

**Progress Report on Carer Support Project for  
Carers of Adults with a Learning Disability**

Durham & Chester-le-Street



Carers Support

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# Progress Report on Carer Support Project for Carers of Adults with a Learning Disability

The post of Carer Support Worker for Carers of Adults with a Learning Disability commenced in April 2003. The outputs resulting from the project to date are summarised below under the subheadings that were listed in the original Community Fund Application made by Durham and Chester-le-Street Carers Support (DCCS)

## Effective emotional support to Carers

### Home Visits and Regular telephone contact

There has proved to be a high demand for emotional support. Older Carers in particular have valued home visits and welcomed the opportunity to share their concerns and know that they will be listened to non-judgementally. This is important to them, because other professionals such as social workers are obliged to focus on the needs of the cared for person. In any case, they often have time only for crisis intervention. Social workers have increasingly referred Carers to the Carer Support worker because they know he will be able to make time to talk over difficult issues with them.

Many Carers face complex emotional dilemmas about their role. For instance, many wish to encourage a more independent way of life for those they care for, but are informed that funding for support to enable this to happen is extremely limited. A number of Carers have informed the relevant agencies for several years that they are too frail or ill to meet the needs of the person they care for, but because of the shortage of available housing they are still having to cope, under severe stress. After a lifetime of caring, some Carers find that they are now dependent on the cared for person for practical support, even though they continue their supervisory role. A number of the older Carers and the people they care for have spent a lifetime in isolation from other sources of support, remaining entirely unknown to the local social services until the Carer Support worker became involved.

Carers from across this spectrum are prone to expressing guilt about "not coping", or wishing for the cared for person to "move on". The Carer Support Worker's initial priority is to gain more awareness and understanding of their perspective, before encouraging them to consider all the available options for taking action that may alleviate the pressures on themselves and the family. A patient and unassuming approach is essential because Carers often feel stereotyped by agencies as "overprotective". When older Carers are offered support, and when listened to, they are often able to become less defensive or fearful about the cared for person experiencing change or spending more time away from them.

### Support to Carers in Reviews, initial Assessments or meetings about grievances

Carers are frequently the only non-professional present at formal Reviews, Assessments or at meetings to discuss grievances or complaints. This can be an intimidating and stressful experience. The Support Worker has been asked on numerous occasions to attend such meetings with Carers in order to support them in putting forward their point of view as well as acting as a witness to the conduct of the meeting.

### The co-ordination of a regular Support Group encouraging mutual support between Carers

Carers receive emotional support from each other. Many say they get most of their information about services, projects and their rights from each other. When his post commenced, the Support Worker therefore prioritised forming a support group specifically for Carers of adults with learning disabilities.

# Providing Effective Practical Support

## Facilitating Carers Assessments

The Support Worker has supported many Carers to complete Self Assessment Questionnaires in order to prepare them for a Carers Assessment. Many of these Carers had prior to the Support Worker's intervention, known little or nothing of their right to such an Assessment. For many of these Carers the practical outcome of the Carers Assessment carried out by Durham County's Carer Development Team has been their direct access to the Carers Special Grant, which affords them breaks from their caring role. Access to paid "Befrienders" has been an especially popular option because it provides Carers with peace of mind, knowing that the person is "out and about" and socialising, whilst they are having a break.

## Facilitating Access to the **DCCS** Direct Access Short Break Service

Funding has recently been awarded to **DCCS** to provide direct access to Short Break services. This provides Carers who have no current access to services with a break through spot contracts with sitting or befriending agencies. The Support Worker has to date identified three Carers of people with a learning disability who are now accessing this service

## The role of the Learning Disability Support Group

This has operated successfully over the lifetime of the project. Carers have chosen the topics and decided which speakers to invite. Topics have included Respite, Carers Assessments, Accommodation and Planning for the Future of Day Services, Person Centred Planning, Welfare Rights and Direct Payments. Some Carers have formed friendships with other Carers as a direct result of attending this group. Carer Support provides transport for these sessions and this ensures older Carers and those from isolated rural areas can participate fully.

