Agenda Item	13.
Report No	ACS/73/13

THE HIGHLAND COUNCIL

ADULT AND CHILDREN'S SERVICES COMMITTEE

21 August 2013

Respite Arrangements for Children

Report by Director of Health & Social Care

Summary

The report focusses on the role of short breaks/respite in ensuring that children and young people are nurtured and included by all of those with key roles in their lives and the lives of their families, enabling them to feel that they belong, be that in their nursery, school or community.

It outlines the impact of a range of factors resulting in increasing need for short breaks/respite provision and other kinds of support for children with disabilities and their families, and the need for continued deployment of resources to support these needs.

The impact of implementation of the Social Care (Self-directed Support (Scotland) Act 2013 by April 2014 is also taken into consideration.

1. Background

1.1 A key role of the local authority through health and social care and other services is to sustain children with their families, and support parent/carers of children with disabilities to be successful parents for their children.

1.2 The implementation of The Highland Practice model and the Named Person role has resulted in a greater awareness of the needs of children with disabilities at all stages in their lives.

1.3 This means that universal health and education services play a huge part in supporting children with disabilities and their families to lead as normal a life as possible. Knowledge and understanding of the impact of disability on the wellbeing of the whole family, on the learning potential of the child and on other aspects of their lives, has improved.

1.4 At the same time the need for input from the specialist Children's Disability Service has been maintained to provide focussed input to families coping with children with more complex needs.

1.5 The provision of short breaks for carers enables them to continue caring, and is best achieved when the family have a real break from caring and the child is provided with opportunities for growth - e.g. of self-confidence or trust in other carers or in the development of life skills which will promote their inclusion as they mature towards adulthood.

1.6 Respite can also provide carers the opportunity to spend time with their partner, other children, and friends, pursing hobbies etc.

1.7 However, much of the short breaks provision is to compensate for the exclusion of children with disabilities from the opportunities afforded children without disability, such as regular after school and weekend contact with friends, sleep overs, attending parties, school trips etc. Short breaks can reduce the isolation often experienced by children and young people with disability.

1.8 Some of the respite provided for parents and carers is also to compensate for the lack of support from families and friends. This reflects the fact that a significant proportion of children with disabilities are cared for in single parent families. Many families also have significant health needs of their own. This mirrors changes in society in general with stress related conditions affecting their physical, emotional or mental health.

1.9 As a result of improving medical intervention, an increasing number of children with significant and complex disabilities are surviving into early years and beyond into childhood.

1.10 In the past these children would have been looked after in hospital, but now the expectation is that they will be brought up in families who clearly have to be supported in a range of ways.

1.11 The continuing increase in the numbers of children and young people diagnosed with Autism Spectrum Disorder requires a more flexible approach to providing respite/short breaks. Many children and their families cope well with their autism. Other children are very affected by an associated learning disability which can lead to difficulties in their communication, understanding and subsequently their behaviour. Such difficulties can impact on the whole family.

1.12 A smaller but significant number of able children and young people on the autistic spectrum are affected by very high levels of anxiety associated with their need for predictability. They are often unable to contemplate being away from home and respite has to be provided in ways which does not increase their anxiety.

1.13 There is also a recognised rise across Scotland, in the number of children affected by Foetal Alcohol Syndrome. Many of these children are looked after by Local Authority Foster Families who also have need for regular respite.

2. Additional factors impacting on the need for short breaks/respite

2.1 Committee is aware that in recent years there has been a significant number of children and young people with disabilities being placed on part time timetables or not in school at all. This is being actively addressed and is the subject of on-going reports to Committee, and the numbers are now reducing. However, the resultant stress on families, perhaps through loss of employment, or increased stress and anxiety, has required increased input from the Children's Disability Services in a range of ways, including respite in order to sustain a carer's capacity to continue caring. The range of support is outlined in Section 4 below.

2.2 There are a small but significant number of children and young people with disabilities who are considered for statutory measures and/or compulsory measures, either as a result of Child Protection proceedings and/or referral to the Reporter to the Children's Hearing.

2.3 There is a high proportion of children with disabilities subject to statutory measures - around 25% of children on the Children's Disability Service (CDS) case-lists have had some form of legal or protective information or intervention about them throughout their life.

