



## Respite Review Report 2015/16

### Action on the Report

Following presentations of the findings and recommendations of the Respite Review to the Adult Services Commissioning Group and NHS Highland Health Board, the Carer Improvement Group has been given the task of creating a new Respite Strategy for adult carers of adults in Highland.

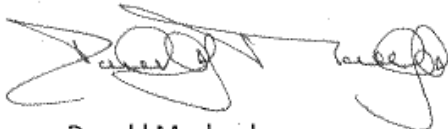
This Strategy will be developed through a partnership approach involving carers, those working in health and social care and users of services with the aim of producing a quality re-design of respite services for 2017-18 onwards.

There are several work streams which we will all, as partners, need to progress to enable the production of an effective Respite Strategy. Some of these flow directly from the Respite Review, while others, which were already in progress, need to be taken into account when considering what needs to be done to improve respite for carers.

These work streams include:

1. the development and implementation of eligibility criteria for carer support - as required by the Carer (Scotland) Act - including respite
2. Review of Carers Support Plans and implementation of new process
3. Community/ District engagement around need for and provision of respite
4. Testing of new models of respite
5. Redesign of respite booking
6. Review of Social Work role, systems and processes.

The Carer Improvement Group intends to have a Respite Strategy (Action and Delivery Plan), to include proposals for changes to investment and disinvestment available for consideration by the Adult Services Commissioning Group on 13 June 2016.



Donald Macleod  
Co-Chair Carers Improvement Group



Jan Baird  
Director of Adult Care NHS Highland  
Co-Chair Carers Improvement Group

12<sup>th</sup> April 2016

<b>CONTENTS</b>	<b>Page</b>
Part 1: Introduction and Methodology	3
Part 2: The Recommendations	7
Appendix A: Key Findings from Conversations and Consultation with Carers and Carer Support Organisations	31
Appendix B: Key Findings from Conversations with Staff in Health and Social Care	34
Appendix C: Key Findings from Conversations with Respite Providers	37
Appendix D: Key Findings from Conversations and Information Gleaned from the Commissioners, Planners and Administrators of Respite Services	40
Appendix E: Additional Context	47

*“We tell carers here there’s respite available somewhere that’s far away and they say, ‘no thanks, we don’t want to go with the frail person we’re caring for that long distance; they won’t be able to make that journey!’”*

*“If I could have had ‘respite’ my husband would be able to live at home...  
he wouldn’t be in a care home now.”*

*“I don’t want to have to shout for respite.”*

## PART 1: INTRODUCTION AND METHODOLOGY

### Beginnings

As part of the implementation of the **Equal Partners in Care (EPiC) Highland Carer's Strategy 2014-2017** it was agreed to undertake **a review of respite for Adult Carers of Adults (aged 16+)**. As independent consultants we (Anne McDonald and Donald Macleod), were commissioned by NHS Highland through Connecting Carers to undertake this work with Theresa James (Lead Officer for Carers) being responsible for managing this Review.

### Methodology - Conversations and Feedback Reports

There are **four groups of people – totalling an estimated 200 people - with whom conversations have taken place during the review:**

- **Carers and staff from carer support organisations** – more than 75 carers have given their views;
- **Health and social care workforce** – we have met with just over 50 people who have given their views and shared our initial findings with more than 60 others;
- **Respite providers** – we have met with staff from 15 organisations that are providers of respite
- Those staff responsible for overseeing the **commissioning, planning and administration of respite**.

During this review we have **travelled throughout Highland** and met people in every district partnership area. **We are very grateful** to everyone who participated so willingly in these conversations which took place with the guarantee that we would **anonymise** what was said.

After **our meetings with staff in the health and social care workforce we produced a report which was circulated to staff members** with an invitation to respond if readers felt that we had not captured accurately their views. The response we were given was that they felt their views were represented.

We also **produced for carers a brief document** detailing key points about respite that carers and others had expressed and asked them to respond as to whether it accurately reflected their views. The responses we received were favourable. Additional comments were made that amplified the findings with which people had been presented.

In seeking the **views of respite providers** we began by devising and then piloting – in person – a questionnaire with staff in these organisations. It rapidly became clear that any electronic or paper questionnaire would have been likely to have been put to the bottom of the pile – and indeed may not have generated the quality of information that was arising through our initial conversations. We therefore decided not to circulate the questionnaire but used it instead as a structure for our conversations with providers. We found that approach invaluable.

In this **report, concluding this stage of the review, we have continued our attempts to represent accurately what we have heard** and we have therefore included many quotes so that people can read for themselves the views of many people on a subject about which they feel passionately.

Throughout **the process of this review, updates have been provided** to the Adult Services Commissioning Group, the Carers Improvement Group and various other key groups and committees that have a stake in the findings.

## Key Background Information

Before we turn to the recommendations it is critical to set this report in the context of other developments affecting carers directly. Here then is some key background information through which, we believe, it is helpful to view the contents of this report.

### (a) The Carers (Scotland) Bill and imminent major legislative changes

At the time of writing this Bill is working its way through the Scottish Parliament. Its provisions are not all finalised but the following are clear:

#### **Carers Assessments will change their name to Adult Carer Support Plans.**

At the moment only carers providing care on a 'regular and substantial' basis are legally entitled to a carers' assessment. **This test will be removed so that all carers can access an Adult Carer Support Plan.**

**"The Bill will provide for both a duty and a power to support carers. Under the duty, the local authority will be obliged to support carers in accordance with eligible needs (i.e. those needs which cannot be met by general services and which meet the eligibility criteria). In determining which support to provide to carers local authorities need to consider, in particular, whether the support should take the form of a break from caring.** Support for the purposes of carrying out this duty will exclude information and advice and universal services available in the community. It will also exclude services provided to cared-for person(s). ...

**It is essential that full consideration is given to whether access to short breaks will help to achieve the carer's identified personal outcomes (e.g. to support the carer to sustain the caring role and to have a life alongside caring).** This is because a short break, which does not have to be a costly intervention, can support the carer in a meaningful way. Short breaks should include all manner of innovative and flexible provision as well as more traditional forms of provision." (*Extract from: Policy Memorandum, Carers (Scotland) Bill, March 2015*)

**"Carers will not be charged for replacement care that meets their assessment needs; neither will the cared-for person be charged for support that meets a carer's eligible needs."** (*Jamie Hepburn, Minister for Sport, Health Improvement and Mental Health, Nov 2015*)

### (b) Rising Number of Carers providing high levels of Care per week

**A steep rise is taking place in the number of people identifying themselves as providing high levels of care per week.** This is consistent with the increasing caring responsibilities that would have been expected to follow the aging demographic profile of the population.

**Between the 2001 Census and the 2011 Census** there was a **13.45% rise** in the number of carers in Highland from **18,505 to 20,993 (9% of the population)**. But this overall figure disguises the fact that while there was a change of just 2 in the number of people providing 1-19 hours of care (12,284 in 2001 to 12,282 in 2011), there were major rises in the number providing 20+ hours weekly:

**- 63.1% rise in the number of people providing 20-49 hours of unpaid care a week from 2,089 to 3,408**

**- 28.2% rise in the number of people providing 50 or more hours of unpaid care a week from 4,136 to 5,303**

### (c) Support to Carers in Highland

In presenting this report it is critical to acknowledge that there is much support already being offered and supplied to carers in Highland through organisations within the voluntary, statutory and independent sectors. There is also much work going on in the implementation of the **Equal Partners in Care (EpiC) Highland Carers Strategy 2014-2017**. Carers are seen within that Strategy as equal partners in the provision of care.

#### General Observations at the Outset

There are **three general observations** we would like to make:

- **Respite is, in principle, believed by all involved to be invaluable.** Though there are many problems with the provision of respite, it is, in principle, seen as essential by all the people with whom we spoke – carers, staff in health and social care and respite providers. One person said:  
  
*“We cannot underestimate the value of respite. I feel confident in saying it is respite that plays a huge part in maintaining the home situation for as long as possible in the majority of cases.”*
- **Respite is equated, by most people, first and foremost with residential respite.** From the very beginning of our conversations about respite we found, almost invariably, that carers, members of the health and social care workforce, and many respite providers spoke first and foremost about residential respite. Other forms of respite were discussed but often much later in our conversations. There are obvious exceptions to this rule – those providing day care or services that originate in the homes of carers and the people for whom they care naturally saw their services as providing respite. Nevertheless it is instructive that the common understanding amongst carers and many members of staff in health and social care is that respite equates with residential respite in settings other than the carer and/or cared-for person’s home.
- **Carers – in their caring role – are not users of services; they are providing care.** The support people receive as carers through respite does not make them service users – rather this support is seen as that which enables them to continue to provide care (or to disengage from caring) and to have a life alongside caring.

#### Main Messages

Distilling the message to their very essence sees these **main messages** emerge:

1. **Although respite is seen as a service for the carer, access to this service is through an assessment of the cared-for person.** It is as though there is an unwritten assumption that the obtaining of a break from caring through provision of the respite service in and of itself is the sole outcome for carers. Where other outcomes are achieved, it is the case that this often relies on the serendipitous and the incidental rather than on being intentionally designed into provision via conversations with carers. This then leaves unexamined much else that could be accomplished through discussing a range of possible outcomes for carers via an effective **Carers Support Plan**.
2. **There is a lack of accessible, core residential respite services (however provided) within Highland** and this lack is having a detrimental effect on the well-being of carers and a demoralising effect on those working closely with carers and those for whom they care in health and social work services. **There are gaping holes in the provision of residential respite services for carers of older people in Inverness, Nairn, the Black Isle and much of Easter Ross.** We have seen the very reverse of what is often the case in other settings in that people from Inverness and surround are travelling long distances to access services. If this situation was rectified there is the potential for freeing up resources elsewhere in Highland. **As far as other forms of respite are concerned more analysis needs to be done to examine the allocation and use made of these resources in all parts of Highland.**

## Format and Style of This Report

**Recommendations** now follow. The vast majority of these have been generated by people with whom we have had conversations. **We bring them forward as suggestions to be discussed.** For the presentation of these recommendations we have deliberately retained the style of the Highland Carers Strategy 2014-2017.

**Several Appendices** then follow these recommendations. There you will find key findings from many of the conversations we have had as well as some statistical analysis of respite data.

### More work needed

We have found across Highland, amongst carers, staff in health and social care and respite providers, a willingness to engage in the conversations which have been a feature of the review out of desire for improvements in the quality of respite provision. **We believe that there is considerable merit in continuing in a different form (workshops/gatherings at pan-Highland and at district/community levels) these conversations with a view to developing an effective way forward.** This process matters in establishing a sense of joint ownership of the whole approach and the way in which it is monitored, evaluated and progressed. It is a process in which carers need to be fully involved as equal partners.

When we commenced this review, it was envisaged that there would be a need for several stages to the work. There is still a need to look at the data relating to other forms of respite as well as the financial data about respite. There is also a need to engage with people who are being cared-for. And we envisage too that there would be benefits for piloting and evaluating different forms of respite.

### Finally....

We are conscious that we did not get a chance to speak to all who have an interest in this complex subject. We hope that this report will be a tool able to be used by those with whom we have had conversations and those with whom we have not been able to converse to enable all involved to work together to construct a variety of effective, accessible, quality respite solutions to the benefit both of carers and the people for whom they care throughout Highland.

## PART 2: THE RECOMMENDATIONS

### Introduction

We listened to all that was said to us during our respite conversations, and the recommendations are made as a result. They include solutions that people came up with when asked to 'dream' about respite in the future, and suggestions made about ways to fill the gaps and solve the issues that we heard about again and again.

**Common to all recommendations is the value of all involved - carers, commissioners, health and social care workers and respite providers - working together on the solutions.** Throughout the review the importance of listening, and being listened too, was raised frequently. This listening needs to continue. The way this is taken forward is critical to all the proposals, and **we are proposing a process which develops trust, starting with sitting down together to discuss this report and its recommendations and agree future processes.**

We have **4 key recommendations**, each with a number of different areas that need addressed:

**1. Improved Procedures for Planning and Accessing Respite:**

- 1.1 Respite Services to be accessed through a Carer Support Plan
- 1.2 Introduce separate systems for planned respite and emergency care
- 1.3 Self Directed Support (SDS) to be fully functioning across Highland
- 1.4 Transport is available to take cared-for person to respite when needed
- 1.5 Carers not to be charged for services
- 1.6 Develop accurate systems for recording current respite provision and planning for future need
- 1.7 Smoother Transition between children and adult respite services

**2. Quality Respite Information and Education Produced and Implemented:**

- 2.1 Develop, and promote across Highland, a clear definition of respite / short breaks
- 2.2 Respite to be promoted to carers
- 2.3 Produce clear information regarding respite entitlement, access, and costs

**3. Respite Resources developed to Meet Need:**

- 3.1 Develop appropriate 'core' overnight respite services to meet need
- 3.2 Ensure Locally Based Respite Provision with an even distribution across Highland
- 3.3 To make the most efficient and effective use of existing resources
- 3.4 Pilot a variety of solutions to meet need and known gaps in provision, improving equity of access
- 3.5 Encourage respite providers to support carers directly
- 3.6 To find alternative solutions for people without a carer

**4. Quality Respite is Crucial:**

- 4.1 Respite to be 'good' for those being cared for
- 4.2 Personal Outcome Plans (POPs) to be completed to a high standard across the board

Finally, a **5<sup>th</sup> recommendation** on the next steps, the process for taking all of the others forward:

**5. Next Steps**

- 5.1 Respite Conversations to be an ongoing feature of a focused approach to developing and delivering respite services



## 1. IMPROVED PROCEDURES FOR PLANNING AND ACCESSING RESPITE

### 1.1 Respite Services to be accessed through a Carer Support Plan

There are **three main reasons** why we are advocating that Carer Support Plans occupy this role:

- Legislation is imminent (April 2017 is the date of likely implementation at least in part) that will give **Carer Support Plans a strong statutory basis** and it will place on authorities a duty to provide support to enable carers to realise their personal outcomes – so by moving now there is an opportunity to prepare more fully for effectively implementing any necessary changes in approach.
- This approach will allow carers **to look at all aspects of their caring and identify**, in conversation with those developing their Support Plans with them, **their personal outcomes** (which are seen in their essence as supporting them in their caring role and to enable them to have a life outside or alongside caring) **and the place that respite/short breaks is to play** in assisting them to realise these outcomes.
- **Carer Support Plans are already under development** within Highland, and while there is still much to be done (and crucially, resource such as respite/short breaks to be linked to their implementation), the evidence is growing that carers are being enabled through this approach to obtain a good measure of support to assist them in achieving their personal outcomes.

In the course of this review we found that people in services in the provision of respite tend to focus their attention on the cared-for person – understandably believing in so doing that they are meeting the primary needs of carers. This has tended to mean that the attention has not been on carers.

