

<i>item:</i>	7
<i>report:</i>	CYP44/08

CHILDREN AND YOUNG PEOPLE'S RESPITE CARE **by Bill Alexander**

Summary

This report sets out the key issues with regard to respite care for children, including the ongoing work to review provision, and the progress that has been made to date.

1. Introduction

- 1.1 The terms 'respite' and 'short breaks' are both used throughout this report. The term 'respite' is commonly understood, but the phrase 'short breaks' is preferred by many.
- 1.2 Respite care aims to enhance and develop the quality of life of a person who has support needs and their carer/s, and to support that relationship. The distinctive feature of such short breaks and breaks from caring is that it should be a positive experience for both the carer and the cared for. Respite can be provided within or outwith an individual's home.
- 1.3 Caring for a disabled child, 24 hours a day can be very challenging for the child's family – physically, emotionally and often financially. Short breaks and building families' capacity to care can have positive benefits for both children and carers, helping to alleviate carer stress.
- 1.4 For young people with care needs and for young carers, short breaks provide opportunities to participate in activities with their friends and peers, vital to their personal, social and educational development, contributing to their self confidence and wellbeing.
- 1.5 Respite and short breaks can:
 - help carers safeguard their own health and wellbeing, thereby enabling them to sustain the caring role;
 - prevent inappropriate levels of caring, or at the very least reinforce resilience in the caring role;
 - combat social isolation and enable carers to pursue their own them to take part in leisure interests or other activities;
 - help address a crisis, such as the carer not coping, cared for person's health deteriorating, or bereavement;
 - prevent children becoming accommodated;

- help people (particularly those cared for by their parents) develop independence and prepare for the time when the carer cannot continue caring.
- 1.6 For young carers, respite also provides
- a break from feeling responsible;
 - recognition of their caring role, to help them feel valued;
 - an understanding that respite is provided to ameliorate the potential negative impact of caring.
- 1.7 Short breaks have been found to be most effective in providing a break for carers when the carers are confident in the arrangements and do not need to worry about the person with care needs. This finding supports the observation that some carers and those they care for can be unwilling to take up some types of short break and reinforces evidence for the value of choice and personalisation in provision.
- 1.8 Respite can be offered in a wide variety of ways including:
- in residential units;
 - breaks in the home of another individual or family who have been specially recruited ;
 - breaks at in the person's own home;
 - access to 'normal' activities for young carers, such as school trips;
 - facilitated access to clubs, interest or activity groups;
 - supported breaks for the person with care needs either with or without their carer;
 - befriending schemes where volunteers provide short breaks;
 - peer support groups (e.g. for young carers).
- 1.9 Local authorities have a duty under the Children (Scotland) Act 1995, to work with partners to safeguard and promote the interests of children in need, including disabled children and young carers, and to assess the support needs of children and, where appropriate, their carers, which can include short breaks.
- 1.10 The Concordat between the Scottish Government and the Convention of Scottish Local Authorities includes a commitment to '*progress towards delivering 10,000 extra respite weeks per year*'. The Scottish Government is working towards a manifesto commitment that '*by 2011 carers in greatest need will have a guaranteed annual entitlement to breaks from caring*'.
- 1.11 The Government has also made a commitment that young carers will become a policy priority, and is promoting respite and other support for an additional 1000 young carers. In Highland, this would be equivalent to around 40 young carers.

- 1.12 Based on these government figures, Highland's share of that funding would enable around an additional 400 weeks/year for all client groups.
- 1.13 There is also additional funding for carers information. NHS Highland's allocation for all client groups in 2008/09 is £65k, rising to £195k in 2009/10 and £326k in 2010/11.
- 1.14 Responsibility for the planning and delivery of short breaks, lies with the local children's services planning partnership. There is national guidance dating from 1996, which is presently under review.
- 1.15 The main purpose of the new guidance is to help local service planners improve short break provision in line with the overall principles of protecting young carers, enabling self care and working with adult carers as partners in care, by:
- improving planning of short break services;
 - shifting the balance towards preventative support; and
 - personalising support to improve outcomes both for carers and those with care needs.
- 1.16 The new guidance is likely to stress the need for partnerships to make explicit plans for respite provision, building on the implementation of 'Getting it Right for Every Child'. This is likely to include:

Service development aims -

- priorities for strategic change;
- aims and outcomes that have been identified as important to improving short break services;
- measures to address anticipated barriers to progress.

Targets and actions -

- the specific targets that need to be achieved;
- action that needs to be taken to meet these targets;
- target dates and milestones by when action should have been taken;
- names of officers/partners responsible for meeting these targets.

Performance indicators -

- the performance indicators that will be used to measure success;
- the key performance results necessary to achieve the strategy outcomes;
- measures for involving carers, service users and other stakeholders in ongoing review and evaluation.