3. Raised expectations

3.1 All of the above factors raise the need for provision and the expectation of families that they will be supported in a range of ways to enable them to raise their disabled child(ren). Clearly this requires services to carefully consider the needs of the carer(s), the needs of the other children in the family and the child with the disability.

3.2 Sometimes, other professionals suggest to parents that they request respite. In most occasions this is appropriate, but can lead to parents not appreciating that there requires to be a full assessment of needs and sometimes respite is not the most appropriate way of meeting the needs of the child - for example, when there is a need for behavioural change, and the parent/carer may be required to engage in programmes of intervention.

4. The range of provision

4.1 The landscape of provision to meet the needs of children and young people with disabilities has changed significantly over the last 10 years, and more so recently with the outcome focussed approach of the Highland Practice Model. Self Directed Support (SDS) is adding to this changing picture

4.2 The range of provision includes the following:

- Local Authority directly provided services including support work by the Children's Disability Service (CDS): day/overnight/week-end/week periods provided by our own residential respite providers and family based respite through the respite care scheme.
- Purchased support and respite from a range of independent sector

providers.

- Home based respite purchased from Carr Gomm.
- Self-Directed Support.

4.3 4.3.1 The range of respite and short breaks provision delivered and purchased by the CDS is considerable.

4.3.2 Support Work is provided directly to children and young people to enable them to achieve the outcomes outlined in their Child Plan. In other situations, the support is specifically targeted to support children at risk.

4.3.3 Support Workers also provide a range of group opportunities, assisted by CDS professional staff and other relevant staff in their Area such as Youth Development Officers. A wide range of Groups are run all over Highland. They all provide families with respite at the same time as providing opportunities for children to meet peers learn how to interact, explore their community and develop skills.

4.3.4 This is a cost effective and beneficial way of meeting the needs of a number of children, providing assessment and intervention opportunities, developing skills and capacity to respond to local changing needs and circumstances. The outcomes for children and young people are very positive.

4.3.5 Support is purchased in varying amounts from a range of providers and can provide opportunities for direct work as well as respite for families. The providers include Direct Child Care, Richmond Fellowship, Highland Home Care, and Reality Adventure.

4.3.6 Places are also purchased in the specialised Holiday and After School clubs including SNAP in Inverness, Soar in Mid, No limits in Caithness. Many families fund or part-fund such placements themselves.

4.4 4.4.1 The need for 3 residential respite resources, namely the Orchard, Thor and Staffin is recognition of the demands of the geography of Highland and of the specialist care needs of some children, in particular those with complex health needs and with challenging behaviour as a result of their learning disability and/or ASD.

4.4.2 An average of 35-45 overnights per child per annum are provided, which compares well with the level provided by the Positive Partnership scheme. However the provision varies depending on assessed need.

4.4.3 The Orchard and now Thor provide a level of respite to a small number of families which can be considered ‘shared care’. This is regular weekly/week-end nights and is sustaining such children with their families in difficult and challenging circumstances. Crucially it is preventing them from being looked after out of authority.

4.4.4 Recent financial scrutiny of residential provision in Highland demonstrates that they are cost effective resources, when bench marked with similar provision.

4.5 The Orchard has recently experienced unprecedented levels of pressure due to the increase in the number of children requiring to be accommodated. Their waiting list is considerable despite continued flexible management of places to maximise the value of placements for the young people as well as their families with a range of day, outreach, after school, group activity opportunities as well as overnight provision. Just over 60 children are provided with overnight respite and an additional 15 have day time, mostly after school placements.

4.6 The Orchard provides:

- A local, experienced and skilled staff group capable of supporting very challenging children.
- Outreach provision supporting an even larger group of children and families.
- Expertise in supporting children with life limiting conditions.
- Absorption of considerable hidden un-costed expenditure on Out of Authority placements.

4.7 All of the Inspections Reports regarding The Orchard are excellent, and consultations with parents confirm how valued the service is and, in particular, how skilled the staff are, recently evidenced by one of the staff becoming the SASW Highly Commended Residential Care Worker of the Year for 2013.

4.8 Staffin in North Skye is a small and rural resource, providing a flexible pattern of operation offering both mid-week and week-end placements. They also respond to crisis situations in families.