We heard of superb examples where alert respite/short break providers have enabled carers to achieve so much more than an essential – but basic – form of respite. However, these outcomes were not part of any explicitly recorded and intentionally designed support that had been developed in conversation with carers.

**Making such conversations intentional and capturing them in generating with carers their own personal Support Plans could enable a considerable step change in the support carers are able to access effectively.**

**Carer Support Plans need to take into account the impact on carers, with regard to their respite requirements, of changes to the circumstances of people for whom they care.** For example, if services providing “meaningful activities” to a person who has a carer reduce their hours or cease altogether then that can have a considerable impact on the life of the carer who has been receiving a break from caring during that period. Some people have labelled this a “**hidden form of respite**” which only becomes fully apparent when “meaningful activities” cease.

#### **Views of health and social care workers ...**

*“Carers Assessments are not used as much as they should. Respite needs SSA, RAP paperwork, SDS paperwork - Carers Assessment is lower down than the rest.”*

*“Emphasis in Carers Assessment is not on getting services, first and foremost it is about carers being able to express themselves.”*

#### **Views of carers...**

*“Carer’s needs are not taken into account. The assessment for respite should be a joint assessment. I have a Carer Support Plan. When I requested a review because more help was need, I was requested to delay until the annual review. The case was then closed without an annual review. My Support Plan is meaningless.”*

*“I would like the carer to be considered as the beneficiary of respite care and assessed on that basis, rather than the assessment being done based on the needs of the cared for person.”*

#### **Views of respite providers...**

*“Sometimes it’s the carer who is at risk, rather than the cared-for. I have never seen a CSP or Carers Assessment. Sometimes will get a carer’s point of view in a SSA. We point people, carers, in the direction of the Care Manager”*

*“Carers might not be so free and open if they saw me writing things down. Might be more of a barrier.”*

*“Everything we do with carers is informal.”*

## Implementing this Recommendation

There is much to consider in enabling the personal outcomes of carers to be achieved: training; quality control; the provision of information and advice; ensuring an equitable, reasonable level of availability of quality services – including respite/short break services. Crucially, there is a need to identify the financial resources required in addition to identifying the assets which carers (and critically, their communities) can use to support themselves.

Carer Support Plans require to be done as smoothly, efficiently and effectively as possible. It is vital that all those engaged in the process are equipped with the tools and the resources to enable identified outcomes to be realised to an extent that is seen as just and equitable.

While there is no statutory entitlement at present to respite/short breaks, the forthcoming legislation looks likely to lay upon authorities the duty to provide support to those satisfying eligibility criteria and this will entail have to consider whether a short break would be beneficial. It will also require the production of a **Short Breaks Statement** detailing what is available to people requiring respite/short break services. However it is important to note the legislation will fall short of creating a right to respite. **The publication (and regular updating) of a Short Breaks Statement in Highland** will form a key part of the information made available to carers and the people for whom they care and for those who support both carers and the cared-for.

## Support for the Cared-For Person

In making the above recommendation we do not mean to lessen any focus on the cared-for person. **Time and again carers told us that they could only obtain true respite if they were confident the person for whom they care is receiving a high quality service with which they are satisfied.** For that to happen there is an obvious need to identify and work towards achieving the personal outcomes of the cared-for person, and we realise the Personal Outcome Plan (POP) for users of services is designed to enable this.

Ideally the **Carer Support Plan and the Personal Outcomes Plan will dovetail**. In the event that they do not, there will be a call for **skillful mediation and negotiation and advocacy**.

### ACTIONS NEEDED:

1. Facilitate conversations about effective processes for the implementation of Carer Support Plans in line with the soon-to-be Carers (Scotland) Act and the regulations that accompany it, as well as lessons learned from the development of Carer Support Plan in Highland and elsewhere to date.
2. Ensure the resources are there to enable effective Carer Support Plans to be created and implemented – and monitored, evaluated and re-imagined as necessary.
3. Review the current Carer Support Plan to ensure it is fit for purpose prior to the introduction of the Carers (Scotland) Act.

## 1.2 Introduce separate systems for planned respite and emergency care.

### ⇒ Vision

Separate systems for planned and emergency respite care.

**(a) Emergency Respite Care or 'Replacement Care' service** is established so that carers no longer have to stay in situations where they have stated they no longer wish to care; preventing caring situations coming to a crisis where the caring relationship breaks down irretrievably. Features people wanted include:

- Capacity for spot purchase locally.
- A means of dealing with situations when a cared-for person on a planned respite placement cannot return to the carer and this starts to prevent another person on planned respite from accessing the place.
- Carer are fully informed about the nature of the emergency respite; primarily the distance to the location and the cost.
- Sufficient information in the POP to provide emergency respite care including: equipment required; falls history; medication; capacity; GP; practical information (shower or bath); jewellery.

**(b) Planned Respite Care service** is established. Features people wanted included a service that is: easy to book; available quickly; reliable; and readily accessible in every sense. Specific suggestions included:

- A respite / short breaks bureau - or perhaps a Carer Support Bureau - with a whole suite of measures for carer support, including respite / short breaks. People wanted to explore how this would work if a range of organisations are doing Carer Support Plans - would they negotiate the support package with the Carer Support Bureau?
- A Booking.com model: *"People allocated respite through an on-line booking system where they can see what is available, and then choose where and when they wanted to go."*
- Carers having a High Life Highland-type card with their respite entitlement pre-loaded per annum. They then access the service via on-line or telephone booking.

**Note:** For both planned and emergency respite there is a need for carers to be presented, in a manner that they fully understand (and that understanding is evidenced) with clear information about costs.

#### **Views of health and social care workers ...**

*"Can't mend a bike while you are cycling it."*

*"Emergency role sits uncomfortably within Placement Team role. We are a booking service."*

*"Emergency respite came with only 3 pages of POP completed."*

*"Placements Team is an unnecessary bureaucracy. Another layer where mistakes can occur. Someone needs to take ownership of the need to collect information."*

*"Trying to get respite in an emergency is impossible. It just isn't there."*

*"Emergency tends to be with the carer, not the individual."*

*"Emergency respite is where the problem is. Emailed by placement team to say when a space comes up, but it's gone by the time you try to access it."*

#### **Views of carers...**

*"Not much planned unless I make a nuisance of myself."*

*"Care Homes can pick and choose whether they take people or not / how much they charge."*

*"Must be provision of respite in emergency situations. In my case a sudden hospital stay with heart problems and needing immediate respite care for my husband with Alzheimer's. A big worry with the proposed closure of hospital and shortage of beds."*

#### **Views of respite providers...**

*"Person with a fractured femur, living on her own, came for the weekend for 'emergency respite'. Pressurised to take her. Stayed in respite bed for weeks and then no-where else for her to go. She didn't have capacity so social work and health tried to say that she couldn't be moved."*

## ACTIONS NEEDED:

1. Investigate the Respite Bureau idea.
2. Consider renaming emergency respite as 'emergency replacement care', to distinguish it from respite as the carer is not getting the break in order to enjoy a rest.
3. Consider the option of Replacement Care / Emergency Respite being organised directly by the professional involved at the local level.
4. Recognise that time and resources will be needed to introduce new systems.

### 1.3 Self Directed Support (SDS) to be fully functioning across Highland.

#### ⇒Vision

Features that people spoke about were:

- A robust infrastructure being in place across Highland to allow Options 1, 2 and 4 to be realistic choices, and to have transparency about Option 3.
- More education provided around SDS, raising awareness of all four options, and of appropriateness for all client groups, including older people.
- SDS is promoted to those caring for older people, who are encouraged and supported to access it.
- Overcome challenges (e.g. relating to employment, recruitment, retention, deployment, replacement care when people are ill) that are causing some people to either not take up the option or even to end SDS when difficulties overwhelm them.
- SDS structured in a way that enables and empowers carers to achieve the outcomes they desire.
- Those supporting people to access SDS given sufficient time to carry this out, acknowledging the additional time required when people are working with a new system.
- Frontline workers to feel supported by the SDS team.
- Enough care workers to carry out SDS work.
- Brokerage services available for those with SDS.
- SDS set at the same level as the cost of statutory respite services.

#### **Views of health and social care workers**

...

*"SDS – certain amount of toe dipping going on. Not used for anyone with dementia that I know about"*

*"Great way of providing younger adults with respite where traditional model is not appropriate".*

*"Fantastic concept as part of the dream world. No infrastructure in Highland to back this up. No resources."*

*"Aspirational, in reality most will go into residential setting".*

*"Problem because family can employ anyone they want. No experience necessary. No support system, supervision, training".*

*"Risk for social worker. In control, but not in control. Triplicate in terms of bureaucracy. Hurting my brain thinking up numbers."*

*"Very few older people accessing SDS. Care home is more appropriate. Need formidable family member to take it on."*

#### **Views of carers...**

*"SDS works well for me. I knew about it because I had recently moved from England"*

#### **Views of respite providers...**

*"We're having a person using SDS to fund a week's respite in our care home soon"*

*"Mixed messages from professionals about SDS. A lot of negativity about it. Parent's look to us for answers".*

*"None of our SDS is recorded as respite, even if that is what it is for."*

*"Hitting a brick wall. No people who are prepared to work with individuals to provide care. Won't work for the money that is on offer under SDS".*

*"Not enough £ to provide replacement to Brora service. Not familiarly or regularly. Too much time to set it up."*

*"Carers don't know what they can spend SDS on."*



## ACTIONS NEEDED:

1. Training provided to all those involved in SDS. Practical guide to SDS processes.
2. SDS targeted at older people and their carers.
3. Promote enabling SDS conversations with people.
4. Explore the possibility of a number of organisations already supporting cared for people and carers acting as option 2 support agencies.
5. SDS set at an appropriate rate to cover respite costs.

### 1.4 Transport is available to take cared-for person to respite when needed.

#### ⇒Vision

Transport provision is equitable across Highland.

People spoke of the need for services to have the following features:

- Lack of transport is no longer a barrier for carers accessing respite.
- Carers have the option not to use a significant period of their respite transporting the cared-for person to a care setting.
- Carers have clear information about the availability and cost of transport to take the cared-for person to respite.
- Respite transport is reliable and if it has to be cancelled at the last moment alternative arrangements can be made.

Specific solutions suggested included:

- Respite provider mini-buses available to transport people to and from respite.
- Volunteer transport developed further.

#### **Views of health and social care workers ...**

*"We used to provide transport and support staff to go to respite. 3 individuals from day centre went to respite together, sharing support worker and transport. When this stopped they couldn't go anymore".*

*"Highland Council Transport Policy says Social Work don't provide any transport for respite".*

*"I do transporting if required - we do what we have to do"*

*"Deprivation is a huge issue for accessing respite – how are you going to get there?"*

*"GP can get patient transport"*

#### **Views of carers...**

*"More helpful transport information is needed".*

*"Transport issues use most of the break".*

*"No transport apart from through Red Cross – 45p a mile. Red Cross are brilliant but volunteers may cancel at the last minute, the day before sometimes".*

#### **Views of respite providers...**

*"Most people provide their own transport. If local we will use the mini bus but not supposed to. A few come by taxi. For some I worry about them driving so far. I worry about their ability, ... her husband has cancer, and I do worry about him bringing her here".*

**ACTIONS NEEDED:**

1. Implement Transport Policy for accessing respite uniformly across Highland with carers, social work and health professionals all being clear about the nature and implementation of the Transport Policy.
2. Explore local transport options and funding for these.
3. Clear information on the availability of transport for respite, how to access this, and the cost, to be provided to carers.
4. People travelling to respite together able to share transport.

## 1.5 Carers not to be charged for services.

### ⇒Vision

- The Scottish Government has pledged that following the anticipated introduction of the Carers (Scotland) Act neither carers nor the people for whom they care will be charged for any replacement care that is put in place where carers are deemed to be the primary beneficiary of respite services. Financial circumstances will therefore not be a barrier to carers receiving respite.
- Given that the timing of the full implementation of the Carers (Scotland) Act means there will be a delay before this recommendation can become a reality, clear information about the cost of respite care, and how the calculation is made, ought to be given to carers prior to the respite service being delivered. Timeous financial assessments will prevent worries about cost clouding respite.

### ACTIONS NEEDED:

1. Clear, up-to-date, information produced on respite charges.
2. All people involved in respite aware of charging process and able to communicate this information to carers and cared-for people.
3. Respite providers to have copies of the charging leaflet to distribute to carers.

#### **Views of health and social care workers ...**

*"Charging system is so distressing. Clients don't know how much services will cost. No up-to-date information or leaflets. Very much affects purpose of the respite".*

*"Carers presume that if the doctor is making a referral for respite then it's a free service. That generation has been brought up thinking NHS services are free"*

*"Even though they are not charged directly, carers feel they have to come up with money. Respite cost has significant impact on family resources"*

*"Parent booked holiday for 2 weeks. Called social work and demanded respite. The cared-for person didn't want to receive respite. What is the financial impact of this?"*

#### **Views of carers...**

*"My husband had a week's respite last month and I am still waiting to hear what the cost will be"*

#### **Views of respite providers...**

*"We don't hear about finance – social work and billing do all that".*

*"I give all carers the charging leaflet. I think it's very important that they know what the cost will be"*

*"Private homes prioritise privately funded people before others".*

## 1.6 Develop accurate systems for recording current respite provision and planning for future need.

### ⇒ Vision

- Planning in place to deal with the increasing demands for respite from an aging population.
- Accurate system in place for recording provision of all forms of respite so that it is clear how much is being provided and to whom. Ability to say exactly how many carers are receiving all the different forms of respite (including in-house and independent sector residential, SDS, day care, Carr Gomm and Crossroads, Key etc) in Highland.
- System in place for recording demand for respite (Carer Support Plan information) and information used to evidence the nature of unmet need.
- Process of ongoing evaluation of respite outcomes and quality.
- Anticipating the upcoming demand for adult respite services by obtaining information from children's respite services.
- Potential to use a percentage of any resources saved as a result of a more effective use of respite, to fund further respite.
- Improve anticipation of changing circumstances, and the need for increasing respite support for carers as the needs of the person they care for increase.

### ACTIONS NEEDED:

1. Demand profiling in general – link to national work.
2. Improve system for monitoring service user and carer respite experience. Include ongoing evaluation of carer and cared-for person's outcomes.
3. Children's services to share statistics for adult services to enable better planning to meet future demands.
4. Develop processes for recording all respite provision across Highland and use that information to monitor, evaluate and plan.
5. Monitor unmet need by looking at Carer Support Plan information and statistical data of provision.
6. Consider optimum ways of anticipating future carer support needs through the Carer Support Plan processes.

