services. Around 450 of these adults live with family carers.

This suggests there are a significant amount of people who are not known to services, but may become eligible for services in the future. There are also a number of people already known to services that may need to access short breaks as they get older and their needs, and the needs of their carers, change.

**7.1** Short breaks are a planned service, offered after a Community Care Assessment has been carried out on the service user or in some cases a Carers Assessment has been carried out to understand the needs of the carer.

Sometimes short breaks have to be used in an emergency. This will be unplanned care or care required in a crisis, but it should be easy to get at any time. The Adult Social Care Emergency Duty Team are contactable at any time of the day or night and will always try and place the person with a service they have used before. However, as there is no specific emergency short break service and as there are no allocated emergency beds in health or social care within existing services, this is not always possible.

2070 emergency bed nights were provided during 2008 and 2009. This was mainly as a result of safeguarding, although some was to cater for general issues such as poor ill health of the carer.

Just over a third of adults with learning disabilities who live with family carers currently access any short break services. This includes an increasing number of people who live with family members who are elderly and may themselves require additional care and support.

Age of Carers Accessing Short Break Services			
Age Range	Percentage of Carers		
30 – 39	1%		
40 – 49	12%		
50 – 59	18%		
60 – 69	23%		
70 – 79	10%		
80 – 89	5%		
90 +	1%		
No age given	30%		

#### 7.2 Presently, short break services are arranged in two main ways:

- Services that are directly provided by the councils or are commissioned from independent and third sector organisations
- A health service that is provided by Leicestershire Partnership NHS
   Trust and is available to people with learning disabilities from all three
   Local Authority areas

At the moment the referral process, ways of arranging breaks and the eligibility criteria for short breaks that are arranged or provided by the Local Authorities and those that are provided by Leicestershire Partnership NHS Trust are different. Also Local Authorities are able to ask service users to make a contribution towards the cost of their care, whereas the NHS cannot.

The inconsistency in processes and systems make it even more difficult for carers to understand what they are entitled to and how to go about arranging and accessing short break services.

**7.3** The range of services provided in Leicester City in recent years that give the person with a learning disability and their family carers the chance to have a break from one another include overnight stays in a registered Local Authority home, independent sector residential care homes, in NHS homes and in Shared Lives (Adult Placement) Schemes.

The average capacity of Short Break services utilisation is 71%. This is largely due to the compatibility of people accessing the services. Leicester City uses 60% of Leicestershire Partnership NHS Trust short break services, even though it is responsible for only 38% of the total learning disability population across Leicester, Leicestershire and Rutland who are known to health or social care services.

There are also some more flexible, community based services that can either support people in their own family homes to allow carers to go away, or support people with learning disabilities to take part in activities outside the family home.

People with learning disabilities and carers also have the option of arranging and paying for short term break services for themselves using Direct Payments or Individual Budgets. Following a community care assessment, a sum of money can be allocated which people can use to purchase services of their choosing that meets their assessed needs. Currently, 11 people are using all or part of their Direct Payments funding to purchase respite or sitting services.

We should also acknowledge that many of the day or community services provided for people with learning disabilities also have a valuable "respite" function for both them and their family carers. The majority of people who access short breaks services also use day services.

**7.4** The following table relates to the Short Breaks costs for individual packages for 2008 to 2009 within Leicester City Council's Learning Disability Pooled Budget.

Supplier	2007 – 2008	2008 – 2009	2009 – 2010 (forecast)	Users 2008 - 2009	Current Banding
Shared					
Lives	22,696	19,852	35,200	10	£285
Leicester City Council	112,550	125,701	0	48	£544
Private	364,836	455,851	533,735	17	£351
Total	407,384	601,404	568,935	75	
Flexible					£14,33
Respite	65,872	86,247	81,804	33	per hour
Direct					
Payments	19,732	61,029	95,826	11	
TOTALS	585,686	748,679	758,972	157	

The NHS contribution is based upon the contribution of each partner to the Pooled Budget as per the financial protocol of the Section 75 Lead Commissioning Agreement.

The Council commissions NHS short breaks on behalf of the Primary Care Trust via the Pooled Budget. This needs further work to understand the contribution the NHS makes via the Pooled Budget. Service users are not currently charged for NHS short breaks.