- 1.17 This detail will be reflected in the new Children's Plan, and this report identifies some of the key local issues in relation to these various points.

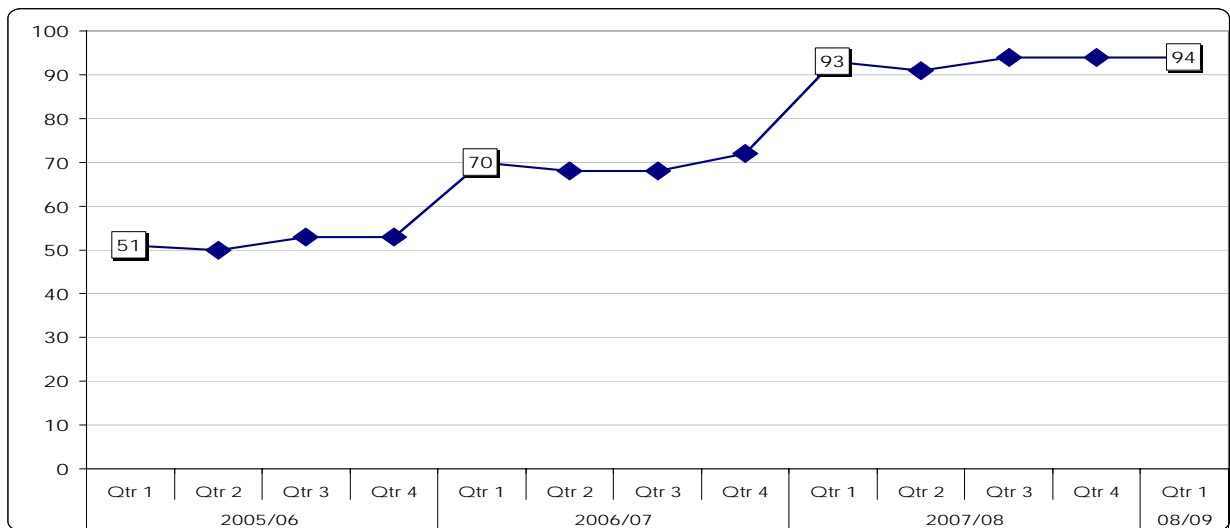
2. Short breaks and respite for Highland's children and carers

- 2.1 As the developing national guidance indicates, there are many significant issues about respite provision for children and families. In Highland, these issues are inevitably closely associated with the implementation of Getting it Right for Every Child. In particular, there has to be a clear relationship between the assessed needs, eligibility and expressed wishes of children and their families, and the appropriate model of respite. This is largely in relation to assessment processes and referral routes, and about the balance of provision across different client groups. As far as possible, there should also be choice.
- 2.2 The current position is that agencies endeavour to provide the model of respite that children and families need and wish, but there is not always the necessary close linkage with assessed needs, and for many families, often for geographical reasons, there is only limited choice.
- 2.3 These various issues are presently under review as part of Children's Plan processes. Given the likelihood that there will be few additional resources in this area of activity, change will have to be achieved incrementally, largely within the current funding pot. The key challenge is to provide the range and diversity of respite provision, to address the range and diversity of needs of children and families.
- 2.4 The recorded use of respite provision shows increases in both the amount of overnight and daytime respite provided to children between 2005/06 and 2007/08, albeit there appears to be poorer performance in 2007/08 than was achieved in 2006/07. The colour coding and the ranking figure in the table below refers to Highland's performance in comparison to all local authorities.

RESPITE	SPI Ref No.	EC8	Year					National Ave.
			2004/05	2005/06	2006/07	2007/08	2008/09	2006/07
Total overnight respite nights provided per 1,000 population			N/A	54.2 (13) amber	83.6 (8) green	76.3	DATA NOT AVAILABLE UNTIL YEAR END	59.0
Percentage of respite nights not in a care home			N/A	65.2 (4) green	33.6 (14) amber	24.8		33.2
Total daytime respite hours provided for children per 1,000 population			N/A	323.2 (21) amber	697.3 (14) amber	654.9		680.5
Percentage of daytime respite hours provided not in a day centre			N/A	63.2 (20) amber	34.4 (29) red	93.0		65.9
Comments: 2007/08 data is provisional at this stage. Ranking positions are shown in brackets. Colour code: Green = top quartile ranking (1-8), amber = quartiles 2 & 3 (9-24), red = bottom quartile (25-32)								

2.5 The following chart confirms that there have been increases in recent years in the amount of daytime respite hours that are provided outwith a day care centre. This is a national performance indicator, based on the assumption that it is preferable to achieve more flexible and less institutional models of provision.