### Views of health and social care workers

*"Respite is not looking at carers' needs. They are in a lot of anxiety and don't know what's going to happen. They do a fantastic job. I worry for the families."*

*"Service User surveys' monitor service user experience. Not able to fulfil because of clunky system."*

*"Tsunami of dementia coming."*

### Views of carers...

*"Lack of anticipation for changing circumstance - I concur with this. Our case was closed. We care for a 95 year old. Were the needs going to reduce?"*

*"I have a Carers Support Plan. When I requested a review because more help was needed, I was requested to delay until annual review. Case was then closed without annual review. My Support Plan is meaningless."*

*"Not a 'hope in hell' of getting regular respite. In the past it was a responsive service which was able to help."*

*"I went absolutely bananas, its either respite or he goes into care permanently. No future planning, but as soon as I come back (from respite) I will ask. Always wonder what will happen if something happens to us (carers). No plan B, not even a plan A! Would like to find out if I could get respite in an emergency."*

### Views of respite providers...

*"Don't share statistics with adult services. No contingency plans – no emergency planning. Start transition earlier. It really is about planning. We can be part of the transition."*

*"Need early intervention. Just now carers have to hit crisis before support kicks in."*

*"Staffed by the accountant, not by need."*

*"People say; 'isn't a good service', but it really wasn't, was it."*

*"Will speak to SW when carers are really struggling to continue caring. People should have a choice about continuing to care."*

*"Respite doesn't come up at every review these days. Unless there is a specific reasons SW don't bring it up proactively every time."*



## 1.7 Smooth Transitions between children and adult respite services

### ⇒Vision

- Statistics about numbers of children - whose carers require respite - moving into adult services to be shared annually, enabling forward planning.
- Start transition process early – at least 2 years before the move.
- Young people from 14 to 24 able to receive respite services together.
- Young person's respite provider is part of the transition to adult services. Staff go to new respite facility with young person. Share information with shared Care Plan. Children and young people can be so different in respite, and there is a need to be able to pass this information on to respite providers.
- Early intervention and hit crisis before something else kicks in. Contingency plans and emergency planning.
- Transparency about what Direct Services really cost.
- Respite services for adults needs to take into account the 'hidden respite' such as school and transport, that carers may lose when their child moves from children's to adult's services.
- Options available for overnight respite for young adults with high needs.

### ACTIONS NEEDED:

1. Investigate extending Orchard registration so that it is able to take young people to age 24.
2. Explore the idea of an 'Adult Orchard' in Inverness for profound and multiple, high need, high tariff, families and children. 4 or 5 bedded. Strict criteria for places.
3. Children's respite providers to promote idea of SDS to parents whose children are approaching adult services.
4. Develop process and infrastructure to track young people from children to adult services, enabling forward planning.

#### **Views of health and social care workers ...**

*"Sense of responsibility – what will happen to them now. Lead them to the cliff edge and just say bye bye".*

#### **Views of carers...**

*"Transition was ok for the cared-for person, but for me as a carer I felt completely lost. Not even mentioned in the brochure."*

#### **Views of respite providers...**

*"Start transition earlier. It really is about planning".*

*"SDS has taken away some of our flexibility to respond. If there was a crisis, we would do what we could. Cancel other families. Now we can't use spaces that occur".*

*"Creative respite opportunities that are available - what are these going to do for our very complex client group?"*

*"Families who can't recruit staff with SDS will return to the Orchard".*

## 2.QUALITY RESPITE INFORMATION & EDUCATION PRODUCED AND IMPLEMENTED

### 2.1 Develop, and promote across Highland, a clear definition of respite / short break

#### ⇒Vision

- To develop a commonly accepted, widely understood definition of respite/short break.

**Answers to the following questions need to be agreed by and provided to all relevant people** (carers, commissioners, providers, health and social care professionals etc):

- **Who is respite for?** Carers are the ones for whom respite is intended; and the word 'respite' describes services which are put in place to give the carer a break from caring. Respite should not be confused with short breaks for people with no carers, or with those who have a need for convalescence.
- **Is respite the right word?** Some carers prefer the term short break as they associate the word respite with relief from a burden, and they refuse to regard the person(s) for whom they are caring as a burden.
- **What is the difference between respite and short breaks?** Could 'short break' be used to describe breaks for people who do not have a carer?
- **What is the purpose of a respite break?** A need for clarity in the purpose of the break. Does the carer have to 'rest', or can respite be used to carry out activities such as attending hospital appointments, operations, or shopping? In emergency care situations where the carers is unable to care for health or personal reasons, rather than because they are choosing to have a break, a different terms such as 'replacement care' may be clearer.
- **What are the various forms of respite available?** When asked about respite, almost invariably people spoke first and foremost about residential respite. Carers, and those supporting them, need to be aware of the availability of other respite services such as day care and Carr Gomm / Crossroads type services, which should be clearly marketed as respite. What too about care at home services too and their relationship to respite provision?
- **What is the role of 'hidden respite'?** Need to consider 'hidden respite' such as education and training when planning future service delivery.

#### ACTIONS NEEDED:

1. For all involved - Commissioners, Carers, Health and Social Care workers, and Respite Providers - to have a facilitated conversation about defining respite care.
2. To agree a Highland definition of respite care and short breaks.
3. Planning processes to include 'hidden respite' when planning for anticipatory care needs and during transition processes.
4. To include statistics and outcomes from non-residential respite - Care at Home, Day Care and SDS etc - in respite data.

#### **Views of health and social care workers ...**

*"There is a huge misunderstanding of what respite is. We suffer when hospitals are trying to deal with delayed discharge. They bombard us with calls saying what people are needing is respite, when it's not...often mean convalescence...Respite is for the carer."*

*"Respite can be seen as the first thing to try, even if the situation is beyond a person being able to stay at home."*

#### **Views of carers...**

*"What is respite and what is a break? It feels like it has been switched round by the NHS. Doing the shopping or going for a cup of tea is just living, it is not respite. If that is respite we may as well all have dementia".*

#### **Views of respite providers...**

*"Respite is for carers, but also for individuals with no family or friends".*

*"In terms of recording outcomes none of what we do (Care at Home) or SDS is represented as respite"*

*"Doesn't make a difference to us if there is a carer or not, we still provide the same service".*

## 2.2 Respite to be promoted to carers

### ⇒Vision

- Carers are able to expect to access high quality, responsive, regular and reliable respite. This is essential for the health and well-being of many carers and enables them to carry on caring.
- Respite is promoted to carers as a preventative service. A preventative, health and well-being sustaining approach is embraced, rather than waiting for crisis to arise.
- Carers are informed about respite services at an early stage, before a crisis point.
- Respite is, in the first instance, a service for carers and should not be confused with “meaningful activities” for the cared-for person. However, those supporting carers note “hidden” forms of respite that carers receive, and draw them into the open. (“Hidden respite” was defined as activities set up for the cared-for person but which resulted in the carer getting a break.) Avoid situations where changes in the services provided for the cared-for person results in carers finding that what they, in effect, view as “respite” is no longer available to them.

### ACTIONS NEEDED:

1. Respite to be proactively offered to carers during their Carer Support Plan.
2. Carers should be encouraged to access respite before a crisis occurs
3. Clear information given to carers about their respite entitlement and the process to accessing respite.
4. Carers Support Plans to take account of “hidden respite” that carers rely upon and any potential changes to this form of “respite”.

### Views of health and social care workers ...

*“We cannot underestimate the value of respite. I feel confident in saying it is respite that plays a huge part in maintaining the home situation for as long as possible in the majority of cases.”*

*“SW need to make sure carers have information available to them. Most will brush it to one side until they need it.”*

*“I bring up respite as soon as I can with a carer.... Respite is part of tick list of a CPN service.”*

*“Carer had to re-arrange hospital appointment as no respite available – need for education within NHS regarding respite.”*

*“A lot of times carer reluctantly accepts or agrees to respite – guilt, costs, can anyone else do what I do. Never accepted at the start. 9 times out of 10 wait until a crisis. Would like people to become more proactive in seeking respite. People who do it well can end up caring for much longer. Common statement – better to be fit and well and caring, than drive yourself to an early grave.”*

*Older carers cancel respite because they feel that is isn't fair on the staff. Feel they are imposing. Worry that the difficult behaviour of the cared-for person reflects on them.”*

### Views of carers...

*“She's (social worker) is a nice lady who has a big work load and no resources”*

*“I don't want to shout”*

*“Not a ‘hope in hell’ of getting regular respite. So much worse since NHS took over care home. In the past it was a responsive service which was able to help”.*

### Views of respite providers...

*“Respite now happens at crisis point, was different 5 years ago. People often don't want to go home after respite – both the carer and the cared-for person find this. Now more advanced care needs, more challenging. Families caring for people at home for longer.”*

## 2.3 Produce clear information regarding respite entitlement, access, and costs.

### ⇒ Vision

- Clear information and guidance on what carers can expect in terms of accessing respite care, including how respite is allocated, charges, amount of respite and transport.
- Well informed carers to have realistic expectations, based on accurate, up-to-date information, of the respite care they can access; and support from professionals to access it.
- Information and guidance on respite entitlement and monitoring. Clarity about the level of residential respite that is available to be allocated.
- Clear information regularly up-dated about guidelines for recommendations, availability of facilities and up-take. This is to enable expectations of carers, cared-for people and professionals to be realistic. Information of this type is seen as vital to enable effective, efficient and high quality planning.
- Transparency in the way in which decisions about respite are arrived at in the District Care Planning (DCP) meetings.
- Ensure that information and advice supplied through Connecting Carers about support for carers is closely tied to what is available for respite to try and ensure carers' expectations are grounded in reality – and thereby reduce the potential for conflict between carers and health and social care workers.
- Speeding up the process so that the interval between need being assessed and services delivered is minimized.

### ACTIONS NEEDED:

1. Guidance on carer's entitlement to respite and the process of allocation.
2. Produce accessible information about availability of respite facilities and up-take in Highland.
3. Transparency in the relationship between Carer Support Plan / POP and the RAP funding allocation.
4. Results of respite monitoring published.
5. Information sharing between respite planning and processes, and Connecting Carers Information service.
6. Clear referral processes to Highland Carer Advocacy.

### Views of health and social care workers..

*"Sometimes carers are sure of their entitlement to respite, which can be challenging. As a general tool assessment process is quite good; share with individuals what the service is and isn't about, reassurance, providing information, let people down gently, encourage people to be as independent as they can."*

*"What is carer's entitlement to respite? Legally entitled to an assessment, but not any services from it. What is a reasonable expectation? A steer from someone higher up would be helpful."*

*"Huge inequities. People look at others who are getting more. Some aren't getting any because places haven't worked."*

*"Should be about what people need. The less they need the further it will stretch, even 26 weeks saves money on full time long-term care. Don't see extra money from saving NHS costs."*

*"Learning to play a system – if you put in for 12 might get 4."*

*"Carer had to re-arrange hospital appointment as no respite available – need for education within NHS regarding respite."*

*"DCP had no management at it. Not clear about criteria. In years gone by would depend on mood."*

### Views of carers...

*"I would like to have a menu of service providers that I could access in different circumstances."*

*"I do not want to be a case manager. I want the professionals who are paid to provide services or manage them for us to be the case managers and act proactively so that I can get on with the job I do expertly – being a brilliant carer."*

*"Such a complicated system with so many people involved. Which one to contact!!"*

### Views of respite providers...

*"We don't have anything to do with charging. Clients don't know how much services will cost. No up-to-date information or leaflets."*

*"I inform carers about the cost as they are often unaware, and think there will be no charge because the GP has made the referral so it is a free NHS service."*



### 3. RESPITE RESOURCES DEVELOPED TO MEET NEED

#### 3.1 Develop appropriate 'core' overnight respite services to meet need

##### ⇒ Vision

- **Meet the demand from carers for 'core' respite care – overnight residential respite.** This is the type of respite that, when asked about respite, carers described needing to give them a real break. The type of respite that keeps carers healthy and prevents caring relationships breaking down.
- **Increase bed availability in the Inverness / Mid Ross area** to meet the needs of those who are unable to access appropriate respite currently – people with the most challenging behaviours or those with complex care needs – in particular the increasing numbers of people with advanced dementia, people with drug and alcohol problems and young adults with complex care needs.
- **Expand existing respite providers to provide appropriate care for those** who have compatibility issues within existing respite settings.

Explore a variety of possibilities for increasing residential respite:

- **Larger residential units (20-beds or so).** Develop larger units to cope with an increasingly overwhelming situation. A larger unit could be so structured that it would have the capacity to provide respite for people with the most challenging behaviours or those who had complex care needs. There would be no refusals to take people. People wanting to book respite would be greeted with “yes, we can!” and not, “no, we’re not able to take that person.” Larger units could have, for example, a large garden and other on-site facilities that allowed for people to enjoy additional stimulating activities.
- Consider Beachview Respite Unit for older people’s respite.
- Key type respite provision for older people.
- Home care organisations could rent a property that had been adapted for respite.
- Beds for respite in proposed or new care home developments.
- Reduce respite bed allocation in the North after other services are put in place in Inverness, Nairn, Easter Ross and Black Isle.

Also look at increasing **home based, overnight respite:**

- Supporting community-based organisations like Black Isle Cares and others that are established to offer respite. Encourage communities to generate solutions and investigate their networks.
- Extend Day Care services 24/7 – into weekends and evenings.

#### ACTIONS NEEDED:

1. Increase respite bed availability in Inverness / Mid Ross area.
2. Address compatibility issues within care homes between permanent residents and those coming for respite with dementia and / or challenging behaviour.
3. Work with existing (and potential) respite providers to explore ways they increase their provision to meet this need.

#### Views of health and social care workers ...

*“Basic respite provision is inadequate in quantity, but basically sound. We need more of what we have got.”*

*“I know of two or three caring situations that have broken down. It happens to carers especially when they can’t sleep or they have mental health problems.”*

*“Whenever you cut services at one end, it unravels at the other – caring situations have broken down because the carer is unable to get support”.*

#### Views of carers...

*“Respite is where the cared for person goes away”.*

*“When he’s well my sleep’s okay but when he’s not it’s awful. Sometimes I’m up ten times in the night with him. Twice I’ve got lost when out due to lack of sleep. I became disorientated. It’s frightening when I get lost due to sleep deprivation but generally sleep doesn’t worry me”.*

#### Views of respite providers...

*“We’ve refused to take people for respite when we don’t have appropriate level of staff for the needs. Felt bad because she is local and her carer really needs a break. Sometimes it’s about the carer who is at risk, rather than the cared-for”.*

*“People staying for respite used to be continent and mobile – now that’s unusual. People are staying at home longer. We only have one room. Could do with another 5, and would fill them.”*

*“If charged more for respite, homes in Inverness may provide it again.”*

*“Lack of funding is only thing that stops us increasing the amount of respite we provide.”*

### 3.2 Ensure Locally Based Respite Provision with an even distribution across Highland

#### ⇒ Vision

Locally based respite facilities would enable carers who are currently turning down respite they consider inappropriate because of the distance to the facility, to have a break.