NHS Leicester City Short Breaks Budget (Currently 38 users)			
2007/08	2007/08 2008/09 2009/10 (committed)		
1,294,762	1,324,541	1,347,058	

Leicestershire Partnership NHS Trust mainly provides NHS short breaks. The amounts quoted are for the entire NHS Short Break expenditure, includes the cost of maintaining buildings, paying staff and providing individual packages of care. This will need to be further broken down in order to understand the true cost in relation to city users, and therefore the potential implications for the City Council and the Primary Care Trust.

#### 7.5 Trends and future demands

Compared to the national picture, Leicester has a higher than average prevalence of learning disabilities.

Locally in line with national trends we have found that:

- Better health care is resulting in longer life expectancy, which in turn impacts on diagnosis of further health conditions
- People with learning disabilities are living longer which will significantly change the age profile of people we support over the next 15 years, including older carers who are caring for family members
- The number of people with a moderate to profound learning disability will continue to increase by 1.2% per annum with a greater prevalence amongst some South Asian communities. People with profound and multiple learning disabilities may require substantial support during the day and at night which has an impact on the families
- The number of young people with high support needs and young people with Autistic Spectrum Disorder is increasing which will require the retention and further development of some specialised services
- The number of carers who care for more than one person is increasing and there is the tendency to look at each caring situation in isolation, without taking account of the cumulative effect
- Increasingly, people with learning disabilities are providing regular and substantial care for their ageing relatives. Without proper support both parties are at risk of maintaining independent living
- The range of caring roles undertaken by young people is significant as it can have a dramatic impact on the overall aspects of the young person's life

Local research identifies a range of gaps in current service provision. This not only allows improvements to be made to current services, but also enables us to have a better understanding in order to shape future provision.

- There is a shortage of accessible residential/overnight provision for people with profound and multiple disabilities
- There is a shortage of residential/overnight provision for people whose behaviour can challenge services
- There is a limited range of services that can provide an emergency response
- There is a shortage of culturally appropriate services
- There is a limited range of options available for people wanting to use direct payments
- There is a limited choice of residential/overnight services
- The use of non-traditional types of provision such as holiday breaks has not been fully explored
- Some carers and some adults with learning disabilities like the services they are already receiving, for example building based short breaks are still the preferred option mainly for carers of White British origin who make up approximately 60% of all carers
- South Asian or Indian communities, which are the biggest group of people from BME Communities accessing services, expressed a clear preference for culturally appropriate Shared Lives services and care in the family home

 Carers using health short breaks value the service and have great trust and confidence in the staff

By 2012, Leicester is expected to be the first City, outside of London where the BME population will make up more than 50% of the total population. This is a key factor for consideration in the development or provision of any services in Leicester, as this trend is reflected in the local population of people with learning disabilities and their family carers.

Language and a lack of cultural knowledge, means that many short break services find it difficult to adequately meet the needs of people from BME Communities. This can lead to a lack of confidence and low usage of services.

Short Break Take Up by Ethnicity			
Ethnicity	Percentage of People		
White British	57%		
Asian or Asian British: Indian	25%		
Any Other Asian Background	5%		
Black or Black British: Caribbean	4%		
Dual Heritage: White and Black Caribbean	3%		
Asian or Asian British: Pakistani	2%		
Other White	2%		
White Irish	1%		
Any Other Dual Heritage	1%		

#### 7.6 What Carers want:

- Alongside the more traditional types of Short Breaks options, parents and family carers want the opportunity to explore and experience more innovative options
- Carers want quality services they can trust in and believe are safe
- Emergency Short Breaks and Day Provision are vital in addition to other short break services
- More culturally appropriate short breaks, particularly home based short breaks, to meet the needs of people from the BME Communities
- People with different needs, particularly people who challenge, should not be mixed

#### 7.7 What People with learning disabilities want:

- Direct Payments and Independent Living Funds to give people the ability to buy their own tailor made Short Breaks
- The ability to mix and match short break support packages

- Shared holidays with family, and with friends
- Some of the more traditional services like Community Opportunities and Building Based services
- Befriending Schemes as a way of socialising and having a short break
- Holiday type breaks away from the family

#### 7.8 Transitions

Over the next three years, the number of younger people with learning disabilities likely to be seeking support from Adult Social Care will be 126 in total.

The criteria and expectations in children's services are different to those of Adult Social Care. Not all young people currently receive a short break, so the exact number of young people who will require a short break is not known. Currently about 200 young people access some type of overnight or community based short break service.

We know that the number of young people from BME Communities who will become adults is increasing. 45% of all young people, who are expected to transfer to adult services over the next three years, are from a BME background.