## The production and distribution of a Directory on local services and projects relevant to people with a learning disability

Carers rarely have access to up to date information, either about local projects and services relevant to people with a learning disability, or about their own rights and options. One way by which the Support Worker has attempted to address this gap is by organising the support group as outlined above. However, information distributed in this way only reaches a proportion of Carers. It is therefore also distributed via articles in the **DCCS** Newsletter, and perhaps most importantly, through face- to -face contact and home visits or by sending information on request. To assist in this process, the Support Worker also collaborated with the Co. Durham Learning Library to produce and distribute a local Directory of provision for people with a learning disability and their Carers.

## Carer's Holiday

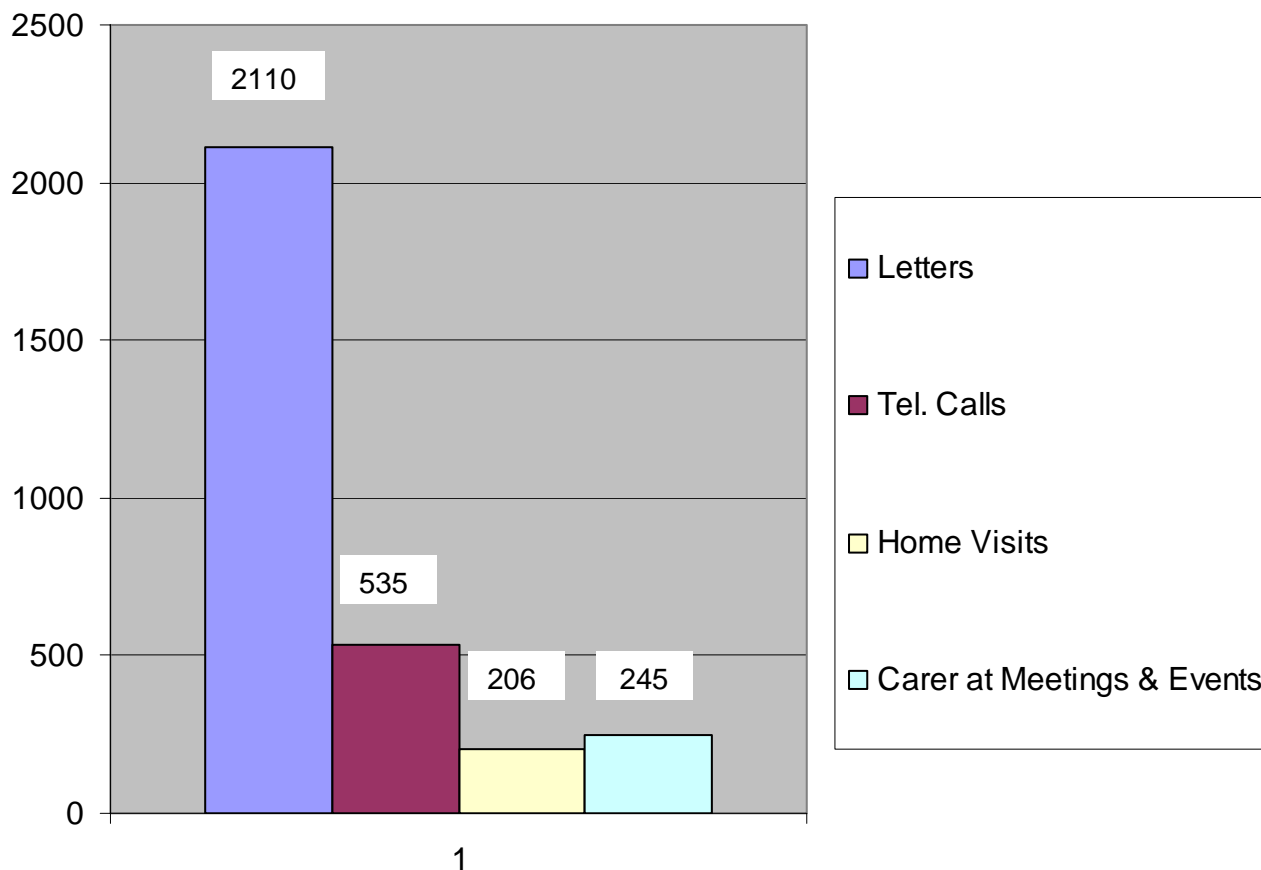
As a member of the Princess Royal Trust for Carers, DCCS has been able to fund and organise a holiday at Pontins, Blackpool for a small number of Carers annually. These are Carers who would not otherwise have the opportunity for such a break. DCCS also provide the transport. Last summer 5 Carers of people with a learning disability benefited from the break. One of the most valued aspects of the break, according to the families concerned, was the friendships established by all concerned.