- Carers can visit the people they care for during respite, and family and friends can visit too. Prevents isolation.
- Carers able to appreciate their whole respite break, rather than 'loosing' up to two days of it travelling.
- Frail cared-for people would not be faced with the trauma of a long-distance journey.
- Cared for person, often with dementia, able to remain in their local area, where they are familiar with services and surroundings.

Development of respite beds in Inverness, Nairn, Easter Ross and Black Isle.

Communities feeling they have a very effective staged process from day care to permanent residency in a care home, where respite is one step on the way. The care facility is able to offer support to carers, and the cared-for person can remain in a familiar environment, among people they know.

#### ACTIONS NEEDED:

1. Development of respite beds in Inverness, Nairn, Easter Ross and the Black Isle
2. Considering ways of supporting resilient communities – respite developments in local community facilities such as Day Care in a community hall.
3. Mapping where people feel their community is in terms of respite need, and looking at ways to fill respite gaps with communities themselves.

#### **Views of health and social care professionals ...**

*"Planned local respite can be very successful. If have respite locally good chance they are known anyway. I (CPN) can call in during respite. Familiar face helps a lot. Can speak to staff during the day. Nobody is a stranger."*

*"Currently respite is more about location than need. Majority would say they don't use it because of location."*

*"Resilient communities rather than Day Care. More flexible. Longer day care hours"*

*"People can have small geographical mindset - would travel within Caithness, but not go out of County"*

*"Couple cared for by family. Local respite unavailable so family took them to Broadford. Difficult. Will never go to Broadford again. Well looked after but didn't know village. People in home didn't know them. Hell of a journey there and back."*

#### **Views of carers...**

*"Having respite available locally is very important. Frail elderly people are not fit to travel long distances and the carers do not need the extra hassle of transporting before and after a break."*

*"I want to be able to visit during respite, and be available if I am needed, so I don't use respite that is too far away"*

*"Local respite can maintain local networks"*

*"Carer had broken leg and only respite options were Dundee / Glasgow which is incredibly distressing for someone with dementia"*

#### **Views of respite providers...**

*"People are booked in, we get all the information we need together, then they cancel when they realise how far away it is. Waste of our time"*

*"Used to work as a staged process when people came for day care, then respite, then overnight and finally permanent residential"*

*"Compatibility issues with permanent residents have increased since more people coming from out of the area. Have higher level of need and we don't have staffing levels"*

### 3.3 To make the most efficient and effective use of existing resources

#### Vision

**Carers are aware of, and able to gain access to, respite and related support from existing services.**

Organisations/ services suggested included:

- (a) Various respite services ranging from different types of residential (planned and emergency) through sitter services to other short breaks
- (b) Connecting Carers Advice and Information services
- (c) Connecting Carers 'Wee Treats' and 'Take a Break' funding
- (d) Highland Hospice 'Helping Hands' volunteer support for people with a life shortening illness and their carers
- (e) Carer Support Plans provided through Carer Liaison workers employed by Connecting Carers
- (f) Connecting Carers Hospital Liaison workers
- (g) Highland Carers Advocacy service
- (h) Befriending service
- (i) Carer Involvement and Engagement post (to enable carers to become effective partners in care)
- (j) Carer Strategy Implementation post (supporting the Carer Improvement Group and the Strategy implementation)
- (k) Carer Supportive Hospitals Project (to be nurse-facilitated - this project is under development)
- (l) Identifying and Supporting Carers in areas of economic deprivation (under development with public health)
- (m) Carer Positive (employers becoming carer supportive – project under development)
- (n) Carer identification and support in Primary Care (under development)
- (o) Links to work undertaken in support of young adult carers.

There were a number of people who felt that **existing resources – whether of time, funding, or facilities** - could be deployed to relieve some of the pressure on respite more immediately. For example:

- Some wondered whether, for people meeting the criteria, **palliative care resources** could be used to provide more respite as they thought there was more money there.
- Others asked whether there was capacity amongst any Health and Social Care support staff – could they be re-deployed for respite purposes?

In a number of settings people felt that **day care provision needed to be more available**. Here are some of the ideas people would like to see considered:

- Some pointed to the Corbett Centre and said they thought there was capacity within that facility during days, evenings and weekends to provide respite.
- *“Grigor House is a new modern facility that is very unused. Currently day care hours are restricted to 9.30 to 3.30. It would be good to extend day care to longer days.”*
- Some wanted to encourage more residential care homes to have day care provision.

Some people spoke of the need to **increase the hours available for Carr Gomm / Crossroads** to tackle the demands that they are facing – especially for them to meet quickly changes in the circumstances of people for whom they care.

#### **Views of health and social care workers ...**

*People spoke of day centres remaining open into the evening and opening at weekends for respite.*

#### **Views of carers...**

*“Every case is different, so if one helper from the NHS could be allocated to each family – that ‘helper’ would know the problems and also be in contact with the various agencies who could help with the new problems of the family.”*

*“Bit more relief/respite which is more easily accessible and flexible. At the moment we have to pay for more than is needed, like an overnight stay, when really help is only needed last thing at night and early in the morning.”*

#### **Views of respite providers...**

*“We can see needs changing particularly as carers age or the people they care for become more ill. We need to be able to provide additional services quickly.”*

**Overnight care in people's own homes** is a service which seems to be deployed a lot less than it would be if carers and the people for whom they care knew more about its availability.

**Solutions which enabled a graduated approach to accessing day care and residential respite were suggested.** So, for example, a person might begin with a short visit, which then becomes day care, which then leads to residential respite. Taster visits work well in people's experience. They thought this way of working should be extended to cover all such services.

#### **ACTIONS NEEDED:**

Each of the ideas listed – and others like them – should form part of the on-going conversations, which are mentioned as being key to developing new ways of working around respite.

This would enable people to be fully involved in designing solutions in an environment that is building trust and enabling people to work together more effectively and efficiently.

**In the first instance this could be done via gatherings of professionals, carers and cared-for people in each locality to explore these and other ways of making best use of existing resources.**



### 3.4 Pilot a variety of solutions to meet need and known gaps in provision, improving equity of access

#### ⇒Vision

The **general vision** regarding equity of access included:

- **Particular attention is paid and additional support is given to groups of carers who face added difficulties in obtaining access to respite services** (e.g. carers in areas of multiple deprivation; carers from different minority ethnic groups; carers of people with conditions which have a stigma attached to them). These groups are seen to require more intensive work to identify and support them.
- **National Health and Wellbeing Outcomes** for carers are met in Highland
- **Respite system seen as providing a fair distribution** of limited resources amongst carers.
- **Equality of access** at popular times of year.
- **All area social work teams to have equal access to respite** – both emergency and planned.
- **Carers do not feel they have to shout** to have their respite needs heard

#### Specific Ideas:

**At different times people may want different types of respite so to give people a choice as to what they access** (from home-based to many other types of out of home respite) would be ideal. Imaginative and creative solutions are sought by some. Some ideas include:

1. **Different types of residential facilities for different groups were seen as desirable.** People spoke of residential facilities which suit variously:
  - (a) younger adults with long-term conditions
  - (b) people with dementia whose behaviour is aggressive or inappropriate sexually
  - (c) older people who do not want to enter a care home
  - (d) people with profound and complex care needs
  - (e) people with challenging behaviours
  - (f) those with nursing needs
2. **Family-based respite – “Shared Lives” – approaches**, involving people being contracted to provide respite in their own homes. Seen as working well for children in Highland and for adults in other parts of the country. (Note: a person willing to provide that service who lived on his/her own would also be able to do so.) There were many benefits seen from having such relationship-based, homely, longer-term, consistent, stimulating respite environments available throughout the area.
3. **Small residential units (3-6 beds) in various parts of Highland were thought of as being a good idea-** they were seen as being more home-like than larger nursing

#### **Views of health and social care workers ...**

*“Do we have the right to place people in respite when they don’t want to go, but the carer needs a break?”*

*“Care homes and dementia is a discussion on its own. Not only are the levels of care much higher – resulting in often purchasing additional 1:1 support, but we have to question how positive an experience it is for the person in the mid-later stages of dementia. Often the distressed behaviours ‘challenging’ are addressed by additional hours when ideally a smaller care environment with attention to noise levels, lighting, floor coverings, staff numbers and knowledge is required. I think it is often fitting the person with dementia in to an unsuitable placement which brings about the distressed behaviours, which we then have to purchase additional support for.”*

*“Concerns about younger people in nursing homes, disabling rather than enabling environment.”*

*“Mental health and alcohol respite very difficult, especially if service user retains capacity. Stigma is still there and care homes often refuse.”*

*“Very few establishments have 2 beds to enable couple to receive respite together. One couple in their 90’s refused respite as they didn’t want to be apart.”*

#### **Views of carers...**

*“More provision with teams of home carers whose role is specifically to provide respite is necessary. At present there are not enough employed carers to meet every day demands and there hardly any care available for respite. Care companies would need to employ more people on flexible contracts.”*

homes. The Conon Bridge development for people with autism was spoken about favourably as an example of what might be able to be done. The Key development in Nairn is seen to be one that has distinct promise. Another such facility is under development in Fort William and yet another is proposed for Caithness. It should be noted too that a number of carers said they valued Beachview in Brora for its more intimate setting and were longing for it to re-open (it being closed for much of the period of this review). People have also spoken of small units being part of a cluster of services on a site so that organisations already providing housing-support services, for example, could have a house/flat dedicated to respite provision as part of that cluster. It was also thought that smaller units could provide ideal training opportunities for workers. Could a similar model be used for older people? Could the MacKenzie Centre be developed to have residential facilities as well as day care?

4. **People spoke of buying or renting homes or adjacent flats** as potentially a quick way of addressing respite capacity. Some people noted that you have to think about the mix of people who are taking respite at any one time. Smaller units allow that to happen more readily. People favoured this approach so that it would cater for needs of particular client groups (e.g. younger adults with long-term conditions/ younger adults with learning disabilities/ people with mental health problems).
5. **Being able to use the nurse bank for home-based respite was** an idea advanced by one team. It was seen as an idea of particular merit for emergency respite.
6. **Communities encouraged to become more resilient vis a vis respite.** Examples of developments:
  1. A **good neighbour scheme** whereby people would offer various types of respite.
  2. Using **village halls and other local facilities** to provide services
  3. **Dementia Friendly Communities**
  4. **Bed and breakfast businesses/ guest houses/small hotels** - with training - offering respite during the off-season.
7. **Flagging up the availability of over-night care as a sitter service.** For those not wanting to leave their own home there needs to be, said people, ways of enabling that to happen. People envisaged home care organisations be contracted to provide that type of respite.
8. **Booking own choice of Care Home:** As part of a regular system of respite some envisaged a future where it would be possible to access any care home of their choosing rather than the ones that are block booked.
9. **There were suggestions that had international dimensions.** People raised: night care for people with dementia in New York; home-based respite in Sweden; the dementia village in the Netherlands. People were interested in scouring the world for respite solutions.
10. **Respitivity** (respite breaks + hospitality) is a Shared Care Scotland project that makes connections between local organisations that support unpaid carers, and local hospitality providers. It began in the USA where it is now becoming well established. The idea is that local hotels, for example, are able to make a 'gift' of an overnight stay to a carer (plus companion), examples might be the gift of a day-pass to a leisure club or spa, or a voucher for dinner for two. Generally these 'gifts' are offered in the quieter, shoulder season when there is capacity. Through recognition certificates, presentation events, media interest and promotional campaigns – Respitivity can help providers to increase awareness of their business. After a successful pilot in Fife, 2015 sees Respitivity being introduced in further 4 regions across Scotland; Falkirk, Dumfries & Galloway, Lanarkshire, Midlothian. Highland with its large number of tourist businesses could well be ripe for further pilot work in this area.
11. **Shared Care has** a searchable database of respite/short break opportunities throughout Scotland.

**Note:** The 10th International Short Break Association (ISBA) conference is being overseen by Shared Care Scotland and will take place in Edinburgh, Scotland from 13th -15th September 2016. The title of the Conference is: Right Time, Right Place, Unlocking the Potential of Short Breaks. ISBA's purpose is to support developments in policy and practice which improve the experience of short breaks for

everyone. This should be a timely opportunity to learn about what is working elsewhere in the world as well as elsewhere in Scotland.

**ACTIONS NEEDED:**

1. Provision of additional, appropriate support to communities of interest that find access to respite services difficult for cultural, economic, social or stigma issues. This will mean working closely with people who are trusted by these communities and augmenting their existing work.
2. Address the geographical inequities that currently exist so that the gaping hole as far as respite services in Inverness, the Black Isle, Nairn and much of Easter Ross is filled.
3. Transparency in terms of access to respite to be revealed through reports that detail how equality issues are addressed and evidence what the resulting outcomes are found to be with further measures being implemented if necessary.

### 3.5 Encourage respite providers to support carers directly

#### ⇒ Vision

Respite providers to be encouraged to continue with, and expand upon, much of the unofficial support that many are currently providing to carers.

Suggestion and specific examples include:

1. Information provision – from information leaflets on display to personally handing carers information relevant to them – such as charging, benefits, and Connecting Carers.
2. Provide a listening ear
3. Emotional support at times of change or difficulty
4. Carer groups / mutual support
5. Trips out with the cared-for person
6. Advice on making their home accessible for someone with limited mobility
7. Entertainment – care homes inviting carers in to entertainment such as a Pantomime
8. Developments such as the proposed MacKenzie Centre Carer Café, a collaboration between Connecting Carers and the MacKenzie Centre, explored across Highland.
9. Respite providers providing support to carers using their own fundraising – for example Carr Gomm and Crossroads provide carers with support such as lunches and trips out.

#### ACTIONS NEEDED:

1. Monitoring of respite provider carer outcomes.
2. Build Carer Outcomes into Carer Support Plans.
3. Share existing good practice among respite providers.