4.9 21 children, several of whom are unable to share the placement with other children, were provided with a service in the 12 months from January to December 2012.

4.10 Thor House in Thurso became a resource solely for children during 2012, with a moderate increase in staffing. Their services have been developing a more varied and flexible approach this year and there has been a steady increase in the number of younger children and children with ASD.

4.11 Of the 34 children and young people using the Thor House service from April to June this year: 8 had a very high level of provision, 7 had medium provision; and 19 had a lower, but regular use. 4 children were aged 0-5yrs; 6 were aged 5-10yrs; 15 aged 10-15yrs and 9 were 15-18yrs.

4.12 Family based respite is provided to 25 children across Highland. The quantity and frequency varies from a few hours per week to overnights and weekends. There has been no increase in the number of family based respite carers. In fact, there has been a reduction in the number of places available, due to some respite carers becoming full time foster carers.

4.13 Currently, 15 families provide family based respite, including 4 Positive Partnership families who provide multiple places. One new family is currently being assessed for this.

4.14 Each Area of Highland has several children waiting for respite places. A Respite Monitoring Group has been meeting regularly in Inverness and is being expanded to encompass all Areas of Highland to clarify priorities for family based and residential respite services.

4.15 Carr Gomm is now the main provider of home based respite in Highland with 900 hours being purchased annually by Children's Services, for 56 children. Although this is an average of 16 hours, the amount provided per child varies from 4 to 54 hours per month.

4.16 Carr Gomm has recruited a broad range of staff, and are able most of the time to match staff to children and young people. The exceptions are in the more rural areas of Highland, where recruitment of appropriate staff has been more challenging.

5. Responses to changing needs - increased resource for the Children's Disability Service (CDS)

5.1 Additional resource was allocated to the Children's Disability Service by the Council in 2012 and 2013, to improve the capacity of the service as a consequence of an analysis of the above factors on levels and complexity of caseloads. The additional resource also acknowledged the time consuming nature of much of the work with families affected by disability.

5.2 An additional Team Manager post was created at the time of integration and the CDS now has three Team Managers.

5.3 2.5 additional Social Worker posts were created in key parts of Highland where social workers with disability experience were lacking, bringing the total number of CDS Social Workers to 10.5. Alongside this, the Family Key Worker posts were re-graded to reflect the levels of responsibility expected of staff carrying complex cases.

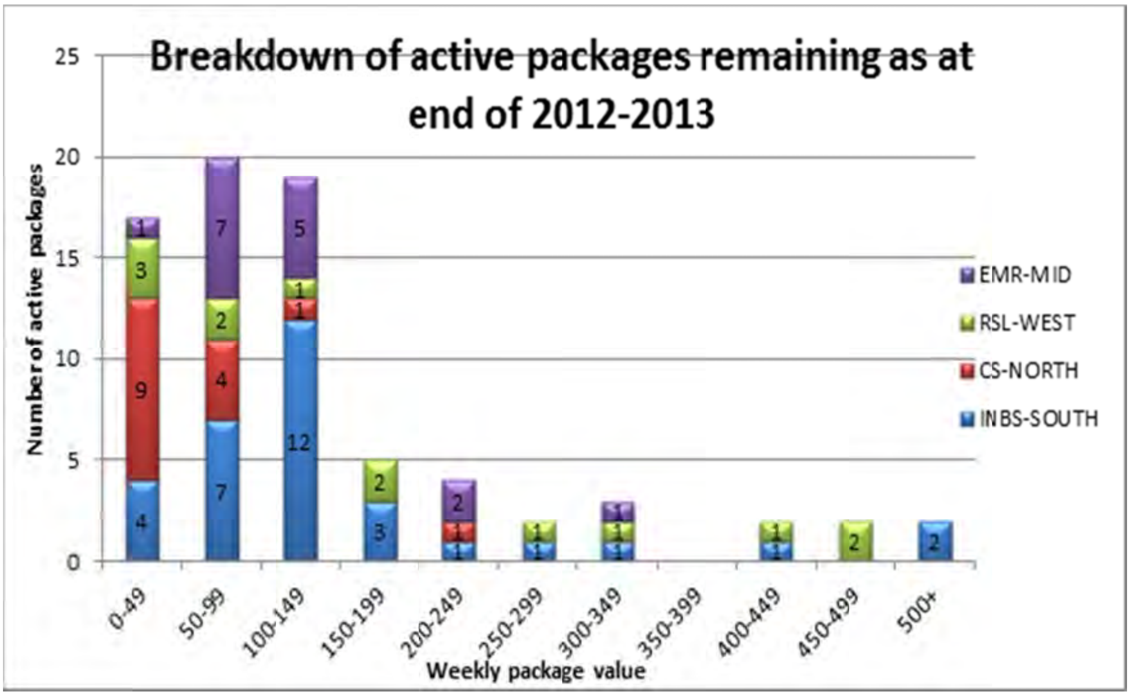
5.4 This has enabled more targeting of interventions for children and young people with complex needs, and improved management of cases where the support needs of the parent/carers are significant and, in some instances chronic. Interventions of this nature, as well as significant multi agency work, is succeeding in sustaining many children at home.