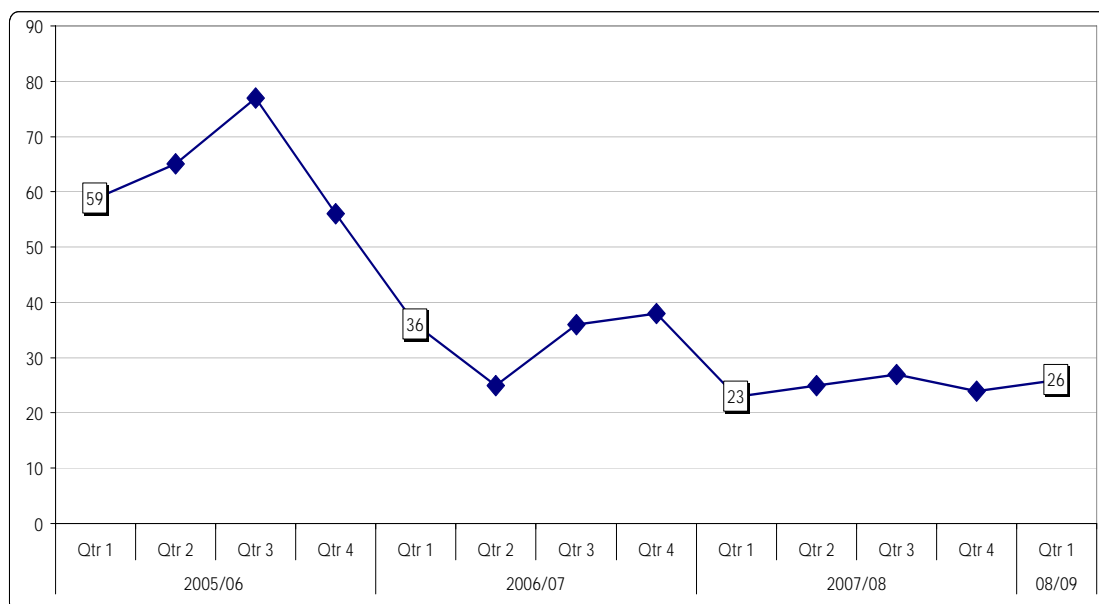
Percentage of daytime respite hours not in a day centre



2.6 It is likely that these figures significantly under-report the amount of daytime respite that is actually provided. Given the greater use of flexible models, and the growth in the number of support staff who undertake this role, it is increasingly difficult to ensure that all of this activity is recorded.

2.7 The percentage of overnight respite that is not provided in a care home is also generally regarded as an indicator of good practice, as it is predicated on the assumption that provision should be based on non-institutional models. However, in Highland, mostly because of the increase in residential provision at Staffin, but also because of the difficulties in recording non-institutional provision, the statistics indicate a steady reduction in the recorded percentage of respite nights not in a care home.

Percentage of respite nights not in a care home



3 Respite Provision

3.1 Residential care

In Children's Plan consultations, many families of children affected by disability have expressed most confidence in residential provision. This was one of the key reasons for the development and opening of the Staffin unit.

Also, those children who have particularly high level needs are likely to be dependent on residential provision, and particularly on the facilities at The Orchard in Inverness which offers high level, multi-agency support in a purpose-built setting, with waking night staff.

Over the last decade, there have been increasing number of high needs children. Because the capacity at the Orchard is always moderated by the level of needs of the client group at any time, as need has increased, the number of children that the establishment can support at any time has reduced.

Young people are also supported at Thor House in Caithness and Staffin in Skye. Both establishments operate on a part-time, residential basis.

The unit at Staffin can though be operated flexibly at different times of the week, and also provides outreach support. It is presently working at capacity, and is being reviewed, to examine how it might be further developed to best meet needs.

A small number of children receive occasional residential breaks in out of authority placements. This is due to exceptionally complex needs or

particular conditions, where services cannot be provided outwith specialist centres.

Also, a very small number of children with life-limiting conditions attend Rachel House in Fife.

The use of all residential establishments is inevitably highly constrained by geography, and the home location of each family. For some children, travel to a relatively distant resource can pose health and safety hazards. Accordingly, families within certain parts of the authority, including Lochaber, North Ross and much of Sutherland, may find it more difficult to use current residential provision.

3.2 Emergency crisis respite

Emergency provision for children whose living situations are in crisis is provided at a number of locations. The Council operates one place in Inverness, and purchases another place from a private provider in Ross-shire. On occasions, support workers will use a range of other accommodation to provide short-term emergency crisis care.

There is also one place operated by Action for Children (formerly NCH) as part of the Intensive Support Scheme (ISS), for children who present a significant risk to themselves or others. Discussions have been taking place with Action for Children to extend that scheme, partly to provide additional capacity for ISS, but also to ensure that appropriate Places of Safety are available to avoid children being kept in police detention.