#### **Views of carers...**

*"Can't be a carer all the time, but I can be some of the time."*

#### **Views of respite providers...**

*"Carer put an acknowledgement in the Courier; 'thank you not just for looking after J, but for looking after me as well'"*

*"Carers they come in and have cup of tea. Join in the morning Sing Song. Depends what is going on at home."*

*"Tried carers group in evening but not successful."*

*"Planning to provide a Carer café, working together with Connecting Carers"*

*"Family ask if care home can tell cared for person that they can no longer care. Good to be able to say they can go back to being a daughter rather than a carer"*

*"Husband caring for his wife with dementia. One comes here for day care and the other gets reflexology."*

*"Promote respite as a break from their caring role. Carers can feel they have failed."*

*"I advised the carer on how to make their home accessible for the person they care for, so they could return there after a hospital stay. They were delighted and it prevented the need for residential care for the cared-for person."*

### 3.6 There is a need to find alternative solutions for people without a carer

#### ⇒ Vision

- Systems that provide beds for people who have no carers need to be developed because clearly just removing them from the respite classification does not address their particular needs.
- For those without a carer the decision to remove a person from his/her home or postpone return home needs to be re-framed as, for example: re-ablement; convalescence; emergency care; step up/step down; prevention of hospital admission; palliative care; temporary extra care; treatment.
- Because there is still a need for convalescence, palliative care, step up/step down beds, and short breaks for people with no carers, there needs to be services that catered for these requirements so that there is no encroachment on respite provision.

#### ACTIONS NEEDED:

1. To change the way of recording care for people without carers, so that it is no longer represented as respite.
2. Develop systems to provide beds for people who have no carers.
3. Explore the level of unmet need for carer respite beds, and the potential for the freeing up of non-carer respite beds to meet this.

#### **Views of health and social care workers ...**

*"Care home staff don't know the difference between respite beds and step-up, step-down beds."*

*"Care Managers will disguise something as respite that isn't."*

#### **Views of respite providers...**

*"Don't have a record of whether people have a carer or not."*

*"Have taken people from hospital if carers not able to care at home. No provision for respite in hospital anymore. People just need a bit of TLC. Regular food. Allow family member to get back on their feet. Step up, step down bed could happen more, but needs resourced."*

*"Another person with a fractured femur, living on her own, came for the weekend for 'emergency respite'. No capacity. Managed to find her a permanent bed straight away."*

## 4.QUALITY RESPITE IS CRUCIAL

### 4.1 Respite to be 'good' for those being cared for.

#### ⇒Vision

1. Both cared-for people and carers know that respite for the cared-for person is a positive experience. Respite will occur in an enabling, rather than disabling, environment.
2. Respite is appropriate in terms of location, time, place, compatibility, activity and choice, for the cared-for person, so that carers are able to take respite without feeling worry or guilt.
3. Respite services should ensure that those receiving respite together are compatible with each other both in terms of age and condition. In terms of age this can mean both not being the only young adult in a facility supporting older adults, and also not being in a respite provision for older adults with dementia when you are a 'young' older adult without dementia.
4. Good communication, depending on what is needed, between the respite provider and the carer during respite.

#### ACTIONS NEEDED:

1. Carers and cared-for to be offered choice in respite services.
2. If respite is refused due to the service on offer being inappropriate for the cared-for person, this should be recorded as unmet need.
3. Respite providers should be able to say no to respite requests on the basis of compatibility without additional pressure being placed on them.
4. Appropriate systems –both in terms of technology and process - need to be developed to enable respite to be regularly evaluated and reviewed.
5. Documentation to be recorded of how satisfied carers and cared-for people were with the respite they received and whether it achieved the outcomes they wanted, and if not then changes to be made.
6. Feedback from evaluation to be given to respite provider.

#### **Views of health and social care workers ...**

*"Respite should be the person being cared for having a good time, not just being looked after."*

*"Service User surveys should monitor service user experience. We are not able to fulfil this because of a clunky system."*

#### **Views of carers...**

*"I was under pressure to put mum into somewhere that wasn't appropriate and it wasn't where she wanted to go"*

*"I would like respite to be suitable for my cared for person, and not just a 'holding area' that they can be put into until I come back to collect them"*

#### **Views of respite providers...**

*"Carers have to trust the home. May call 3 or 4 times a day to check how the cared-for person is. Would find it quite odd if someone didn't. We reassure them, just talk to them."*

*"Lady thought she was coming here for a holiday – we had to make it clear that we are not set up for that."*

*"Feel bullied by line manager into taking people who are not appropriate. The needs of people coming for respite have increased. Have to think of the needs of other residents who are not getting the attention they need. Staff rushed off their feet."*

*"Contracts have a resident's questionnaire which goes back to them. We don't get any feedback."*

*"Sometimes people are so desperate for respite that we will get someone that isn't appropriate. When this happens we go back to the Placement Team and explain about compatibility issues."*



## 4.2 Personal Outcome Plans (POPs) to be completed to a high standard across the board

### ⇒Vision

- Regular training provided for all who use POPs, including completion of form and relationship between POP and the Resource Allocation System (RAS).
- POPs fully completed, with all the information respite providers need including practical information such as preference for bath or shower, next of kin and GP, falls history, medicine requirements.
- True Multi agency completion, of POP – shared responsibility – no longer assuming that Social Worker / Care Manager will complete. Respite providers are able to update POP, and have access to Care First to do this.
- Streamline care plan process by having information required in the POP so avoiding production of multiple care plans / respite plans.
- In persistent cases where information is lacking in a POP, professionals to be identified and the practice rectified.
- Professionals and carers clear about the need for both a POP and a Carer Support Plan to be completed for respite, rather than assuming that carers needs will be included in the POP. Carer Support Plans promoted to carers during the POP process.
- Where possible all updates to POPs made online.
- POPs to record unmet need.
- Avoid unnecessary gathering of information at Care Home level, where risk of respite being cancelled.
- Look at ensuring simplified POP if only needing respite.

### ACTIONS NEEDED:

1. More training for all involved in completing POPs.
2. Carer Support Plans to be promoted during the POP process.
3. True multi-agency completion of POP, challenging assumption that this is predominantly a social work role.
4. Respite Providers to have access to Care First to enable them to update POPs.
5. Provide the information required by respite providers within the POP to avoid duplication of care / respite plans.
6. Keep the completion of the POP totally separate from the RAS process.

#### **Views of health and social care workers ...**

*"POP is a generic assessment where the needs of the client and carer are interwoven".*

*"Outcome and goal focus doesn't have info that care home would need".*

*"Not very person centred to compile a system around a spreadsheet. Nobody likes being outsmarted by an excel spreadsheet".*

*"POP is a cover to fit around the RAS. Making the tail wag the dog".*

*"Not recording unmet needs".*

*"POP not fitting with older people, patronising and insulting to speak to some people about future plans. What do you want to achieve? To get through each day".*

#### **Views of respite providers...**

*"Respite paperwork is phenomenal".*

*"POP allows people to be creative in getting to know people"*

*"POP's are starting to get better. Quality depends on who fills them in. Need to get a grip of where things are in it".*

*"1 in 3 of the POPs might be right. I'm being generous here. Always involved a bit of detective work. Could spend majority of day chasing people up. Reply back to Placements. I phone social work and say 'give me a story' – then put that into our paperwork. I go to panel meetings. Give written report back to SW so they can update POP. I don't have access to Care First."*

*"Skilled manager should make it possible to care for someone without full info in POP".*

## 5) NEXT STEPS

### 5.1 Respite Conversations to be an ongoing feature of a focused approach to developing and delivering respite services.

#### ⇒Vision

- Respite conversations, which have been a key part of the respite review, to continue in the planning and development of respite services for Highland. All involved in respite; Carers, Commissioners, Health and Social Work professionals and Respite Providers to be brought together as part of the process, creating trust and mutual understanding between all involved.
- Recognition of and all working according to Equal Partners in Care (EPiC) principles.
- Carer Support Plans fully accepted and implemented.
- Understanding and agreement as to the joint responsibilities in Personal Outcome Plans in terms of who should complete and what information is necessary.
- Valuing of different professions contributions to the respite process. Integrated approach followed.
- Effective communication amongst all involved. Trustworthy communication is seen as essential with carers and the people for whom they care, between staff, with other professionals and with those who will be providing the care.
- Transparency amongst all involved in processes such as delayed discharge and respite.
- Ensure high standard of quality of across all contributing to POPs / SDS.

#### ACTIONS NEEDED:

1. Respite conversations to be recognised as a key feature of the process of improving respite in Highland.
2. Facilitated sessions held for key representatives from all involved in respite to come together and discuss future development.

#### **Views of health and social workers ...**

*A social worker said: "I'll make someone's tea, clear toilets, house clearances, because if I don't it won't happen. Community Service wouldn't because it's too dirty. Care at Home staff won't clean. We get into trouble with the manager because of using our time this way".*

*"Difficult for Social Workers. Assess situation and see need, but don't have armoury to deal with this."*

*"Co-habitation, physically being in the same building, has made things easier".*

*"Problem with info that GPs provide to carers about respite as it gives them false hope".*

*"Delayed discharge means we are bombarded with respite requests. Nurses requesting respite for patients to free up beds. Ward staff are not honest with Case Workers. Significant paranoia behaviour wasn't mentioned. She was a delayed discharge."*

#### **Views of carers...**

*"I would like SDS to be fit for purpose and explained properly to carers so we are not left with the impression that it is a way of cutting costs and making us complete loads of paperwork and become tax accountants."*

#### **Views of respite providers...**

*"All booking is through Placements. Have seen me contacting carers directly because they can give me more information".*

*"Needs to be more dialogue between respite providers. I don't have any contact with the independent sector care homes that provide respite. If someone has been to respite somewhere else, would be good to have that recorded".*

*"We always carry out our own assessment. Speak to carers to check if POP is accurate... can be poor, though starting to get better. Quality depends on who fills them in. Not ideal but improving. We need to get a grip of where things are in it".*



## Appendix A: Key Findings from Conversations and Consultation with Carers and Carer Support Organisations

### Introduction

We begin this part of our report by reminding ourselves of some of the reasons **why carers need respite**. Here are some of the comments carers made during our review:

- *"I'm always so exhausted. I worry about not sleeping and how that will affect me the next day. I get one or two good nights sleep a week. I can't concentrate or follow a line of thought when I'm sleep deprived. It worries me if I'm awake all night."*
- *"I have to get up frequently throughout the night to help my wife. After getting up many times I can't get back to sleep. I'm lucky to get a full six hours once a fortnight. I have less patience due to lack of sleep and I'm less efficient if I have jobs to do. I worry about my lack of sleep if I have a long drive to do. I use games to distract me from thinking about other things."*
- *"When he's well my sleep's okay but when he's not it's awful. Sometimes I'm up ten times in the night with him. Twice I've got lost when out due to lack of sleep. I became disorientated. It's frightening when I get lost due to sleep deprivation but generally sleep doesn't worry me".*

For carers **who do receive quality respite it is seen as enormously beneficial**, a service that simply enables them to keep on caring. As an example, one carer whom we met was about to go away for a week's holiday because she had obtained respite. She was in a state of delight.

### Key Findings

**1. Respite care is a service for the carer, but it is granted through an assessment of the cared-for person.** Carers are not assessed in their own right when respite care is accessed. The process for accessing respite is through what was the Single Shared Assessment and is now the Personal Outcomes Plan. This process may include some assessment of the carer, but it is not formalised. Carers with whom we spoke generally remain unaware of the role of Carers Assessment or Carer Support Plans and even when they had been in receipt there was some feeling that it was trumped by the assessment for the cared-for person. The result is that the cared-for is generally the primary focus of the respite service, rather than it being primarily a service for carers.

- *"Carers' needs are not taken into account. The assessment for respite should be a joint assessment."*
- *"I have a Carers Support Plan. When I requested a review because more help was needed, I was requested to delay until annual review and then the case was then closed without annual review. My Support Plan is meaningless."*
- *"I would like the carer to be considered as the beneficiary of respite care and assessed on that basis, rather than the assessment being done based on the needs of the cared for person."*

**2. Respite needs to be in the right place, by the right service / person, to be of use.** For it to be effective respite Carers feel that it is vital that the respite is a positive experience for the person that they care for. Quotes from carers that illustrate this finding include:

- *"I would like respite to be suitable for my cared for person, and not just a 'holding area' that they can be put into until I come back to collect them."*
- *"I was under pressure to put mum into somewhere that wasn't appropriate and it wasn't where she wanted to go"*
- *"Lack of local provision forces other alternatives, which are not always ideal."*
- *"There is nowhere appropriate in Inverness, nearest place is Forres (for a person with MS) but that's NHS Grampian."*

- *“Travelling long distances is inappropriate for frail elderly people.”*
- Talking about day care one carer said: *“It is like a child’s first day of school. They don’t want to go but when they get there they are fine. You also want to call up and see if they are ok.”*
- *“Having the same person delivering care is really important to the person with dementia and the carer.”*
- *“Consistency can be important to help them accept the support and ensure the carer gets the assistance they need. They get to know the person and they have an added befriending role. Consistency is important to get the person with dementia to accept someone.”*

**3. There is a lack of core residential respite care** – this is the type of respite that carers say they need to give them a real break from their caring role. It is what carers think of when asked about respite, and they often responded to say of that form of respite:

- *“it is non-existent”*
- *“There’s no respite for me, I feel completely stuck”.*
- *“If I could have had ‘respite’ my husband would be able to live at home...he wouldn’t be in a care home now”*

**4. Often there is no emergency respite available.** Carers have to stay in situations where they have stated they no longer wish to care. Carers report the absence of emergency planning.

- *“There must be provision of respite in emergency situations. In my case a sudden hospital stay with heart problems and needing immediate respite care for my husband (in his mid 80s) with Alzheimers – needing 24hr care. Beds should be available.”*
- *A group of carers said that a big worry is getting ill and what will happen to the person they care for in that situation.*

**5. Much of what can give some carers a short break from their caring role is often regarded by them as not constituting respite.** This includes attendance at day care and Carr Gomm / Crossroads type services and support services for the cared-for person. When asked about respite, carers almost always discussed overnight, residential care or nursing home services.

- *“Respite is where the cared for person goes away overnight”.*
- *“Getting a break is not respite. What is respite and what is a break? It feels like it has been switched round by the NHS. Doing the shopping or going for a cup of tea is just living, it is not respite. If that is respite we may as well all have dementia.”*
- *One group of carers said that respite would need to be a couple of days, or a week to really count. Even an afternoon off is not respite.*

It is not that such services are regarded as of no benefit – as the following story shows – it is that they are not classified as respite.

- *A carer said she was “lucky” that her husband accepted a support worker who built a relationship with him making her more confident about going out during the visit. She added that this was a great benefit to them both. She got a ‘break’ to do the shopping or visit friends and her husband had a friend who he could talk to and about.*

**6. Conflict between the wants and needs of carers and the cared-for person can arise.** A group of carers said this made life difficult for them:

- *“If the person for whom they care wants to stay at home, not go out and have them as carers there all the time, then that is what they tend to do.”*

**7. There is very little information and guidance on what carers can expect in terms of accessing respite care.** Carers are saying they often feel they have to *“fight for it”*. This includes how respite is allocated, charges, amount of respite and transport.

