

EQUALITY ANALYSIS

Children with Disabilities Short Breaks and Respite Care

Report completed by Bridget Cameron, Lead Commissioner for Short Breaks and Respite Care

The purpose of this Equality Analysis is to determine the impact of a reduction of £100,000 on the overall budget in terms of potential risks and to identify the groups that might be particularly affected by this proposal.

What are short breaks and respite care services?

Home-based short breaks are provided under section 2(1)(a) of the 1970 Act (i.e. as 'practical assistance in the home') and community-based support is provided under section 2(1)(c) (i.e. as recreational/educational facilities 'outside his home'). Some short breaks are linked to a disabled child's preferred leisure activities, for instance a play scheme at a local football club, horse riding, swimming, etc. If a child has a need for short break/respite care which has to be provided in their own home or a community-based setting and which has to be provided in a care home or foster placement, than it cannot be provided under the 1970 Act and generally is provided under the Children Act 1989, paragraphs 3.59-3.62.

Under the Children and Young Person Act 2008, the Local Authority must offer short breaks as part of a preventative model. The responsibility of the Local Authority to provide short breaks for carers of disabled children came into effect on 1st April 2011 (Breaks for Carers of Disabled Children Regulations 2011). These regulations place a duty on Local Authorities to have regard to the needs of carers who:

- would be unable to continue to care for their disabled child without a short break or would be able to care more effectively if breaks are given,
- to look after other children in the family more effectively,
- to take part in training, education or leisure activities, or
- to carry out day to day tasks in running the household.

Consultations with local Herefordshire families gave rise to the following definitions of a Short Break.

- A wide range of opportunities, activities and support so children and families have choices.
- An activity which becomes an ordinary part of life for children and young people with disabilities and their families.
- Anything from a couple of hours to overnight stays.
- The opportunity to have fun and take part in enjoyable experiences that contribute to personal and social development.
- Support for day to day tasks at home.
- Learning new skills and becoming independent.
- Opportunities to develop new interests and take part in different activities.
- Opportunities for children and young people to have something to do – especially at weekends and during the school holidays. They can see their existing friends at the Short Break and make new friends.
- Enable parents and families to have a break from their caring responsibilities.
- Enables parents to support families, catch up with everyday activities as well as having more time with their other children, their friends and hobbies.
- Flexible, responsive to need and able to offer support at times of urgent need.

Outcomes from Short Breaks/Respite Care

The outcomes for the short breaks and respite care provision have been developed from Herefordshire's local joint commissioning plans and produced with the involvement and co-design of service users, carers and other stakeholders.

The overarching outcome is to enable children, young people and families living with disability and complex needs to live ordinary lives. Children, young people and their families will benefit from:

- Increased engagement in universal services and services that build resilience
- Improved emotional health, self-esteem and confidence
- Developing dignity and respect
- Improved family resilience and family relationships
- Increased choice and involvement in social activities, supporting personal development
- Social development, peer group friendships and social interaction
- Help early on when difficulties develop, preventing problems getting worse
- Opportunities for parents and families to have a break from their caring responsibilities

There are 3 outcomes:

Outcome 1: Children with additional needs in Herefordshire will have fair access to a range of short breaks and respite care that meet their needs and those of their family

Objective 1.1: Children and young people are able to achieve personal goals and learn new skills
Objective 1.2: Children and young people are able to spend time with their friends and make new ones
Objective 1.3: Children and young people are able to take part in exciting activities that interest them
Objective 1.4: Children and young people are supported to maximise

Outcome 2: Parent carers are supported in their caring role

Outcome 2.1: Parent carers feel less stressed and have some time for themselves including time during the day/overnight when they can be 'off duty' and relaxed knowing their child is in safe hands

Objective 2.2: Parent carers are able to spend time with their other children or together as a family

Objective 2.3: Parent carers can get to know other families who share similar experiences