Support to alleviate social isolation and the impact of caring and the reduction of physical, financial and social consequences of caring in older age.

Carrying out benefit checks with Carers and the people they care for. Helping Carers to make benefit applications

Many Carers have limited awareness of their full entitlements. Checks are always offered at initial meetings and when the Carer support worker is aware that circumstances have changed. The Support Worker has assisted both with applications on behalf of both Carers and the people they care for. Disability Living Allowance and Attendance Allowance forms are particularly daunting to complete. The Support Worker routinely spends 2-3 hours with the family preparing the application. A further 2-3 hours is spent wording it and completing the form itself. Overall **£27,000** has been gained by Carers through the input of the Support Worker.

### Breakdown of Contact Information



## Joint planning with other Support Workers of regular Alternative Therapy Sessions

Funding for Alternative Therapy sessions was awarded to DCCS shortly after the project commenced. The Support Worker now promotes these amongst Carers of adults with learning disabilities. Many have benefited from weekly aromatherapy, reflexology and Indian Head Massage sessions. **DCCS** Health Promotion days have also been especially popular with older Carers.

Carers frequently find meetings about "caring issues" stressful and in contrast enjoy breaks in the day that provide them with opportunities in the week to have "quality time" just for themselves. In recognition of this, the Support Worker has been involved in collaboration with his colleagues in co-ordinating and planning taster sessions and short courses in, for instance, art, creative writing and Local History.

## Outings and pub lunches for Carers (transport provided)

Other Carers prefer more informal and less structured social opportunities. The Support Worker has participated fully in the regular day trips and luncheons organised by DCCS. On such occasions Carers often make good links with each other and this has sometimes been a trigger to them making independent friendships.

Carers have been able to access a range of social, information and participation events, which have included:

- Luncheons (9)
- Information Events :
  - Arthritis Care.
  - Patient, Advice and Liaison Service.
  - Direct Payments (Community Care)
  - Parents as partners.
  - Creative writing and its therapeutic benefits.
  - Wills and Trusts.
  - Healthy Lifestyles and staying well
  - Welfare Rights
  - Be good to yourself course.
  - Respite Care and Short breaks.
  - Housing.
  - Transition.
  - Women with Care Responsibilities in Employment.
  - Carers influence on Social Work Training.
- Excursions:
  - Eden Camp
  - Alnwick Water Gardens
  - Newcastle Quayside and Baltic Centre.
  - York
  - Blackpool( 5day)
  - Washington Wild Fowl Park
  - Hamsterley Forest

The improved co-ordination of support offered to Carers by liaising with voluntary and statutory bodies, facilitating events and contact to enable Carers and those they care for to make informed decisions.

#### Advocating on behalf of individual Carers

A key role of the Support Worker has been to advocate on behalf of Carers who feel their point of view has been ignored or misunderstood by those taking decisions. The Support Worker has frequently fulfilled this role at meetings. He is also regularly in contact with the relevant professionals by letter or telephone to relay Carers concerns or seek clarification for the reasons certain decisions have been taken. Where appropriate, he will also make referrals to Citizens Advice Bureaux, Patient Advice and Liaison Service (PALS) or occasionally solicitors. At times a mediation role has been more applicable, particularly when the interests of the cared for person appears to be suffering because the Carer and the agencies concerned are unable to find common ground.