- *"I do not want to be a case manager. I want the professionals who are paid to provide services or manage them for us to be the case managers and to act proactively so that i can get on with the job I do expertly – being a brilliant carer."*
- *"Such a complicated system with so many people involved. Which one to contact?!"*

**8. Very limited transport available.** Carers report that transport issues include: the expense of it; cancellations (sometimes at the last minute); having to ask friends, family or neighbours to assist; or carers providing own transport, which reduces the amount of a break they get with the respite.

- *"Transport for the cared-for is difficult to get."*

**Another issue impacting on respite that confronts carers who do not have their own transport is when carers have to attend hospital for appointments for themselves** (as opposed to accompanying the cared-for person to hospital). They say the lack of suitable transport to hospitals increases the length of time for which they require respite.

**9. Respite and Transition issues.** Carers say are bemused by the changes in the availability of respite when the person they care for enters adult services. They wonder why provision that works well is no longer available to them (especially when they see it being under-utilised). If the reason given is that children and adults do not mix then they ask why a similar sort of provision cannot be made available for adults.

**10. Carers often do not expect that Social Workers will be able to access the respite resources they require.** They say:

- *"I would like to be sure that I could call someone and achieve a result, and not just be told that I would have to wait to be assessed or that there was no suitable service locally."*
- *"I would like to be confident that if I contacted social work I would be allocated a worker who would act proactively on my behalf, knowing that if I am not supported, my cared for person is going to have a lower standard of care, or I am going to burn out."*
- *"As for his [the cared-for] social worker I have found him of very little use whatsoever. He seems to forget that he is only partly in charge of my father's care (and this had to be done in case I was ever in hospital when they needed a decision on something) and I am fully in charge of my father's money care. He never gets in touch with me and if I need anything done I now go via my own social worker."*
- *"She's a nice lady who has a big work load and no resources."*
- *"Always the care and support of local staff is EXCELLENT and much appreciated."*

**11. Experience of Self Directed Support is mixed.**

**(a)** Some report Self Directed Support is of limited use to them as carers because of the lack of available support.

- *"SDS funding is of no use if resources are not available which is very much the case where I live and within a wide surrounding area."*
- *"The current procedure takes too long. This leads to added stress for carers."*
- *"I would like SDS to be fit for purpose and explained properly to carers so we are not left with the impression that it is a way of cutting costs and making us complete loads of paperwork and become tax accountants."*

**(b)** On the other hand a number of carers speak of how *"SDS is improving"* or has been a success for them. One said that she is *"delighted with the service and feels less stressed"* now SDS has started. Another carer said SDS had enabled her to continue in employment and be able to support other members of her family.

## Appendix B: Key Findings from Conversations with Staff in Health and Social Care

We had very helpful and engaging conversation with over 50 staff in health and social care across the Highlands. Here are the **Key Findings** from these conversations.

1. **Respite, as a term, is generally understood as first and foremost being about residential respite.** Other forms of respite were discussed but often much later in our conversations. Respite was often used to describe a break, regardless of whether it was for the carer or the cared-for person. Therefore people who have no carers receive 'respite'. Some social workers point out health professionals can ask for respite for a person when it is convalescence, not respite, they are talking about. People reported there was a lack of clarity in what was being referred to when using the word 'respite' including; what it is; who it is for; and who provides it.
  - *"There is a huge misunderstanding of what respite is. We suffer when hospitals are trying to deal with delayed discharge. They can bombard us with calls saying what people are needing is respite, when it's not. People often really mean convalescence when they are talking about respite. Respite is for the carer."*
  - *"Respite can be seen as the first thing to try even if the situation is beyond a person being able to stay at home."*
2. **The necessary resources are not available to provide the core respite carers need.** Carers in many situations are seen to be under major pressure but the consensus is that the respite resources available fall far short of what is required to meet the needs of carers/ carers' desired outcomes. And that pressure on carers is seen to be growing and the respite resources available are nowhere near keeping pace with the increasing demand. People cited examples of caring situations that have broken down because carers were unable to get the support they required. Emergency respite poses significant additional challenges.
  - *"My heart goes out to people we are not supporting. It's awful going out to people and seeing situation they are living in. Don't want to raise hopes."*
  - *"I know of two or three caring situations that have broken down. It happens to carers especially when they can't sleep or they have mental health problems. Acute infections act as a trigger for carers – they can't cope."*
  - *"Difficult for Social Workers. Assess situation and see need, but don't have armoury to deal with this."*
3. **There is seen to be a gaping hole in availability of residential respite in Inverness, Nairn, the Black Isle, and much of Easter Ross.** The absence of respite in these areas was noted by many. We were told:
  - *"We tell carers here in Inverness there's respite available in Skye or Thurso or somewhere else that's far away and they say, 'no thanks, we don't want to go with the frail person we're caring for that long distance; they won't be able to make that journey!'"*
  - *"Carers often want to visit their loved one during their respite period especially initially and they can't do that if the person is on respite more than 100 miles away so they turn down respite opportunities."*
4. **Trust amongst health professionals, those in social care, and respite providers is at a premium in a significant number of settings.** People acknowledge that staff everywhere under pressure. Single Shared Assessments (SSAs) are seen at times as having been largely the province of social workers. A significant number of social workers told us that they believe many health professionals will avoid completing the SSA forms. Some social workers say they feel their whole profession is being devalued and integration was equated by one person as being like "an abusive marriage". Delayed discharge and the need to move people on from acute hospital settings has resulted in concerns that assessments are not always completed honestly, as full information may result in a respite setting refusing the patient.

- *“Ward staff are not being honest with us or with carers. I am quite angry about it. There are lots of communication problems with hospitals. Carers tell us we were promised A,B and C and nothing is being done!”*
  - *“It’s like being a baker with no yeast or flour. We are asked to do our job with no resources. That’s what it feels like to be a social worker today.”*
  - *“We’re encouraging people to stay at home. They want practical support. But how do we get out to them with that support?”*
  - *“People think we are being obstructive!”*
  - *“People say to us: ‘My doctor said social work will be able to give you respite.’ And we don’t have the respite they are looking for straightaway.”*
- 5. Carers’ expectations of respite are often inaccurate, either expecting too much, or equally, not enough.** These expectations are seen as not based on accurate, up-to-date information, (as in the paragraph above where for examples) and can impact on carers’ relationships with staff in health and social care:
- *“People are unrealistic. They don’t realise they’ve got to give up to 8 months’ notice for respite.”*
  - *“I had one carer who said he was going away on holiday for 4 weeks the next week and could we arrange care. We get requests like that from some people who don’t realise what’s involved in arranging respite.”*
- 6. Carers are not routinely assessed, and their respite support is based on an assessment of the cared-for person rather than of their needs as a carer.** Where they gain access to respite it has come through the Single Shared Assessment (SSA) or the Personal Outcome Plan (POP), not through a Carers’ Assessment or Carer Support Plan. The Personal Outcome Plan is being viewed sceptically by many. People have told us they have not been trained in it. They also believe that the time taken to complete it is far greater than for a SSA. They say too that they don’t want to be beaten by a spreadsheet/algorithm.
- *“Carers Assessments are not used as much as they should. Respite needs SSA, RAP paperwork, SDS paperwork - Carers Assessment is lower down than the rest.”*
  - *“Emphasis in Carers Assessment is not on getting services, first and foremost it is about carers being able to express themselves.”*
- 7. Inappropriate respite is refused by carers, who have been assessed as needing it.** They are then left without support that they require. Respite can be inappropriate in terms of location, time, place, compatibility, activity and choice. Available residential respite is seen by a significant number as not being available where carers and cared-for people often want it – in their own localities. Available respite is seen by many as unsuitable for younger people (that can mean not only younger adults with long-term conditions but people in their 70s in that care homes are seen to be for people who are in their 80s upwards).
- *“Younger adults with long-term health conditions are poorly provided for. Often we are left suggesting placements for younger people in an older adults care home. There is often no Wi-Fi access or decent TV reception. One person described to me having a very lonely experience and he would not go back.”*
  - *“Currently respite is more about location than need. Majority would say they don’t use it because of location.”*
- 8. There is a lack of information and guidance on respite entitlement, allocation, and monitoring.** There is uncertainty about the level of residential respite that is available to be allocated. Some said 4 weeks was the norm; others said there was no norm, it depended on individual requirements and could vary from 2-10 weeks. Many social workers say they do not understand how decisions about respite are arrived at in the District Care Planning meetings.

It has been said that the residential respite available is under-utilised. When that information has been communicated to those with whom we met it has been greeted with disbelief. We were told that if there is a cancellation people scramble to book every available bed.

- *“Duty of care transcends any policy.”*
- *“The pressure on carers is escalating all the time. We’re trying to manage a crisis but we can’t get the services for them because there are waiting lists.”*

9. **Transport availability has a significant impact on the ability of carers to access respite.** There are a variety of practices regarding transport to respite. Some say social work will never provide it; others do supply it if other options have been exhausted.

- *“Transport can be the deal breaker if people are reluctant to go to respite.”*
- *“Moral obligation to find support.”*

## Appendix C: Key Findings from Conversations with Respite Providers

1. **Speaking generally the focus by providers is primarily on the cared-for person and the outcomes that they are seeking or requiring – and not on the carers themselves.** Effectively it is often assumed that the carers' outcomes are being met by being given a form of respite where they are assured the person for whom they care is receiving quality care. Providers are well aware that the carer's mind will be restless unless he or she knows that the person for whom they care is receiving good care and is as settled as possible. Providers can and do listen to carers but in most cases this is not a sustained and consistently applied form of support largely because the providers have to concentrate on the needs of the cared-for person. In other words it is not designed into provision.
2. **Opportunities to provide additional direct support to carers is something a number of day centre and care home providers would welcome and indeed some are already doing work in this vein** – and looking at more they can do. Examples of work underway include: a regular carers' café which is planned for the MacKenzie Centre, Inverness in conjunction with Connecting Carers; carers being invited to lunch in more than one setting; and information and advice is given on accessing other services.
3. **From another non day-care, non-residential provider came some startlingly good examples of outcomes that carers had been enabled to achieve with the additional support of the provider's staff. However, these outcomes arose not from intentional conversations about desired outcomes with carers and therefore were not intentionally designed into the support given to them.** These outcomes appeared as by-products of support that arose from high-quality staff being alive to the interests and needs of the carers for whom they were providing respite. Examples include:
  - *A carer being taught about the practicalities of caring in a systematic and empathetic way and as a results becoming much more confident in the provision of additional care. If this guidance given had not been successfully communicated and willingly received by the carer the person receiving care would, by all accounts, have already moved into long term care. Instead that person is at home and the carer is receiving short breaks (measured in hours) from a provider with whom they are much engaged and in whom they feel very confident.*
  - *Another carer was at a loss to know what to do with the time that had been allocated to her. A particularly able member of staff spoke with her about the things she liked to do and aided her to achieve these ends.*
  - *Other carers too have been actively assisted to access opportunities in their communities that would otherwise not have been possible.*

From these and other examples it became apparent that there is a considerable opportunity for carers to be supported in ways additional to the provision of a break of a few hours.

4. **Providing respite for carers living a distance away from the source of provision is seen by many as far from ideal.** No-one with whom we spoke invoked the idea of a holiday – except to discount it. One person told us of a client who arrived “thinking she was going to be able to go out and about but we told her we didn't have the staff to go out with her.” (Note: while nobody spoke of people attending going on a holiday, there are some facilities that offer opportunities for those on respite to go out. One residential facility spoke of enabling clients to go for walks - accompanied and unaccompanied - and visit the local shops.)
5. **Providers frequently find the information with which they have been supplied at the time of referral to be inadequate.** Providers cited examples of incomplete, inaccurate, out-dated information accompanying those arriving for respite. For some providers this on occasion placed them in a position where they did not have either the staffing or the equipment they required. At times it resulted in what they saw as unsafe admissions. Trust again is at a

premium. To guard against the possibility of being left with inadequate information, some providers are now dispatching detailed forms to carers for them to complete before the cared-for person's admission which some see as being overly bureaucratic.

6. **Residential providers spoke of the paperwork surrounding admission for respite as being considerable, pointing out that it, rightly, they said, was the same as for a new long-term resident.** A number felt that the time required for completing these administrative tasks was not always understood by other people within the system.
7. **One major consideration for residential providers is compatibility - how a person arriving for respite might fit in with the longer-term residents of their facility.** They are conscious that this is the residents' home and a disruptive arrival may have a profound effect on the well-being of such residents. Some have said they see what amounts to a culture clash between managers from health, who are accustomed to hospitals being able to accommodate people in all sorts of conditions, with managers of care homes who view their facility as being primarily a home for the people residing there long-term. Pressure to take people is applied to managers who view the referred person as inappropriate for their facility given their concern for the welfare of their residents. Note that this issue of compatibility works the other way too – one manager spoke of a person on respite who was distressed to find residents of the home in which she was staying entering her room without being asked and taking food from her table.
8. **Some providers felt pressurised (one even said “bullied”) into accepting the admissions of people who were not suitable for their settings.** This seemed to be an especially critical area in the case of emergency admissions.
9. **A number of people spoke of an ideal care pathway for those thinking of attending for respite** – one where there is a progression from a low-key introduction to day care via attending for lunch or a short visit followed by a longer day-time visit and then a brief residential stay (with the carer remaining in hailing distance should anything go amiss). Should each of these stages be passed successfully the longer stay becomes much simpler and straightforward. Or where there is no day care on site, providers spoke of ideally going to visit the person who is coming on respite in their own homes.
10. **Practice varies from residential facility to residential facility as to whether there is an admission on the same day that another person is discharged.** Some providers who say that they need a day between cite two main obstacles to a same-day turnaround: firstly, the amount of paper-work that needs to be completed; and secondly, the deep cleaning that is required on occasion. Others indicated that provided they had the necessary staff they could provide the same day turn-around.
11. **Older people and their carers using Self-directed Support (SDS) to obtain any form of respite is a rare phenomenon.** If SDS in its various forms is to become truly available for all who could benefit from it concerted action is needed on a variety of fronts to make this a reality. There are a number of providers who have experience of SDS and they are keen to expand their work in this area.
12. **Conflicts between the carer and cared-for person about respite can and do happen.** It was reported that at times carers want a complete break but the cared-for person does not want to leave their home. That can be an issue both for residential respite and also for those providing short breaks during the day. Sometimes carers are wanting to have the home to themselves and therefore want the person for whom they are caring to go out for a few hours or go to stay elsewhere - a care home or other facility – for respite.
13. **A number of the managers of day centres spoke of their readiness to expand their hours – into the evening and during weekends to provide additional support for carers.** Already some which also have residential facilities do operate with a degree of flexibility that sees carers being able to obtain respite into the mid-evening to accommodate, for example, day-



long trips that they are making to Inverness. One day centre manager who did not have any residential rooms in her facility thought that an attached dedicated 6 bed residential respite unit would work.