The number of younger people with high support health and social care needs is also increasing. 30% of all young people, who are expected to transfer to adult services over the next three years, have complex health and social care needs.

At present 19 young people are expected to require some building based health and social care respite in the next three years. This includes 13 people with a profound multiple learning disability and 6 who present challenges to services.

#### 8. Future provision and where we want to be

- **8.1** All short breaks future provision will focus on individual outcomes and deliver flexible, person centred, services.
  - Day services and community care services built into an integrated support or care package for short breaks
  - Mainstream organisations and departments supported to build the capacity of community services such as library services, swimming pools, gyms and clubs to increase opportunities and support for short social and leisure breaks
  - Increased number of people experiencing real choice and control over the way they receive their short breaks through the use of individual budgets and direct payments

- In partnership with the independent and voluntary sector provide adequate and appropriate building based and flexible short breaks for people using self-directed support
- Health services meeting the needs of people with learning disabilities wherever they choose to access their short break
- Refocus and redesign of building based short breaks for those that need them to ensure good outcomes for individuals and their families
- A single point of access for all Short Breaks, and a service that meets both health and social care needs
- Clear and transparent eligibility criteria and a clear framework for asking for contributions towards the cost of care
- A range of "holiday type" short breaks locally, nationally and abroad
- An exchange scheme to operate across the country to encourage individuals to visit other parts of the country, whilst still being able to access a building that can support them
- Expansion of the Shared Lives scheme
- Expansion of flexible and home based services
- Identified emergency short break provision
- Commissioners to engage with people using services, and providers, to stimulate a change in the market and service options available
- Commissioners to contract and buy new services

#### 8.2 Areas for joint working

The joint review of Short Break services between Adult Social Care Services in Leicester, Leicestershire and Rutland, NHS Leicester City and Leicestershire Partnership NHS Trust identified a number of key areas in which partners can work together to make the best use of resources and achieve added value for people with learning disabilities and carers;

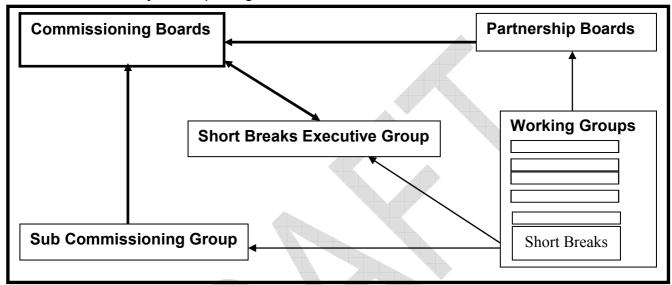
- Commissioning specialist learning disability health staff to provide a community based service to support other services across the Counties and the City. The aim is to ensure that health needs can be met in the community where people live
- Redesign of health short breaks to meet the personalisation agenda and be more outcome focussed
- Commissioning services that can respond to the needs of people with learning disabilities and carers, in emergency or crisis situations. These services form an essential part of a holistic range of support services for parent and family carers
- Commissioning Short Breaks to meet the needs of people from BME groups
- Clarity and consistency around carers assessments and the Decision Support Tool, this is a nationally used tool that determines if a person is eligible for NHS funding

#### 9. Governance

The Multi Agency Leicester City Learning Disability Partnership Board and the Commissioning Board will oversee the implementation of the Short Break Strategy.

A Strategic Implementation Group, which will report to both Boards, will monitor the progress and development of the strategy and the Delivery Plan. The Group will set outcome measures and receive regular progress reports as well as help to identify resources and overcome problems.

Accountability and reporting framework



#### 10. Evaluation

We will annually review the key delivery areas and evaluate the strategy, setting priorities for the future and ensuring the strategy priorities are fed into the annual planning and funding cycles of the Council and NHS. People using the service and our colleagues in the provider and commissioning sector will be integral in the measuring of progress in terms of planned service developments, and to evaluate the extent to which services are leading to better outcomes for people with learning disabilities and carers.

#### 11. Equality Impact Assessment

Carers, people with learning disabilities and professionals have all been involved in the Equality Impact Assessment of the strategy. A copy will be available on Leicester City Council's website and on the website of the Leicester Disability Information Network.

#### 12. Resource implications

Work streams that have been established to implement the strategy will identify resource implications that will need to be met within existing finance.