5.5 Five additional Children's Service Worker posts were also created to enhance the early intervention and preventive responses to children with additional support needs as a result of disability. These posts are spread throughout Highland and have been a crucial and positive development. There is evidence of several children being sustained in school and with their families where this might not have been the case had there not been input from the Children's Service Worker. This prevents increased need for respite/short breaks in such families and improved quality of life for the children.

6. Responses to changing needs - implementation of Self-Directed Support

6.1 Ahead of the legislation, we have gradually and successfully been changing the way in which resources are used in Highland, so that many families already receive a range of directly provided services and direct payments. See case examples in Appendix 1.

6.2 This includes 69 families already in receipt of Direct Payments with the weekly amounts shown below.



6.3 The much more explicit message in this legislation is the notion that “resource” has multiple meanings reaching beyond Local Authority and NHS “funds”. It is also not about reducing or cutting funds, but viewing them as adding value to the “wealth” of communities and families through extending and supporting their capacities.

6.4 Successful implementation of SDS is therefore dependent on a significant transfer of social care resource to facilitate the development of a broader range of options, preferably local, for supporting children, young people and their families from the Third and Private Sectors.

6.5 It also requires continued shift of resource from direct provision of service in order to make available the 4 options under the Act: Individual Service Funds; Direct Payments; directly arranged services; or a combination of all three.

6.6 To be able to offer these options, we have to affect the transfer of resource whilst maintaining a balance that enables families to continue to have choice. This is especially critical with regard to Family Support, where it will be addressed as part of the current review, and Care at Home.

6.7 It is our view that a majority of families will wish to continue using the directly provided local authority ‘in house’ services outlined above. Nevertheless we have been actively exploring with in house services how to meet this challenge and continue to offer more flexible approaches.

6.8 The challenge is to manage this shift in resources in a way which sustains our in house services and enable us to meet our duty to the most vulnerable children and does not disadvantage those most at risk.

6.9 The private/independent and third sector providers are also aware of this challenge, and many have been have been actively exploring how to meet this need and ensure that their service provision is attractive to families and promotes achievement of the individual outcomes of children and young people in their daily and future lives.

6.10 The introduction of a Resource Allocation System (RAS) is intended to result in a much more transparent and equitable allocation of resources. It has been developed collaboratively, and is a tool which sits as part of the Child Plan for use with families. It takes account of their needs as well as their own resources.

6.11 Use of the RAS tool with ten current pilot families is producing feedback on a better way of looking at needs jointly with the family, and helps plan the more effective use of the resources.

6.12 The Highland RAS is the result of examination of 40 care packages provided in 2012-13. This work is on-going, and the RAS continues to be refined by analysis of more care packages. The table below shows the spread of care package amounts.

6.13 It can be seen that a small number of families receive very high amounts, sometimes for 2 children in the family, where the Direct Payment provides much more than respite or a short break and is sustaining such children with their families.