#### Participation in the Learning Disability Partnership Board and its associated sub-groups. - the key local policy making groups under the auspices of the Valuing People White Paper

Many of the barriers Carers and those they care for face as they attempt to gain a better quality of life are structural. Poor co-ordination of services, lack of a Carers voice on decision-making bodies, lack of funding and resource led models of service delivery are examples of this. Another frustration commonly experienced by Carers is the rigid interpretation of Eligibility Criteria by service providers. Funding decisions about individual need are often short term "fixes" which do not reflect long-term considerations. They are often crisis driven rather than preventative. The knowledge gained by the Support Worker through his role with individual families has enabled him to contribute effectively within the multi agency structures that seek to address these shortcomings. He has fully participated in the County Durham Learning Disability Partnership Board, which involves service managers, service users, Carers and representatives from voluntary agencies in County- wide policy making. He attends the Local Planning Group, which advises the Partnership Board on issues arising in the North Durham area. He attends two sub-groups, which advise the Partnership Board on Accommodation and Employment issues for people with a learning disability. He is also the **DCCS** representative on the Adult Protection Committee, which oversees the County's policies on protection of vulnerable adults from abuse.

#### Supporting Carers who attend these groups

Direct representation by Carers on decision making committees. The Support Worker has successfully recruited Carers for this purpose and supports them at the meetings. However, only a limited number of Carers have the inclination or stamina to spend the little free time they have participating in such structures. It is has therefore been an equal priority to involve Carers in consultation through the **DCCS** Support groups and information events that many Carers already attend. Members of the local Integrated Learning Disability Team now regularly attend these events to meet informally with Carers and give feedback on any issues to the relevant colleague, if they can't deal with it themselves.

In addition, at the request of the Quality Assurance manager of County Durham Care, the Support Worker carried out a consultation exercise with Carers on their views about a local day service. Carers were consulted through questionnaires, focus groups and individual interviews. The resulting Report has led to a group of Carers becoming involved in meetings with Day Service Managers and staff on a bi-monthly basis. These meetings in turn have led to the production of a regular newsletter and better service user involvement, which were two of the key issues raised in the original consultation.

### Developing partnerships with social service, health and education professionals as well as those from other local voluntary agencies

Participation on the Partnership Board has also enabled the Support Worker to collaborate with multi-agency staff in planning and promoting major information and consultation events. In April 2004 he worked closely with a Social Care and Health manager to organise a conference for Carers on Accommodation and Planning for the Future. A Wills and Trusts Solicitor, Direct Payments Project Manager and a local Housing Trust led workshops to raise Carers awareness about the steps they can take to ensure the person they care for can have a secure future and have the support they need to "move on". The Support Worker has also worked with another local voluntary agency to run Person Centred Planning and Direct Payments awareness raising sessions for Carers

### Collaborating with **DCCS** colleagues to organise Information Days and other events attended by a wide variety of agencies and their representatives

Information events and Carers Rights days are routinely organised by **DCCS** in collaboration with colleagues for all Carers. Carers of people with a learning disability have been well represented at these events. Arthritis Care, the Stroke Association, Age Concern, Social Care and Health Complaints officers and Welfare Rights workers have been amongst those who have given talks and through the events forged closer links with Carers. Recently, the Support Worker organised a successful session on Wills and Trusts. A solicitor gave a talk to a large audience of Carers on this important topic. She has subsequently offered to run several surgeries, free of charge, for individual Carers to discuss their plans for the person they care for.



# The future direction of the Carer Support Project for Carers of people with learning disabilities

This Report has hopefully demonstrated that the targeted support to Carers of people with a learning disability, made possible by the Community Fund, has made a significant impact on the quality of support that can now be offered to Carers of people with a learning disability.

- Levels of support for Carers of adults with a learning disability have become far more consistent. More individual contact time with individual Carers has been achieved by having a worker dedicated to supporting one particular group of Carers.
- Support has also been effectively co-ordinated through more active links with the relevant agencies and projects. The project is assisting Carers to find a voice within the decision making process
- Support is being offered to more people. At the outset, 190 Carers of people with learning disabilities had been identified. This has now risen to 255, not including many Carers of young people who are 16-18 years old who will shortly access adult services.