## 13. Leicester City Short Breaks Delivery Plan 2009 – 2013

### The Big Plan for short breaks

	Action	Outcome	Lead	Resource	Time-scale	
			Responsible	Implication		
1.	Identify the most effective and efficient way to	To have a range of	Commissioning	Identify and	Jan 10 to	
	deliver the existing and new Short Break	Short Break options to	Manager	resource funding	April 13	
	provision/options linking into the	enable people with		implications		
	Personalisation Agenda:	learning disabilities	With the support			
	<ul> <li>Scope and identifying providers that are</li> </ul>	and their family/parent	of:	Work force		
	able to deliver a range of short breaks	carers to have their	Carers	development		
	options	assessed and	CLASP			
	<ul> <li>Establish a system for market</li> </ul>	personalised short		Personalisation		
	intelligence	break outcomes met	People with	Agenda		
	Ensure the availability of information		learning			
	which is up to date and provides prices	To have a robust	disabilities	Increase use of		
	for the market, explore options for a	information network	PCT	Direct Payments/		
	database system and an information	available for short	Leicestershire	Individualised		
	network that are incorporated into the	breaks provision	Partnership	Budgets		
	transformation agenda for ASC and the		Trust			
	council, which ensure value for money	To ensure that		Data collection and		
	and assure commissioners that people	strategic intentions are	Adult Social	maintenance		
	will be safe.	actioned and there is	Care:			
		governance of the	Strategic			
2.	Commissioners to develop and shape the	delivery plans	Commissioning			
	market and develop personalised budgets for		Transformation			
	social care and in the future healthcare to		Team			
	support increased choice and control of short					

	breaks for the person	Providers
3.	Develop services based on evidence offering short breaks by developing the local workforce skills that are transferable into the various community and building based models of health and social care short breaks in the city	
4.	To develop options through personalisation and establish networks and brokerage systems that encourages people to share in funding flexible short breaks that can be provided wherever the people need it and at the time they want a short break	
	The Steering Group will lead on the delivery plan and monitor progress on the action plans and will report to the Executive Group, the Partnership Board and Commissioning Board.	

## Community based services and opportunities (Self Directed Support)

	Action	Outcome	Lead	Resource	Time-scale
			Responsible	Implication	
1.	To implement the action plans to create more	People accessing	Commissioning	Increase of Direct	Feb 10 to
	services and more choice, to ensure the new	Community services	Manager	payments	April 11
	service options offer:	and opportunities to	_		
	Support at home	enable them to have	With the support	Individualised	
	<ul> <li>Holiday options</li> </ul>	more choice in what	of:	budgets	

Bui	Ilding Based Short Breaks Services  Action	Outcome	Lead Responsible	Resource Implication	Time-scale
4.	To consult and engage users and carers in the development of new services and redesign of existing service options				
3.	Providers to be driven by the evidence based demands of needs identified by commissioners focused on the personalisation agenda				
2.	options     Clear eligibility criteria for short breaks  To stimulate the market place to offer health and social care short breaks that are of quality and are safe	health and social care needs of the people using the services	Adult Social Care: Strategic Commissioning Providers		
	<ul> <li>Increase in 'Shared Lives' models of support</li> <li>Day and evening time services available 7 days a week</li> <li>Increased access to community facilities</li> <li>To have access to the right support and equipment</li> <li>Culturally appropriate services</li> <li>Information available on what is available and how to access short break</li> </ul>	they do during the day and evening  Family carers to have flexibility of short breaks options in the Community  To have a range of options that meet both	Carers CLASP People with learning disabilities PCT Leicestershire Partnership Trust	Identify and resource funding implications to support carers	

1.	Move towards the personalisation agenda for	To develop and	Commissioning	The development	Feb 10-
	short breaks services	provide building based	Manager	of services will	March 11
		services that have		need to be within	
2.	Develop quality frameworks and	flexibility, choice, be	With the support	the total financial	
	competencies for health and social care short	safe and provide a	of:	envelope of	
	breaks	holistic approach both	Carers	existing building	
		for the person with a	CLASP	based services	
3.	Build upon the value base that carers have	learning disability and	People with		
	for existing health short breaks to ensure	their family/parent	learning		
	healthcare needs are provided safely	carers	disabilities	Identify and	
	wherever the person has short breaks		PCT	resource funding	
			Leicestershire	implications to	
4.	Redesign the existing Local Authority 'in	The service to enable	Partnership Trust	support carers	
	house' short break service (Beaumanor	empowerment and			
	House)	independence for the	Adult Social		
		person accessing the	Care:		
5.	Building based services to develop the	service.	Strategic		
	delivery of person centred provision enabling		Commissioning		April 11
	services to offer:	The service to fit into a	Transformation		delivery
	greater flexibility	personalisation and	Team		
	more choice for when people have a	brokerage model of	Beaumanor		
	break	commissioning	House		
	who they share the home with		Providers		
	who supports them		FIUVIUEIS		
6.	Task and finish group to consider the				
J.	following and ensure such demands are				
	where possible incorporated into new service				
	models:				
	Holiday experience by developing a				
			I	1	1

service similar to that of a hotel, where people accessing the service are was guests  Look to develop pre-arranged date include a specific service i.e. cultures specific or gender specific at certain times  Look at flexible short breaks, part of	to ly		
weekend services			