Objective 2.4: Parent carers are confident that their child is having fun, with skilled carers who understand his or her needs

Outcome 3: Children and young people with complex, multi-faceted health and care needs have access to a range of short breaks and respite care that meet their needs and those of their family

Objective 3.1: Children and young people are able to achieve personal goals and learn new skills

Objective 3.2: Children and young people are able to spend time with their friends and make new ones

Objective 3.3: Children and young people are able to take part in exciting activities that interest them

Objective 3.4: Children and young people are supported to maximise

Budget for Short Breaks and Respite Care

There was an initial budget of £1,356,000 for the provision of short break and respite care services. This comprised £813,000 from the Clinical Commissioning Group and £543,000 from the Council. This had been allocated according to the needs of the children and young people and was expected to be in the region of:

- £600,000 which will be used to provide services for children and young people with complex health and care needs;
- £200,000 which will be used to provide services for referred children and young people with significant health and care needs;
- £200,000 which will be used to provide services for self-referred children and young people with significant health and care needs, and
- £100,000 which will be used to provide services for children and young people with additional needs.

The remaining £256,000 was to be used to provide:

- brokerage support – i.e. the link person between the short breaks panel and the providers
- additional services when gaps were identified
- additional services should a provider be over-subscribed
- additional services should there be more need than originally identified
- services for specific children/young people where a spot purchase might be necessary to meet particular needs

Protected groups who would be affected by the proposed reduction in budget

- Disability
- Age

In particular, the reduction is likely to affect the lower need services. From the bullet points under the budget heading above, this would be the last two points.

Those children and young people with significant needs who will be self-referred, i.e. who can apply directly to the service provider for their service may:

- Attend a mainstream school but have a statement of Special Educational Needs (SEN)
- Be home educated due to their disability
- Claim lower level Disability Living Allowance (DLA) for mobility and/or care [Standard Personal Independence Payment from April 2013]

They may also have a multi-sensory/sensory impairment.

Where a child has **additional needs** they will be able to self-refer to the service provider for their service.

In the future, these children and young people would be expected to be able to access universal services within the community but it is acknowledged that these services need developing. This is why Herefordshire Council and Clinical Commissioning Group has committed support to develop the universal market to stimulate its growth.

Children and young people who have additional needs will:

- Be at School Action Plus for reasons that include Autistic Spectrum Disorder, Behavioural Emotional or Social Needs, have Language and Communication Difficulties/disorder

They may also have a sensory impairment.

These children and young people with additional needs will be restricted to three of our commissioned activities over the year to ensure everyone has an opportunity available. There is no restriction on these children and young people accessing other universal services.

Unknowns within the commissioning model

Even without taking into consideration the proposed £100,000 reduction in budget there are a number of unknowns which affect the provision of short breaks and respite care services within Herefordshire.

Numbers of children/young people with a disability

The Council does not know how many children and young people there are who might be eligible for short breaks/respite care provision. There are <20 children and young people on the Council's disability register. The only way numbers have been able to be estimated is to use numbers based on Disability Living Allowance and Special Educational Needs.

The February 2012 Department for Work and Pension figures show 1,430 Disability Living Allowance claimants aged 5-24 years living in Herefordshire.

The 2012 Spring School Census showed the following numbers of children with Special Educational Needs (SEN) within the SEN categories:

- 2,622 at School Action
- 1,885 at School Action Plus
- 559 with a Statement of Special Educational Needs

These figures reveal that Behavioural, Emotional and Social Difficulties (BESD) and Specific Learning Difficulty (SPLD) together account for over 20% of the total identified primary need. It should be remembered that we are looking at special educational needs which cannot align directly with disability. At the same time however, it is fair to say that around 1,000-1,500 of these children are likely to meet the threshold for short breaks and respite care services. Many of these children and young people will access universal services but it is recognised that universal provision in Herefordshire needs developing.