14. **Overnight care in a person's own house is a form of respite which seems to be only occasionally used.** Some people referenced Marie Curie as providing such respite in the latter stages of a person's illness (and that this gave carers much needed breaks) but other than that there seemed to be a dearth of this form of respite. One provider indicated that they were ready and willing to provide this service but they had no-one using it.
15. **The organisation KEY is developing a new form of respite within their cluster in Nairn.** A two bedroomed flat will be available to be used flexibly (at least initially) for carers of those young people with profound and complex needs. A similar venture is also to be established by Key in Fort William and there is the prospect of another in Caithness (whether it is a Key facility or run by another organisation). In principle there seems no reason why this form of respite should not be extended to carers of other clients groups.
16. **There is a growing general interest – from what we can gauge – in providing discrete services for young people aged 14 to 24 and this interest has its relevance for respite services too.** Increasingly it appears that a cut-off point at age 18 or 19 is out of kilter with the growing body of evidence that young people need discrete services that cater for their requirements up until age 25. Respite providers make it clear that many parent/carers in receipt of respite services find the cut-off from these services that are working well for their young people distressing and not at all person-centred. The question is asked: can services such as the Orchard develop to cater for 14-25 year olds?

## Appendix D: Key Findings from Conversations with and Information supplied by the Commissioners, Planners and Administrators of Respite Services

1. We were supplied by the Management of the Placement Team with the Respite Booking Procedure Guidance for Contract Staff for both the booking of NHS block beds and Independent Care sector block beds. There is a flow chart accompanying these documents. We were also supplied with a document giving guidance for cancellation of bookings. All these documents appear to be very clear as to the processes and procedures which are to be followed.
2. The documents reference how internal shared drives are to be used to check for availability in various care homes and to go through the booking process. From conversations we have had with staff in health and social care and with the management of the Placement Team responsible for co-ordination and finalising of the booking process (and dealing with cancellations and notifying teams about ensuing vacancies), these are well understood procedures which appear to have a high level of compliance.
3. The list of available beds is also clearly detailed regarding nursing and residential care under the following two categories.

(a) *“The list of Independent Sector care homes providing nursing respite care under the Block Contract is as follows:”*

<i>Seaview House, Wick</i>	<i>1 Bed</i>
<i>Castle Gardens, Invergordon</i>	<i>1 Bed</i>
<i>Home Farm, Portree</i>	<i>1 Bed</i>
<i>Moss Park, Fort William</i>	<i>1 Bed</i>
<b>Total</b>	<b>4 Beds</b>

(b) *“The list of NHS in-house care homes with dedicated residential respite beds is as follows:”*

<i>Melvich CCU, Melvich</i>	<i>1 Bed</i>
<i>Bayview House, Thurso</i>	<i>1 Bed</i>
<i>Seaforth House, Golspie</i>	<i>1 Bed</i>
<i>Pultney House, Wick</i>	<i>1 Bed</i>
<i>An Acarsaid, Broadford</i>	<i>2 Beds</i>
<i>Lochbroom House, Ullapool</i>	<i>1 Bed</i>
<i>Starthburn House, Gairloch</i>	<i>1 Bed</i>
<i>Telford Centre, Fort Augustus</i>	<i>1 Bed</i>
<i>Grant House, Grantown-on-Spey</i>	<i>2 Beds</i>
<i>Wade Centre, Kingussie</i>	<i>2 Beds</i>
<b>Total</b>	<b>13 Beds</b>

- (c) What is evident from the geographic locations in this list of 17 beds is that there are no beds in the settlements of Inverness (pop: 61,000), Nairn (pop: 10,000), or in areas such as the Black Isle (pop: 10,000).
4. Occasional updates on respite booking procedures are also emailed from the Placement Team Management to their colleagues in NHS Highland. As an example of updated information in a recent communication this statement was made:

*“The following Care Homes are not taking overlapping (same day admission-discharge) respite bookings due to understaffing/need to comply with CQC’s standards of cleanliness:*

- 1) *Bayview House, (Thurso)*
- 2) *Wade Centre (Kingussie)*
- 3) *Grant House (Grantown-on-Spey)*
- 4) *Seaview House Care Home (Wick)*

- 5) *Home Farm Care Home (isle of Skye)*
- 6) *Strathburn House (Gairloch)*
- 7) *An Acarsaid (Isle of Skye)*

5. As far as carers of people with learning disabilities is concerned the 6 bed Beachview Respite Lodge Unit in Brora has been the main facility providing respite. Its closure in March 2015 led to replacement respite being organised meantime primarily through Seaforth House Care Home in Maryburgh.
6. In **Table 1** below **the availability and up-take of beds for the planned in house (NHS) block booked respite for 2014-15** is shown:.

Table 1: NHS (In house) Block Booked Bed Availability and Usage 2014-15	
Available Beds	4,783
Beds Booked	3,920
Beds not Booked	863

This gives an **occupancy rate for the year of 82%**.

There were **1,677 nights** which were cancelled during the year. The majority of these were filled by new bookings but some cancellations came too late to allow this to happen at least in full. Reasons for such cancellations include: people moving into long term care; the death of the person who was going to come; and illness necessitating hospitalisation.

7. As **Table 2** below **Occupancy rates vary throughout the year** shows (the Table being ordered according to the levels of occupancy):

Table 2: NHS (In house) Block Booked Bed Occupancy Rates per Month 2014-15	
Month	Occupancy Rate
July	88.5%
February	86.3%
September	84.6%
October	84.6%
January	84.1%
November	83.1%
August	82.0%
December	81.6%
April	80.7%
June	78.3%
March	77.9%
May	73.3%

Table 2 shows that in 2014-15 **the peak month was July (88.5%)** followed by February (86.3%) and then by September (84.6%) and October (84.6%). **For three months rates dropped below 80%** - May (73.3%); March (77.9%); and June (78.3%). April (80.7%) is the next lowest. Though these months belong to different calendar years, this shows that the 4 month period March-June had a notably lower occupancy rate (averaging 77.6% per month) than the 4 month period July-October (averaging 84.9% occupancy). The occupancy rate for the remaining 4 months of November-February (83.8%) is marginally lower than the preceding 4 months.

8. As Table 3 shows, **occupancy rates vary according to the care setting as well as far as the NHS (in house) Care Home block respite services are concerned.** To allow for clarity in viewing, Table 3 is ordered according to average monthly occupancy rate.

Table 3: NHS (In House) Block Respite Occupancy Rates Per Care Home in 2014-15			
Name of Facility	Highest Monthly Occupancy Rate	Lowest Monthly Occupancy Rate	Average Monthly Occupancy Rate
Seaforth House	100.0%	80.0%	93.4%
Telford Centre	100.0%	71.0%	91.3%
Strathburn House	153.6%	74.2%	90.6%
Lochbroom House	100.0%	76.7%	87.9%
Melvich CCU	100.0%	16.7%	82.7%
Grant House	95.2%	66.1%	82.0%
An Acarsaid	100.0%	61.3%	81.8%
Wade Centre	88.3%	51.6%	75.6%
Bayview House	85.5%	43.5%	66.8%

(NB: The MacKintosh Centre was extracted from the above Table because it was only available for respite during 4 months of the year 2014-15.)

It was pointed out to us that there can be a variety of reasons for lower occupancy rates other than the obvious one of cancellations. These reasons include staffing levels and widespread illness within a facility. Another factor is the way in which bookings are organised to accommodate the dates desired by carers and the people for whom they care. That can mean there is a brief interval between bookings that cannot be filled. Some of the care homes too have arranged to have a clear night between bookings to allow, it is said, for deep cleaning and to complete the paperwork involved. As long as that arrangement stands these nights – it could be argued – are not therefore “available nights” and in the future could be removed from the calculations of occupancy rates.

9. There were a total of **3,669 bed-nights occupied by some 207 people with a carer** during 2014-15 in the NHS (in House) Block Booked service. That gives an average of 17.7 nights per client. In looking at the age profile of clients with a carer, the median age of clients is 86. Note in 2014-15 there were an additional 255 bed-nights (6.5% of all bed-nights) in this Respite Service occupied by 21 people who did not have a carer.
10. In Table 4 below you will find the occupancy rates for the **Block Booked Independent Sector Care Homes.**

Table 4: Independent Sector Block Respite Occupancy Rates Per Care Home in 2014-15			
Name of Facility	Highest Monthly Occupancy Rate	Lowest Monthly Occupancy Rate	Average Monthly Occupancy Rate
Moss Park	100%	83.3%	95.1%
St Olaf	100%	45.0%	91.4% (10 months)
Castle Gardens	100%	61.3%	87.1%
Seaview	100%	13.3%	83.8%
Home Farm	96.7%	63.3%	83.0%

11. In all within these 5 Independent Sector beds there were **1,708 bed-nights available** of which **1,499** were occupied giving an overall **occupancy rate of 87.8%**. Of these 1,499 nights some **1,449 (96.7% of all bed-nights)** were occupied by people with a carer. In total **107 people** with a carer occupied these bed-nights giving an **average of 13.5 nights per client** during the year. Note that many of these clients had more than one episode of respite during the year – there being **226 respite episodes in all with an average stay of 6.4 nights per episode**.

### Spot Purchase Bed Night Statistics for 2014-15

12. Table 5 below shows the number of spot purchase beds by Social Work team in 2014-15. The Table is ordered according to the total number of nights which were purchased. As you will see from the names of the teams there was a re-organisation of teams during the year which makes complete comparison difficult. However some patterns are evident.

Social Work Team	Number of Nights (No Unpaid Carer)	Number of Nights (Unpaid Carer)	Total Number of Nights	Percentage of All Nights Purchased
East Inverness	1743	1214	2957	25.0%
Mid and West Ross	1295	1199	2494	21.1%
Sutherland	855	702	1557	13.1%
Caithness	456	566	1022	8.6%
Nairn, Badenoch & Strathspey	404	571	975	8.2%
Easter Ross	78	507	585	4.9%
Lochaber, Skye & Lochalsh, and Wester Ross	389	186	575	4.9%
West Inverness	38	499	537	4.5%
Lochaber	278	161	439	3.7%
Lochaber, Skye & Lochalsh	180	249	429	3.6%
Mid Ross	36	239	275	2.3%
<b>Totals</b>	<b>5,752</b>	<b>6,093</b>	<b>11,845</b>	

Table 5 shows that there are considerable variations by Social Work team according to the number of nights that are purchased:

- Inverness East purchased 25% of all nights while Mid and West ross purchased 21.1% and Sutherland purchased 13%.
- At the other end of the scale West Inverness purchased 4.5% of all nights.

There is another fascinating feature evident within Table 5 and that is the mix of carer and non-carer purchased nights. The Table shows that of the **total 11,845 nights** spot purchased:

- **6,093 (51.4%) nights** were for people who had an unpaid carer
- **5,752 (48.6%) nights** were purchased for people who did not have an unpaid carer.

13. But these overall percentages disguise major **differences in the mix of carer and non-carer nights per social work team**. To facilitate understanding of these figures we have presented them in a separate Table - Table 6. The Table is ordered according to the percentage of nights purchased where there is an unpaid carer.

<b>Social Work Team</b>	<b>Percentage of All Nights Purchased (No Unpaid Carer)</b>	<b>Percentage of All Nights Purchased (Unpaid Carer)</b>	<b>Total %</b>
<b>West Inverness</b>	<b>7.1%</b>	<b>92.9%</b>	<b>100</b>
<b>Mid Ross</b>	<b>13.1%</b>	<b>86.9%</b>	<b>100</b>
<b>Easter Ross</b>	<b>13.3%</b>	<b>86.7%</b>	<b>100</b>
<b>Nairn, Badenoch &amp; Strathspey</b>	<b>41.4%</b>	<b>58.6%</b>	<b>100</b>
<b>Lochaber, Skye &amp; Lochalsh</b>	<b>42.0%</b>	<b>58.0%</b>	<b>100</b>
<b>Caithness</b>	<b>44.6%</b>	<b>55.4%</b>	<b>100</b>
<b>Mid and West Ross</b>	<b>51.9%</b>	<b>48.1%</b>	<b>100</b>
<b>Sutherland</b>	<b>54.9%</b>	<b>45.1%</b>	<b>100</b>
<b>East Inverness</b>	<b>58.9%</b>	<b>41.1%</b>	<b>100</b>
<b>Lochaber</b>	<b>63.3%</b>	<b>36.7%</b>	<b>100</b>
<b>Lochaber, Skye &amp; Lochalsh, and Wester Ross</b>	<b>67.7%</b>	<b>32.3%</b>	<b>100</b>

14. Table 6 shows a notable variation in that:

- the vast majority of spot purchased nights were for people who had an unpaid carer in three of the Teams namely, West Inverness (92.9%), Mid Ross (86.9%) and Easter Ross (86.7%);
- while the percentage of spot purchased nights that were for those with an unpaid carer is much notably lower in Lochaber, Skye & Lochalsh, and Wester Ross (32.3%), Lochaber (36.7%) and East Inverness (41.1%).

15. Some **560 people with a carer were the recipient of spot purchased bed-nights in 2014-15. Of these 560 people some 343 were aged 65+**. The median age of an older person under spot purchase arrangements was 84. These 343 people received 4,454 bed-nights during 355 episodes of care. **Per person that amounts to 13 nights** while per episode of care it amounts to 12.5 nights. **A further 217 people were aged 18-64** and they received 1,639 bed-nights during 265 episodes of care. **Per person that amounts to 7.6 nights** while per episode of care it amounts to 6.2 nights.



16. What is also clear from the statistics for 2014-15 is that a number of people with no unpaid carers who were occupying beds under spot purchase arrangements were doing so for lengthy periods. Table 7 below shows that 26 people with no unpaid carers were in beds for 35 nights or longer. In total 2,589 bed nights were occupied by these 26 people – amounting to an average of 99.6 nights per person

Table 7: Cases of Spot Purchased Bednights (Non Carer Breaks)	
Client	No. of bednights (non carer)
1.	365
2.	365
3	184
4	177
5	116
6	100
7	100
8	99
9	94
10	92
11	87
12	86
13	85
14	75
15	62
16	60
17	59
18	51
19	49
20	45
21	42
22	41
23	41
24	41
25	38
26	35
Total	2589

17. While we have highlighted the above we have learned that in this current year (2015-16) Managers are being alerted to all cases of people who have been placed from more than 28 days under spot purchase arrangements. As we were told of cases of people in care settings for longer than 28 days: *“This is clearly not respite.”* Managers are being nudged to look these cases afresh and consider other provision.
18. Emergency care provision is a notably different service from planned respite. Indeed we were told: *“It is incompatible with planned services.”* Those administering respite and not equipped to deal with emergencies – that is seen as a task which much better sits with experienced social workers. From the perspective of carers too emergency care provision is also incompatible. Emergencies that have arisen in their lives (e.g. deterioration in their

own health; changed family circumstances etc.) that occasion the need for replacement care are not seen by them as resulting in a service that they label respite. Respite is the planned break.