3.3 Breaks in the home of another individual or family who have been specially recruited

There have also been increases in respite provided by community based carers through the Positive Partnerships Scheme – and means of expanding this further continue to be explored.

This scheme recruits and supports foster carers to support children, on either a regular or occasional basis. It allows a level of personalisation of individual support that is not always possible in many of the other services. However, as it involves a ‘substitute’ family in providing the care, it is not always a preferred option for the families of the children.

3.4 Breaks in family’s own homes

Over recent years, there has been a significant increase in the provision of breaks in family’s own homes. This can be for both adult and young carers.

Albeit there is occasional home-based provision supported by the Council with Support Workers, this is generally supported by Crossroads.

Presently, around 16% of Crossroads provision is for children. This varies from around 30% of Crossroads services in Inverness, Lochaber and Badenoch & Strathspey, to around 5% in Caithness.

The organisation of services via Crossroads is complicated by the fact that it is not a single organisation, but a number of local and national groups, who provide services in particular communities. This matter has been reported to the Housing & Social Work Committee, and means to improve the commissioning arrangements continue to be pursued.

A small group of children, who have life-limiting conditions, receive support at home from the Rachel House at Home Project.

3.5 Flexible community support

Recent years have seen an increase in the number of 'para-professionals' who can provide community based respite through a variety of means. This involves support workers and others in a variety of day excursions, assisting access to clubs and leisure activities, and supporting local groups. It includes support activity and dedicated funding to enable young carers to participate in 'normal' activities, such as school trips.

These various activities are particularly under-reported in the statistics above.

3.6 Domiciliary nursing

A number of young people are supported to have short breaks by enhanced health provision. This involves a range of services, from dedicated nursing at the Orchard, to support for social care staff to undertake certain medical processes that are necessary to support social care provision. It also includes a domiciliary nursing service for a small but increasing number of children.

Given the likely increasing numbers of children who will require this service, there is a need to consider assessment, referral and decision making processes, and to further consider how joint social and nursing care can be funded and provided without additional bureaucracy.

3.7 Direct payments

There has been recent growth in the use of direct payments to purchase respite care, particularly in the last two years. These direct

payments are largely for community based services, and they are unlikely to be used as an alternative to a period at a residential centre.

Decisions to award direct payments are based on assessed need, but also on affordability. There is no separate budget for direct payments, and funding has to be vired from existing provision. To date, funding has largely been vired from budgets that support community based provision, but if the use of direct payments continues to increase, funding will have to be vired from residential provision – reducing the capacity of this sector.

3.8 Young Carers

Highland has had a Young Carers Strategy since 2004, and has supported the Highland Carers Project and local projects in Sutherland and Skye to promote respite activity.

The new draft Young Carers Strategy (2008-11) includes the objective to *'continue to develop the availability of effective and structured respite opportunities for young carers in Highland.'* It is proposed that this is addressed by:

- Subsidised access to facilities
- Subsidised transport
- Respite for the cared for person
- Existing young carer projects continue to provide respite for the young carers in their communities.
- Awareness raising amongst children's activity organisers, community groups.
- Organisations running activities for children and young people consider additional support to enable young carers to access them.

When considering a young carer's short break needs, attention must be given to their age, abilities and strengths and the impact of their caring role on their life. The whole child should be central to any assessment and the impact of caring on their physical, social, educational, emotional, spiritual and psychological development understood.

Young carers should be supported to take an active role in decisions about short breaks. This needs to be addressed as part of improved young carer assessment processes.

4. For Highlands Children 3

- 4.1 For Highland's Children 3 will include improvement objectives and delivery strategies to improve respite and short-break provision.

- 4.2 While there is no specific target for respite in either the Single Outcome Agreement or the Council's Programme for the Administration, the Plan will include targets and performance indicators, and the discussion at the Joint Committee can help inform their development.
- 4.3 The provision of children's respite care is presently being reviewed, and this will require to continue, as progress is likely to be incremental over the life of the Children's Plan. The main features are likely to be:
- Ensure linkage with Getting it Right for Every Child processes, in particular to achieve clarity about assessed need, eligibility and respite provision.
 - Achieve increases in all or any models of respite provision as funding allows.
 - Improve recording of the use of the range of respite provision.
 - Achieve best use of the new facility at Staffin.
 - Promote equity across the authority for access to breaks in family's own homes.
 - Consider assessment, referral and decision making processes for domiciliary nursing, and also how joint social and nursing care can be funded and provided without additional bureaucracy
 - Achieve additional crisis capacity for ISS, and also to ensure that appropriate Places of Safety are available to avoid children being kept in police detention
 - Ensure more seamless decision making about the availability of support from health staff as part of a community-based respite package.
 - Implement the young carers strategy, including improved assessment processes.

Recommendation

Members are invited to consider and comment on the issues raised in this report, which will be taken account of in the continued development of For Highland's Children 3.

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