However, despite this progress, huge challenges remain and areas of unmet need continue to be revealed. Areas of work that require development including the following:

## Person Centred Planning

Person Centred Planning (PCP) is key to "Valuing People" and the government's stated aim of enabling people with a learning disability and their families to take control over their lives. Local Authorities must by law offer to facilitate Plans for every person with a learning disability by the year 2006. In County Durham, Plans are already being piloted amongst those leaving school or those leaving day centres. These Plans are intended to replace Community Care Planning. They should be led and directed by the service user, rather than by professionals. They should include long- term goals and aspirations rather than rely on service led, resource driven models of delivery. Family Carers are key to the success of PCP because they know the person they care for better than anyone. They are often their chief advocates.

Unfortunately, most of the Plans to date continue to be led and facilitated by professionals. Many Carers are still not informed that they have a right to access a Plan, let alone of the duty of professionals involved with the family to work towards the aims outlined in it. A greater proportion of older Carers should be using the Planning process to assist the person they care for to move towards independence. The Carer Support Worker has himself completed the PCP Facilitators training and has led a PCP Awareness session for Carers. However, more dedicated time is needed to ensure that more Carers become aware of the potential of PCP and, with our support if required, facilitate the Plans themselves.

## Transition

It is essential that young people with disabilities have well co-ordinated support through their transitional years in order for them to meet their potential as adults.

During the lifetime of the project, the Support worker has been increasingly made aware by parents and Carers that they frequently feel isolated, let down and distressed by the lack of a co-ordinated response to the young person they cared for at such a vital time of their lives. Many of the young people who most commonly appeared to be falling through the net included those with autistic spectrum disorder, ADHD, those with more complex disabilities and

school or college students who attend out of county placements. The Support Worker, in collaboration with his colleague who works with parent Carers, consulted with parents through a focus group and through individual interviews. He produced a Report and presented it to multi-agency service managers on the County Durham Transitional Strategy Group. The concerns were taken seriously. For the first time the Strategy Group are now meeting regularly with Parents and Carers as part of an attempt by service providers to address the current failures in the system.

It has therefore become apparent that families would benefit from support targeted specifically at parents and Carers of young people with disabilities during the transitional years (16-25 years). It would make sense for **DCCS** to develop this area of work in line with its support for older Carers, as young people receiving more support early in their adult lives will be less dependent on their Carers as they grow older. However, targeted funding would be required to fully achieve this.

### The impact of Eligibility Criteria and Fair Access to Care

*Fair Access to Care* is the government's latest guidelines to Local Authorities about eligibility criteria for individuals wishing to access services. In County Durham, only those with "critical" or "substantial" need are provided with services. Those deemed to have "moderate" or "low" levels of need are merely signposted to community facilities. The dilemma for many Carers is that it is their input that often prevents the needs of those they care for becoming "substantial", yet because of their support the family receives no support. Many people with learning disabilities who live at home may have moderate learning disabilities, but they usually remain highly vulnerable and dependant on their families, especially for any social life. They are told they can "access the community" but in reality the support they need to do this usually falls to the family. This is stressful for all concerned and does not lead to greater independence for the cared for person. **DCCS** are increasingly called upon to advocate on behalf of these families. Once again, more dedicated time is needed to work with these families, highlight their needs more widely and campaign for better resources within the local community.

### The ageing population of Carers in Durham and Chester le Street

The vast majority of people with learning disabilities are still cared for in the family home. The Durham and Chester le Street area already has a higher than average proportion of Carers who are over 65 years. Social Care and Health acknowledge that there is a shortage of available housing for people with a learning disability. Therefore, for the foreseeable future, there will be an increasingly frail population of full time Carers. The crisis is compounded because the cared for are themselves now older people and inevitably requiring more support to meet their health needs. Complex patterns of mutual dependency between Carer and cared for can lead to families isolating themselves still further from outside sources of help. All these trends will intensify the need for emotional and practical support, which the Carer Support Worker is well placed to provide. The crisis will also require improved co-ordination of responses from service providers, which again is an important part of Support Workers remit.