19. There is a belief therefore that emergency care should be separated out from planned respite. Planned respite could be part of a booking.com type service – a short breaks bureau that has access to all relevant information and makes that freely available on-line and enables bookings to be completed (with the necessary accompanying information) and changed smoothly.
20. Meanwhile for emergency respite it is suggested it should find its place within social work services so that there could be direct access from social work to care facilities to enable replacement care to be purchased. Obviously there is a need to design any such development carefully to ensure equity of access and the presence of strong quality and financial controls. The belief though is that it is social workers that ought to be making these decisions and organising such care.

### **Additional Information Required**

21. We are aware of the need to consider more data relating to: residential respite (e.g. allocation of nights/weeks by area and how this links to uptake); Day Centre provision (e.g. trends in uptake of services by area); and Carr Gom/ Crossroad- type services (e.g. allocation of hours by area and uptake). In the next edition of this review we will aim to include such information.
22. We also need to consider financial information and how this relates to respite usage. In addition we need to factor in the impact of SDS and how trends in its use is affecting provision and use of respite services.

## Appendix E: Additional Context

### 1. Additional Information

The purpose of this Appendix is to give you as a reader additional background or contextual information about a range of developments affecting carers nationally and locally.

### 2. The Carers (Scotland) Bill

In March 2015 **The Carers (Scotland) Bill** was introduced to the Scottish Parliament and because of the significance of the changes it will bring about - when it becomes an Act and its provisions are implemented - with regard to carer support in general and respite/short break provision we highlight the **main features of the Bill** as it currently stands (early Dec 2015). We begin with a key extract from the **Policy Memorandum** which accompanied the introduction of the Bill:

**In summary the main features of the Bill are:**

- Carers Assessments will change their name to **Adult Carer Support Plans**.
- At the moment only carers providing care on a 'regular and substantial' basis are legally entitled to a carers' assessment. **This test will be removed so that all carers can access an Adult Carer Support Plan.**
- The **requirement that the person being cared for must be someone to whom the local authority provides a community care service** will be removed.
- There will be **two routes to assessment – a carer can request one and the Local Authority can offer one**
- The reference to a carer's ability to provide care will be removed. Instead it will refer to **a carer being 'able and willing' to provide care.**
- Local Authorities will have a duty to prepare and publish a **Short Breaks Statement** as per the following extract from the Bill:

#### **32 Short breaks services statements**

- (1) Each local authority must prepare and publish a short breaks services statement.
- (2) A short breaks services statement means a statement of information about the short breaks services available in Scotland for carers and cared-for persons.
- (3) The information must be accessible to, and proportionate to the needs of, the persons to whom it is provided.
- (4) The Scottish Ministers may by regulations make further provision about the preparation, publication and review of short breaks services statements.

*Extract from The Carers (Scotland) Bill*

- **Local Authorities will have a duty to support carers who meet eligibility criteria and a power to support carers in a preventative manner** where they do not meet eligibility criteria.
- **Guidance will be issued on Adult Carer Support Plans**, which will include information on the different stages of caring and the need for a review to address periods of transition.
- There will be a **duty on Local Authorities and Health Boards to involve adult carers, young carers, carer organisations and other relevant organisations in the planning, shaping, delivery and review of services.** This duty will extend the provisions within the Public Bodies (Joint Working) Act.

- **Local Authorities will be required to take into account the views of the carer when** determining the needs of the person being assessed and deciding what services to provide and how to provide them.
- There will be a duty on **Local Authorities to develop and publish local carer strategies and to involve carers in the development of review of strategies.** Carer strategies must be reviewed every 3 years.
- **Local Authorities will be required to take into account the care provided by an unpaid carer when conducting an assessment of the cared-for person.** Where there is an Adult Carer Support Plan in place they must take account of this. Where there is not they must still take account of the care provided and ascertain what the carer is 'able and willing' to provide.

#### **Further Information on the Bill:**

To the above main features of the Bill we note the following recent developments. Jamie Hepburn MSP Minister for Sport, Health Improvement and Mental Health -who is responsible for the Bill's progress through the Scottish Parliament - in his remarks in the debate on Stage 1 of the Bill on November 5th confirmed that he will be taking forward the following amendments at Stage 2:

- The inclusion of **emergency planning** in both the Adult Carer Support Plan and Young Carers Statement and as part of the Information and Advice Service
- Re-wording the section on the Duty on Local Authorities to establish and maintain an **Information and Advice Service** to clarify that there is no requirement for local authorities to establish an information service where there is one already, but there is a requirement to maintain such a service.

He also said: *'I am pleased to confirm that **carers will not be charged for replacement care that meets their assessment needs; neither will the cared-for person be charged for support that meets a carer's eligible needs.***

In relation to **eligibility criteria**, the Minister indicated that the government's preferred approach is still for eligibility criteria to be developed locally. [NB: National Carer Organisations want a **national eligibility framework** and will be continuing to press for the Bill to be amended.] A **Financial Memorandum** accompanying the Bill lays out the requirement for considerable additional resources with the aim of ensuring the new provisions are capable of being implemented to a significant extent.

### **3. Equal Partners in Care (EPiC) Highland Carers Strategy 2014-2017**

At the outset of this report we emphasised that this Review of Respite stemmed from this Strategy which has been developed in full partnership with carers. Carers are seen within the Strategy as **equal partners in the provision of care.**

**The support people receive as carers does not make them service users – rather this support is seen as that which enables them to continue to provide care (or to disengage from caring) and to have a life outwith caring.**

The following summary from the Strategy highlights how the 6 EPiC Aims relate to proposed strategic activity and personal outcomes for carers within the context of individual Carer Support Plans.

EPiC Aim	Carer Strategy Proposed Action Areas	Carer Support Plan Outcome
2.1 To be identified	<ul style="list-style-type: none"> <li>• Recognising carers – work required to be undertaken in numerous settings</li> <li>• Carer Awareness Training conducted</li> <li>• Information and support for carers</li> </ul>	<ul style="list-style-type: none"> <li>• Informed about my caring role</li> </ul>
2.2 To be supported and empowered to manage my caring role	<ul style="list-style-type: none"> <li>• Carers Support Plan developed</li> <li>• Training for Carers</li> <li>• Carer Advocacy progressed</li> <li>• Emergency Planning</li> <li>• Carers in workforce supported</li> </ul>	<ul style="list-style-type: none"> <li>• Confident in caring</li> <li>• Healthy and well</li> <li>• Appropriate work and caring role balance</li> </ul>
2.3 To be enabled to have a life outside caring	<ul style="list-style-type: none"> <li>• <b>Respite/ Short Breaks</b></li> <li>• Self Directed Support</li> <li>• Benefits Advice and Information</li> <li>• Work/Life Balance</li> </ul>	<ul style="list-style-type: none"> <li>• Appropriate work and caring role balance</li> <li>• Appropriate education, training &amp; caring role balance</li> <li>• Appropriate social life and caring role balance</li> </ul>
2.4 To be fully engaged in the planning and shaping of services	<ul style="list-style-type: none"> <li>• Involve Carers in Carer Awareness Training</li> <li>• Gather Feedback from Carers</li> <li>• Involvement in strategic planning and improvement groups</li> </ul>	<ul style="list-style-type: none"> <li>• Confident in one's ability as a partner to shape services</li> </ul>
2.5 To be free from disadvantage or discrimination related to their caring role	<ul style="list-style-type: none"> <li>• Carers' Own Health – Checks/ extra support etc</li> <li>• Remote and Rural issues</li> <li>• End of caring</li> <li>• Poverty</li> <li>• Carers recognised as a diverse group</li> <li>• Employability</li> <li>• Young Carers Transition Adult Services</li> </ul>	<ul style="list-style-type: none"> <li>• Healthy and well</li> <li>• Confident in dealing with changing relationship</li> <li>• Free from financial hardship</li> <li>• Appropriate work, education, training and caring role balance</li> </ul>
2.6 To be recognised and valued as equal partners in care	<ul style="list-style-type: none"> <li>• Right to choose level of care</li> <li>• Involved in cared-for person's support plan creation and review</li> <li>• Supporting carers to be partners</li> </ul>	<ul style="list-style-type: none"> <li>• Confident in caring</li> <li>• Confident in ability as a partner to shape services</li> </ul>

**We believe that the discussing and agreeing and then the designing and implementation of the key features of recommendations arising from this review needs the full participation of carers and the many others who are existing and potential partners of carers.** This process matters in establishing a sense of joint ownership of the whole approach and the way in which it is monitored, evaluated and progressed. This is consistent with the Equal Partners in Care principles and with what is stated in the following extract from the Policy Memorandum accompanying the Carers (Scotland) Bill.

*16. It is essential that carers are fully involved in decisions at local level about strategic planning decisions of concern and interest to them. A lot of progress has been made over the years in this regard with further developments under the Public Bodies (Joint Working) (Scotland) Act 2014<sup>13</sup> (—the Public Bodies Act<sup>14</sup>) and implementing subordinate legislation which make provision requiring the involvement of carers and carers' organisations in relation to the planning, shaping and delivery of services and support which are provided in pursuance of —integration functions.<sup>15</sup> This is consistent with the principles of co-production which underpin the Government's vision for person-centred public services which use the talents, capacities and potential of all of Scotland's people and communities in designing and delivering services and support to meet carers' needs.<sup>14</sup>*

#### 4. Current Commissioned Carer-Specific Services in Highland

Within Highland we have a number of generic carer-related initiatives and carer support services as well as a range of organisations which provide support to carers as a feature of their work. Resources obtained through the Integrated Care Fund are enabling a number of new initiatives as well as augmenting existing services. In summary we have:

- Various respite services ranging from different types of residential (planned and emergency) through sitter services to other short breaks;
- Advice and information services through Connecting Carers;
- Carer Support Plans provided through Carer Liaison workers employed by Connecting Carers – and a proposed review of how support plans are working;
- Hospital Liaison workers – Connecting Carers;
- Highland Carers Advocacy service;
- Befriending service;
- Carer Involvement and Engagement post (to enable carers to become effective partners in care);
- Carer Strategy Implementation post (to support the functioning of the broad-based Carer Improvement Group - over 30 active member groups participate – and to accelerate the implementation of the Strategy);
- Carer Supportive Hospitals Project (to be nurse-facilitated - this project is under development);
- Identifying and Supporting Carers in areas of economic deprivation (under development with public health)
- Carer Positive (employers becoming carer supportive – project under development)
- Carer identification and support in primary care (under development)
- Excellent links to the work undertaken in support of young adult carers.

#### 5. The Main Statistics re Carers in Highland as per Census Returns

Table 8 below shows the number of carers in Highland is provided in recent Census returns

Table 8: Census 2011: Carers in Highland		
<b>All people in Highland</b>	232,132	100.0%
<b>Not providing care</b>	211,139	91.0%
<b>Providing 1 to 19 hours of care a week</b>	12,282	5.3%
<b>Providing 20 to 34 hours of care a week</b>	1,801	0.8%
<b>Providing 35 to 49 hours of care a week</b>	1,607	0.7%
<b>Providing 50 or more hours of care a week</b>	5,303	2.3%

Table 8 shows that in **2011**:

- The **total number** of people saying they **provide 1 or more hours of unpaid care a week** in Highland was **20,993**.
- The **total number** of people saying they provide **35+ hours of unpaid care a week** (i.e. the equivalent of a person in full-time employment) in Highland was **6,910**.
- The **total number** providing **50 or more hours** was **5,303**.



It is important to look at the trends in the population of carers in Highland and this is what Table 9 seeks to illustrate in making comparisons between the 2001 and 2011 Census Returns:

Table 9: Comparison Between 2001 and 2011 Census Returns for Carers in Highland			
Hours Spent Caring Weekly	2001 Census	2011 Census	Percentage Change
At least one hour of unpaid care	18,505 (8.9% of Population)	20,993 (9% of population)	+ 13.45%
1-19 hours of unpaid care	12,284 (5.9% of population)	12,282 (5.3% of population)	No Change
20-49 hours of unpaid care	2,089 (1% of population)	3,408 (1.5% of population)	+63.1%
50+ hours of unpaid care	4,136 (2% of population)	5,303 (2.3% of population)	+28.2%

Table 9 shows that **between the 2001 Census and the 2011 Census** there was a **13.45% rise in the number of carers in Highland from 18,505 to 20,993** – though the percentage of the population who said that they were carers showed just a marginal increase from 8.9% to 9.0%

However, Table 9 also shows that these overall figures disguise **remarkable changes** that are going on within the group of people identifying themselves as carers namely:

- **A 63.1% rise in the number of people providing 20-49 hours of unpaid care a week**
- **A 28.2% rise in the number of people providing 50 or more hours of unpaid care a week**

**A steep rise is taking place in the number of people identifying themselves as providing high levels of care per week.** This is consistent with the increasing caring responsibilities that would have been expected to follow the aging demographic profile of the population.

**Forecasting what may happen next is difficult** in that there is a suggestion that within Scotland's population as a whole (ref: Stirling University Professor David Bell's work) the availability of people to provide unpaid care may decline (as a percentage of the population if not numerically) because the baby boomers produced fewer children and their families are more dispersed than those of preceding generations. If this change materialise this is likely to mean that we will see the distribution of the carer population continue to change with higher percentages in the 20+ hours of caring per week.

**The implication of this is because it is likely that services could find themselves needing to provide more support for those who do not have any unpaid carers,** it will become even more imperative that those who are unpaid carers are afforded support that enables those for whom they are caring to stay at home for as long as possible.

## 6. Respite/Short Breaks and Meaningful Activities

- (a) It is important to clarify that respite/short break services which are primarily intended to benefit the carer are not to be confused with “meaningful activities” or other forms of support for the cared-for person which may result in the secondary effect of a carer receiving a break from caring. Carers and many of those working with carers argue that services which are designed for the primary benefit for the cared-for person do not constitute respite. It is of course possible that two outcomes can be intentionally realised at one and the same time in that while the carer is receiving respite the cared-for person attends a facility where they engage in “meaningful activities”. But the two services are discrete.
- (b) Note though that in situations where the people being cared-for are not engaged in regular “meaningful activities” or other services designed to benefit them outwith the home, carers in these cases are left with a heavier caring load (at the very least in terms of hours spent caring). Where such a situation prevails this should be a factor in considering the support such a carer requires.