

Guidance for Parents and Carers on Care Packages for Disabled Children

Introduction

As a service we believe it is important to help normalize the lives of families with disabled children, promote resilience, and enable the disabled child to enjoy the life experiences that non disabled children enjoy. We also believe that where possible it is better to promote and enable access to mainstream services, and that not all families with a disabled child will require a care package.

If a parent/ carer feel they would benefit from a care package they can ask for an assessment. To qualify for an assessment, they need to be a resident of Hammersmith and Fulham with a child or young person up to the age of 18 years with a disability who is substantially and adversely affected in their ability to carry out normal day to day activities by a physical or mental impairment: This may include one or more of the following:

- global developmental delay
- physical impairment
- a profound sensory impairment
- a significantly disabling chronic ill health condition
- severe communication or language disorder
- Autistic Spectrum Disorder with communication disorder and developmental delay
- learning disability
- a serious life limiting or terminal illness

Care packages Available

There are a range of services available through a care package. These include:

- Saturday play
- Holiday play
- Direct payments
- Care in the home(short breaks)
- After school and weekend care at the Haven
- Overnight care at the Haven
- Social and recreational activities

For full details see the Hammersmith and Fulham Short Breaks Statement.

Care packages are intended to provide short breaks for the child and the family and are not intended as daycare provision to enable a parent to work. For advice regarding this please contact the Family Information Service

The Assessment

A package of support is determined following an assessment. Packages of support will focus on individual need and the particular circumstances of each family. The Assessment of need for a care package will be assessed on the basis of three components, the level of disability, any social and environmental issues and parenting issues identified through the Social Work assessment.

The number of hours short breaks allocated to a child and their family and the type of service offered, will be explored during the assessment and depends on:

- The level of the child's disability.
- The impact of the child's disability in being able to care for themselves and keep safe.
- The impact of the child's disability on family life.
- The ability of the parents to meet their child needs.
- Any additional problems the parents might face- housing, finance, domestic violence, Physical or Mental health problems, and substance misuse.
- The wishes of the child and their family.

Set out below is a guide of the factors considered in an assessment that would lead to the needs of a child being seen as high medium or low.

Range	Child Disability Issue		Social Environmental and Parenting Issues
High/Complex	Mobility	Totally dependent	Looked After child
	Self Care	Totally dependent	Child subject of a Supervision Order
	Communication	Unable to understand or communicate	Child subject of a Child Protection Plan
	Behavior	Constant significant risk to self and others	Substance Misusing Parents/carer
	Cognitive	Constant danger to self and others	Family Violence
	Sleep Pattern	Needs attention throughout the night	Parent/carer has significant health / mental health or disability problems
	Medical	Needs medication by	Complex family issues

		trained person	
Medium/Additional	Self Care	Dependent for major aspects of care	More than one disabled child in the family
	Communication	Communication often difficult to understand	Parent has significant difficulty managing physical care
	Behavior	Significant risk to self and others two or more times per week	Parent has significant difficulty managing behavior
	Cognitive	Structured prompting / supervision to make appropriate choices and stay safe	Major housing and environment factors
	Mobility	Considerable assistance required	Ongoing health problems
	Sleep Pattern	Needs attention 3 times+ per night	High levels of family stress
	Medical	Requires medication by parent or carer	Relationship difficulties
Low	Mobility	Some assistance required	Socially isolated family
	Self Care	Some assistance required	Two or more children under five
	Communication	Some communication difficulties	Housing and environmental factors
	Behavior	Occasional challenging behavior	Financial problems

	Cognitive	Regular prompting required to make appropriate choices	Family Stress
	Sleep Pattern	Some attention required	Single Parent Family
	Medical	Low level medical needs	Acute Tiredness

A carer's assessment or a young carer's assessment could also be completed if requested and can be helpful in establishing clearly the additional caring demands as a result of the child's condition.

The assessment will be completed, and from this the social worker will make recommendations which will be presented to a panel for a decision. Whilst the social worker will listen to what you would like in terms of care package support, their assessment is based upon the needs they identify and may differ from what you have asked for.

Set out below is a guide as to how many hours the parent/carer might expect in relation to each level of need.

A low level need usually equates to support in accessing mainstream provision. It is expected that many disabled under 5s will access mainstream services including Children's Centres. For older children this could be up to four hours per fortnight additional support and up to 8 hours per week support may be available during the school holidays.

A medium level need usually equates with up to four hours additional support during the week and 12 hours per week support during the school holidays.

A high level need usually equates with up to eight hours additional support during the week and 18 hours per week support during the school holidays. If a child or young person has significant personal care needs, for instance following an operation, support may be set at a higher level according to assessed need. A package of support of more than 15 hours a week would be unusual.

Where the Continuing Care criteria for medical needs are met, packages may be joint funded with the PCT through agreement at the Continuing Care panel.

The residential short breaks service is for children over nine years old who have High Needs. The service is particularly aimed at: children with disrupted sleep patterns; children who share sleeping space with parents or siblings; children whose families experience accommodation problems; and children who need a social experience which is difficult to gain through other services. The basic package for residential short breaks is one overnight stay a fortnight.

The role of the Panel

Decisions regarding Care Packages are made by the Care Package Panel on the basis of an assessment or a review. The panel is chaired by the Head of the Disabled Children's Service and is made up of managers of the Disabled Children's teams, the Short Breaks Team, the Haven and a representative from Children's Community Nursing. Parents are invited to attend the panel along with their social worker. The role of the panel is:

- To ensure that the service appropriately matches the assessed need.
- To ensure the parent /carer and child's voice is heard.
- To ensure consistent quality of assessment.
- To ensure consistency and fairness of provision.
- To ensure the most suitable venue and the level of support required is known prior to arrangements being put in place.
- To ensure the smooth implementation of the agreed care package.
- To ensure the nature and cost of the service is properly logged.
- To enable the parent/carer to attend and contribute.

The credibility of the process partly rests on fairness, so the social worker will be presenting the needs and explaining how a care package might meet these needs, whilst the panel will also have an eye to how what is being proposed compares to others.

A letter from the panel with the decision will be sent out at the earliest opportunity. In the meantime the social worker will advise the parent/carer as clearly as possible the decisions of the Panel and the reasoning behind this.

Reviewing

Packages will be reviewed on an annual basis. Where possible this should coincide with the CIN review. Rather than complete a fresh assessment every year it is the practice to review the assessment and this "review" will follow the same guidance and is satisfactory for informing the decision making process. Key information from these assessments and reviews are brought to the decision making forum through the completion of the Care Package Panel Form.

Appeals

Appeals against decisions regarding Support Packages are made directly to the Head of Service in writing. The social worker can help with this. This needs to be done within 14 days of receipt of the panel decision letter. The Head of Service will review the assessment and the decision making process and make a recommendation for future action. They may request that the situation is reassessed, or that the case is considered by the RBKC panel which he does not chair and has the same criteria. We will seek to complete this within 35 days from the appeal being received.

If you are still not satisfied then the matter is taken to the formal complaints process.

Emergency arrangements

New care packages can be agreed by the Head of Service in an emergency to for example prevent the need for the child to become Looked After . These will however be time limited and any continuation will need to go to panel. Temporary increases in Care packages again can be agreed by the Head of Service in an emergency. These will however be time limited and any continuation will need to go to panel.

Richard Holden.

Bi Borough Head of Disabled Children's Services .

Second Floor Kensington Town Hall.

Hornton Street. London W8 7RX

Tel 0207 361 3751

richard.holden@rbkc.gov.uk

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