### **Health Provision**

	Action	Outcome	Lead	Resource	Time-scale
			Responsible	Implication	
1.	A joint Health and Social Care Task and	People's health needs	Commissioning	Outcome of Health	April 10 –
	Finish Group across LLR: to devise	are met regardless of	Manager	restructure	March 12
	healthcare models that support people in both	the type of Short		Reconfigure LPT	
	specialist services and in the community (a	Breaks Services they	With the support		
	model where the health needs of individuals	access.	of:		
	are met regardless of which short break		Carers	Identify and	
	option the person chooses). The models		CLASP	resource funding	
	should consider the following issues:		People with	implications to	
	The Personalisation Agenda		learning	support carers	
	<ul> <li>Types of health care models required in</li> </ul>		disabilities		
	order to meet need		PCT City and		
	<ul> <li>Emergency breaks – health support</li> </ul>		County	Plan services	
	<ul> <li>Accessing healthcare</li> </ul>		Leicestershire	developments into	
	<ul> <li>Action plan for moving away from</li> </ul>		Partnership Trust	the Local Authority	
	current model to new model			and PCT planning	
	<ul> <li>World Class commissioning Priorities in</li> </ul>		Adult Social	and financial cycles	

2.	Task and Finish Group to: Identify 'Health and Social Care Criteria Protocol for short breaks Protocol for Health staff to train Social Care staff on agreed and specific tasks and procedures for the individual whilst in short breaks To identify the possible options in short break models to ensure that carers healthcare needs can be met e.g. in order for carers to attend their own hospital appointments and screenings Link short breaks for the person and the carer to the Primary Care responsibilities of the PCT Plan for meeting needs of young people and their families coming through to adult services, in meeting both general healthcare and specialist health needs in any setting they choose to receive their short break  Links to the PCTs in order the short break	Care: Strategic Commissioning	for 2010 and beyond	
J.	strategy is included in the PCT strategic financial and planning cycles.			

	Action	Outcome	Lead Responsible	Resource Implication	Time-scale
1.	<ul> <li>A joint Health and Social Care Task and Finish Group: to:</li> <li>To have a common definition of emergency for short breaks</li> </ul>	For people with a learning disability and their family/parent carers to have access	Commissioning Manager With the support	Outcome of Health restructure Reconfigure LPT	Jan 10 – Sept 10
	<ul> <li>To research and recommend different types of service provision for short break emergencies</li> </ul>	to appropriate, emergency short break options that	of: Carers CLASP	Identify and resource funding implications to	Ongoing
	Explore what other areas nationally are developing to meet emergency need	meet both their health and social care needs	People with learning disabilities	support carers Plan services	Jan 10 –
2.	Leicester City Council transformation of ASC to build into the whole systems approach access to emergency short breaks for people with learning disabilities and their carers.		PCT City and County Leicestershire Partnership Trust	developments into the Local Authority and PCT planning and financial cycles for 2010 and	commissio ned by April 11
3.	To devise, implement and maintain a building based and/or community based healthcare emergency outreach service that provides short break support 24 hours 365 days a year wherever the emergency short break is being provided (e.g. home, acute hospital, Share Lives on holiday)		Adult Social Care: Strategic Commissioning Transformation Team Providers	beyond	
Val	ue for Money				
	Action	Outcome	Lead Responsible	Resource Implication	Time-scale

1.	To carry out initial finance scoping exercises that models of short breaks being considered	To ensure all service models options are	Commissioning Manager	Dependant on findings of these	Feb 10 December
	are affordable and could be delivered within the existing financial envelope	affordable	With the support	actions	11 and review
2.	All short breaks delivery plans across the health and social care community take consideration of financial implications and the task and finish group will check all plans do have recommendations included and will report this back to Executive Group.	Local Authorities and partners agree the recharging policy of short breaks across LLR	of: Carers CLASP People with learning disabilities PCT		plans
3.	Work stream specifically to establish a LLR recharge policy for social care short breaks		Adult Social Care: Finance Strategic Commissioning Transformation Team		Jan 10 – Jan 11