Significantly both ASD and BESD show a large imbalance in the proportion of boys and girls identified with the need. In the case of ASD there are more than 6 boys identified for each girl and for BESD the ratio is almost 3 to 1 in favour of boys. From the SEN statistics, it is noted that almost 70% were boys.

Information above taken from Children with Disabilities in Herefordshire: Understanding our cohort report, Improvement Team, September 2012.

Between April and December 2012 365 children and young people accessed short break and respite care services – significantly less than the potential 1,000-1,500 cited above.

Children and young people accessing short breaks and respite care services

There is a discrepancy between the 365 current service users and the predicted maximum of 1,500 who could be eligible for a short break activity. This raises the questions:

- Do parents and carers know about the services they are entitled to?
- Are current service users the children of parents who are IT savvy or who are more socially aware of their child's entitlement and rights?
- With the involvement of parents and carers in the design of the services and the letters going out to all special schools (and mainstream) will this increase demand?

There is no way to determine this before the services are commissioned though some measure of increased demand can be monitored in discussion with existing providers.

Migration of Romanian and Bulgarian nationals

Work restrictions for Romanian and Bulgarian workers and their families, brought in when the countries joined the European Union in 2007, will be dropped on 1st January 2014. There are varying reports about the effect this will have on the United Kingdom but it is known that both groups are present in Herefordshire and are involved often in fruit picking. It is also known that GPs in the countries are encouraging those with:

- Health problems
- Larger families
- Members of their families with disabilities

... to come to the United Kingdom as they will receive help.

View discussed and shared with Equalities Team in Herefordshire

As such, it is not possible to determine the numbers who might choose to come to Herefordshire but, if only those making concrete plans to come to the UK were considered, this would be 61,000 Romanians and 58,000 Bulgarians (see Migration Watch headlines for more details).

There is also acknowledgement that there are some considering moving to the UK from other EU countries, such as Spain and Portugal, which also makes numbers difficult to estimate.

Children and young people with complex and significant health and care needs

Access to provision at Ledbury Road, the Wye Valley Trust Short Break Unit, has been through a mixture of routes – the short breaks panel, multi-agency panels/CAF referrals, CWD social care team (through the short breaks panel) and the CIN team.

Only the CWD social care referrals come, at present, through the short breaks panel route yet, when meeting with the unit's management team, it is clear that referrals come through to them without going through the short breaks panel.

Some children and young people have had short break care packages in place for a number of years without review. The council are not wholly aware of all of these care packages, where the referrals came from and the costs associated with them unless these have been through the short breaks panel over the last 6 months - prior to that the information does not exist.

Ledbury Road has some of this information but cannot say where every referral has come from though they will work with the commissioner to give as much detail as they are able to.

As part of the process for commissioning short breaks and respite care, the panel process and access to services is being determined to have a better understanding of demand, need and cost. At present this is unclear.

So, looking ahead, it is not possible to totally and accurately predict provision demand, need and costs for our most vulnerable children and young people.

Reviews of care packages have not taken place for the provision in Ledbury Road at least for a significant number of years. Where children/young people have been allocated overnight respite in the unit originally due to the family being in acute stress but where the needs of the child/young person not being of the highest complex health need, at a review an alternative short break might be offered to them.

Has the Council set a historic precedence to provide overnight provision at, for example, Ledbury Road? Parents at the 'Meet the Commissioner' event on 2nd May, 2013 asked if they would be entitled to challenge or have right to appeal any decision to change their existing care package.

Have families got used to having overnight respite provision as their care package where, had they been going through at a different time with more options available, some other provision might have been deemed more appropriate?

As the child becomes a young person/adult, has the Council set an expectation in the parents of these vulnerable children and young people for overnight respite care? Would this transfer into adulthood and a residential model of care being required?

Providers within Herefordshire

A directory of services that would be able to meet the needs of all children and young people with disabilities is not available in Herefordshire though Herefordshire Carer Support does have a number of providers registered with them.