Annual Care Packages by amount									
£300 - 1,400	2,000 – 2,800	3,200 – 4,100	6,200 – 7,400	9,200 – 10, 700	12,000 – 14, 200	17,600 – 19,500	20,200 – 22,600	25,200 – 27,600	36,500
No of families receiving these amounts									
5	7	5	6	4	3	3	3	3	1

7. Implications

7.1 The resource implications are as set out above.

7.2 There are no legal or climate change implications

7.3 The recommendations will enable the authority to continue to meet its Equalities duties

7.4 The risk implications are that families opt for SDS at a faster rate than anticipated to allow for gradual change which could, if not managed appropriately, de-stabilise budgets of in house provision.

Recommendation

Members are asked to note and comment on the issues raised in this report, to note the continuing challenges in service provision, and to commend the good services being provided by staff and partners.

Bill Alexander
Designation: Director of Health & Social Care

Date: 8 August 2013

Author: Marlyn Campbell, Development Officer Disability

Background Papers:

Appendix 1

Case example 1: Shared care provision

Esther is a 10 year old girl with profound ASD. Her communication disorder makes her anxious, rigid and driven by obsessive routines, with associated sleep disturbance and a persistent need to run away.

Her pervasive needs dominate family life with her lone parent, with siblings being targeted physically when she is frustrated.

The Child's Plan aims to keep her living at home with her family and in her community. She requires after-school care provision, mid-week overnight and every weekend care in residential respite. Additional support goes into the home on a daily basis. All of this is coordinated via regular core group meetings

Possible need for out of authority 52 week a year care was explored in 2011, but educational needs were being met at school and the parent did not want her isolated from the family or from the community as she moves into adolescence.

A shared care arrangement has brought predictability and routine into this child's life. Her behaviour at home has improved, although other family members can still at times be hurt if she hits out, but there is progress in self-help skills and capacity to go out with close supervision. Family are reporting much improved balance of family life and siblings' levels of assessed emotional stress are significantly reduced.

This level of service will continue to be monitored closely, considering whether such a complex care plan delivered by a lot of people across several settings continues to meet needs through adolescence, or whether at some stage needs would be better met in one combined care and education setting.

However if increased separation from home is unavoidable at a later stage, this young person will still have been part of her home life during her formative childhood years.

Case example 2: High level respite provision

Hugh is a 6 year old child with complex health problems, profound learning disability and communication impairment.

There is a history of child protection concerns. The Child's Plan includes Positive Partnership which has been beneficial for Mum as well as for the child. This provides regular weekly overnight respite, as well as a week end per month. Additional overnight stays are required at the Orchard when health issues are uppermost.

When able to attend school, he also enjoys the after school club and holiday activities.

The respite service needs to be particularly flexible since fluctuating health may mean that planned respite has to be cancelled and then re-planned when his health improves.

A direct payment is not currently suitable in this case as it would place too much demand on the carer. Carr Gomm are gradually building up a rapport with the child and the parent. They may replace some of the other provision or supplement it.

Case Example 3: Direct Payment

Gary is 7 years old, has ASD and limited verbal communication. He is very vulnerable in terms of being able to keep himself safe.

The parents are managing well and welcome being able to talk things through and have feedback to reflect on things that haven't always worked out. Mum is also a carer for her elderly parent.

This family are in receipt of a large Direct Payment, some combined with Adult Services. There is no in-house or other provision.

Case Example 4: Lower level respite provision

Frank (aged 15) is living in rural setting, with severe cerebral palsy. He uses a wheelchair and requires high levels of intimate personal care in daily living, but possesses cognitive capacity to make choices and discuss how his needs are best met. He enjoys holiday visits to residential respite, which allows peer group activity and experience/access to town facilities, etc.

He has a lone parent, who meets the heavy care needs including constant moving and handling tasks, but who values a short break during each school holiday. Additional home based respite is being explored with Carr Gomm, which would assist with reducing the carer's personal task load. There is also an opportunity to explore an alternative provider for this, perhaps through a direct payment.

Respite adds quality and variety to this young person's life and gives experience during sensitive years of adolescence of how others at that stage of development cope with the limitations of a disabling condition. This may sometimes allow expression of emotions which cannot readily be expressed in the normal day-to-day situation and a chance to talk in a different sort of way at a distance from home.

It also provides experience of how to take increasing responsibility for working with non-family or school carers around having intimate care needs met in a way that allows maximum opportunity for the young person to access facilities in the wider community.

A Direct Payment is also being explored for additional support to explore activities connected with Frank's main hobby.