# Meeting the needs of Black Minority and Ethnic Communities (BME)

	Action	Outcome	Lead	Resource	Time-scale
			Responsible	Implication	
1.	All partners to consider the urban rural	The specific needs of	Commissioning	Identify and	Feb 10 –
	aspects of Leicester, Leicestershire and	people with learning	Manager	resource funding	Sept 10
	Rutland and how services can be delivered	disabilities and their		implications to	
	across the counties to ensure consistency	family/parent carers	With the support	support carers	
	and ensuring BME needs are met.	from the BME	of:		
	<ul> <li>consider gender</li> </ul>	communities are met	Carers		

	cultural/race needs     religious beliefs	in relation to the short	CLASP People with				
	<ul><li>religious beliefs</li><li>matching providers to need (market</li></ul>	breaks options available in the	learning				
	management)	counties	disabilities				
	<ul> <li>accessing various health and social care community settings and home based</li> </ul>	Implement actions	PCT				
	service models	identified in Equality	Adult Social				
2.	Depresentation from DME staff families and	Impact Assessment	Care: Finance				
<b>Z</b> .	Representation from BME staff, families and people with learning disabilities on the task		Strategic				
	and finish group to identify ways to meet the needs of BME communities.		Commissioning				
3.	The short breaks delivery plans across the health and social care community to incorporate the BME recommendations included and will report this back to Steering Group.						
	The continued monitoring to implement the action plan will be through Equality Improvement Plans						
Inv	Involvement and Planning Adults with Learning Disabilities and their Carers						
	Action	Outcome	Lead Responsible	Resource Implication	Time-scale		

1.	To continue to involve adults with learning	To ensure Adults with	Commissioning	Funding to enable	Nov 09-
	disabilities and their parent/family carers in	Learning Disabilities	Manager	inclusion	April 13
	the development of future services, targeting	and families are			
	BME communities and specific advocacy	involved in the	With the support		
	groups for Health and Social Care Short	planning and	of:		
	Breaks	development of Short	Carers		
		Breaks Services.	CLASP		
2.	To have continued consultation on the		People with		
	strategy implementation and progression of	Continued	learning		
	delivery plans	consultation and	disabilities		
		engagement	PCT		
3.	Should any Short Break services be changed				
	or terminated during the lifespan of this		Adult Social		
	strategy Leicester City Council, Leicestershire		Care:		
	County Council, Rutland County Council and		Finance		
	Leicestershire Partnership Trust and the		Strategic		
	PCTs will ensure the needs of adults with		Commissioning		
	learning disabilities and their carers are met		ŭ		
	with, and consulted with, when offering future				
	provision and that engagement is maintained				
	at all times.				

## **Review and Monitoring (Governance)**

	Action	Outcome	Lead Responsible	Resource Implication	Time-scale
1.	Annual review of key delivery area including both qualitative and quantitative data.	To review and monitor the	Strategic Commissioning		Annual 2010-13
	Summary report produced each year.	delivery action plans for short	All partners		

2.	Evaluate this strategy, set priorities and plan for consultation to begin for the future, including carer and user as key stakeholders	breaks		
3.	Key requirements for Short Breaks Services i.e. clear policies and procedures included along with service specifications of all new services developed in contracts to deliver the strategy.			
4.	Short Breaks Services to have procedures that adhere to local and national good practice, rules and regulations of procurement and commissioning			

## Key priorities beyond 2013

Action		Outcome	Lead	Resource	Time-scale
1.	To measure the effectiveness of the delivery of the strategy:  • Measure users satisfaction	To continue to improve the experience of people	Responsible Strategic Commissioning	Implication	2013/14
	<ul> <li>Increased choice of services</li> <li>Better commissioning in a wider market place and more providers</li> </ul>	using health and social care short breaks	All partners		
2.	Develop consultation and user satisfaction as a guide to quality person centred short break services that meet the local population's needs.	Ensure services remain value for money and reflect the needs off the local			

the budget allocation.

		population		
3.	To continue to develop services to meet the			
	needs of Leicester's diverse community			
4.	To develop a personalised care management			
	model that keeps the person at the centre of			
	planning and delivery of services and a			
	vibrant personal budget and brokerage			
	system that enables the person to access the			
	services that best meets their needs within			