During the conversations with providers it has become clear that many of those who offer services for children and young people with either complex health and care needs and/or higher level significant health and care needs felt that:

- They should not have to go through this commissioning process – 'the council needs our services, they would be lost without us and we should not have to go through this process'
- If the council wants the service they should spot purchase

It is obvious that providers are anxious about operating in a competitive market and either do not know their own costs for their service or are worried about whether they are too high. Equally they could believe that, as they have had money for their service for a number of years, they feel this ought to continue.

Providers in Herefordshire are also naïve about commissioning processes, the benefits of collaboration (and the need for it in some cases) and the necessity to be flexible to the needs of the service user while meeting the outcomes within the tender. This knowledge has been shared with HVOSS.

The council is using some of the short breaks/respite care budget to develop the universal market. Any reductions in budget are likely to effect this.

Positively, there are a number of organisations being set up currently which will be able to offer support to children and young people with additional and low level significant needs. The money from this short breaks/respite care budget would enable them to develop their business and move towards self-sustainability.

How would the reduction in budget impact on children and young people with disabilities?

The risks associated with a reduction of £100,000 in the short breaks and respite care budget are primarily around uncertainty.

1. The Council is not aware of numbers who might access services and demand may outstrip availability. If only those children and young people of parents 'in the know' are those currently accessing services numbers could increase significantly.
2. There might be gaps in service which are identified as significant by parents, carers and commissioners which may not be able to be met.
3. Numbers of migrant workers cannot be estimated. This means that all services, including adult and children's services, could be significantly affected by this influx. Some of these families will have children and/or young people with disabilities.
4. Costs might rise for provision of services for children with complex health disabilities accessing Ledbury Road/alternative overnight respite care as the revised panel is developed. A number of placements would have to be agreed with the unit to guarantee overnight stays through the short breaks/respite care budget.
5. Given families who are used to accessing high cost high level provision of overnight respite care services, there is likely to be some need to continue this for some families if they challenged any decision to offer an alternative support service. These numbers are unknown.
6. Universal providers are not good at welcoming families of children and young people with disabilities. This market area needs shaping and developing.

Update 6/12/2013

The budget consultation and briefings sent out to parents affected by the re-commissioning of short breaks and respite services have included details of the need to save funding and for council funding to be prioritised on the most vulnerable and those with the most complex health and social care needs. We have explained that the council has a role in ensuring that there is choice and flexibility for parents but cannot fund all this; it is known that there are other funding sources that charities and other organisations can access which the council cannot. All those providers who were unsuccessful in securing awards through the procurement process have been advised to seek support on accessing other funding from the Project Development Team within the Council and HVOSS. The council is funding a small number of activity groups for a 6-7 month period to June/July 2014 specifically while they secure other funding sources; if the Council withdrew funding at this point these groups are likely to stop.

The procurement process itself has provided a new overnight respite foster care service and increased buddying services. Gaps in services which have not been secured through the procurement exercise are now being addressed with preferred providers; this includes overnight respite at Ledbury Road, playdays and holiday schemes, and childminding services for 0-8year olds.

We have had no specific response to budget cuts in this area from parents through the short break briefing events; the general consensus is that this is inevitable given the cuts in the public sector.

Comments included in the budget consultation exercise are the need for support to carers of children and young people with disabilities; short breaks services specifically will support parents and carers. There will be a range of activities, funded by the council and others, that will provide that support but importantly there will be a choice and flexibility of services. There were also comments about the need for communities, charities, volunteers to do more with training and support, and not to be over optimistic as to the voluntary sector providing essential services. Market development needs to be an ongoing approach the council takes, and any services that the council does procure will be monitored to assure quality of service and safeguarding. The council is continuing service re-design work with the Clinical Commissioning Group, and involving parents/carers and providers to ensure there is a diverse range of short break services for children with disabilities available across the county.