## Some examples of effective support to individual Carers

**Mr and Mrs M** are older Carers. Their 45 year old daughter has a learning disability. Mr. M worked as a miner and has chronic and severe lung and breathing difficulties. Mrs M has arthritis and anxiety problems. Their daughter, who has attended a local day centre all her adult life, is highly dependent on them. Prior to the Support Worker's visit, the family had little contact with outside agencies. They had had a disagreement with their daughter's Care Co-ordinator and this had made them wary of seeking help. Mr M had no awareness as to his possible entitlement to Attendance Allowance. The Support Worker informed him of this and helped him complete the forms. This application was successful and consequently Mrs M could then apply for Carers Premium.

Owing to their health problems, Mr and Mrs M were desperate to move with their daughter to a bungalow, but because they had recently turned down an offer made by the Council for a vacancy, they had lost their place on the priority list. The Support Worker wrote a letter on their behalf to the Housing Department, explaining the family's circumstances and their care for a severely disabled daughter. He pointed out that the previous offer had been turned down because its location was unsuitable for their daughter. The Council placed them back on the priority list, and they are now hoping to move imminently.

On first encounter, Mr and Mrs M were adamant that they would not wish their daughter to move in to independent supported living before they died. However, through a period of regular contact with the Support Worker, they became more open about their concerns about their own increasing frailty. Mrs M began to acknowledge that she was finding caring for her daughter as well as her husband increasingly wearing. Mr and Mrs M are now taking the first tentative steps towards planning for their daughter to move on. Subsequently, the Support Worker made a joint visit with a specialist accommodation advisor and Mr M attended a recent information day on Wills and Discretionary Trusts.

**Mrs C** is an older Carer who lives alone with her adult son. Her husband died fairly recently and Mrs C was struggling to cope with her bereavement in addition to being the sole Carer for her son. Her life was becoming increasingly stressful because her son was becoming depressed. He was attending a local day centre for most of the week, but he was far happier when he had the occasional opportunity to do clerical work for his sister's small business. Because this is located 15 miles from his home, he had only been able to do this on a limited basis as and when his sister could call for him and return him home. It was becoming increasingly impractical for his sister to arrange this. The Support Worker suggested that Mrs C's son may be able to access Direct Payments to have a placement working for and supported by her daughter, and may also have as part of this funding access to the work placement. On requesting this, the Care Co-ordinator informed Mrs C that this was a "non starter" because Direct Payments could not be used to pay family members, nor could it be used to pay for transport. The Support Worker contacted the Direct Payments Project, who clarified that the scheme could be flexible and cover both costs, as long as the arrangement was genuine. He then called for a meeting with the family and the Care Co-ordinator, and supported Mrs C and her son in persuading the Care Co-ordinator that such a change would be in their best interests. Mrs C is now living with a more contented son who has a successful 2-day placement every week at her daughter's place of work.

**Mrs D** is an older Carer who cares for her adult daughter, L, who has a learning disability. She was becoming increasingly worn down by her daughter's demanding behaviour. The Support Worker completed a Self Assessment Questionnaire in preparation for a Carer's Assessment. The social worker completed the Carers Assessment and her daughter now goes out twice a week with a Befriender paid for through the Carers Special Grant. Talking over her concerns for the future with the Support worker, Mrs D explained she could not trust anyone but L's sister to care for her after Mrs D's own death. However, this decision caused her considerable

anxiety because she knew how many pressures L's sister already faced in her own life. However, Mrs D began to increasingly enjoy the breaks she was having through her Carers Assessment. After continuing discussions with the Support Worker and L's Care Co-ordinator Mrs D became more open to the possibility of her daughter moving into independent supported living, whilst she was still living. Her daughter is now on a waiting list to move once the housing becomes available.

**Mrs H** cares for her daughter who is 18 years old. Mrs H's daughter has learning difficulties and Cerebral Palsy. A year before her daughter left school Mrs H tried in vain to request a Community Care Assessment on her behalf. She wanted to explore the possibility of her daughter accessing Direct Payments in order to develop a social life appropriate for an 18 year old. She was informed by Social Care and Health that because she'd had an Occupational Therapy Assessment, she was not entitled to a further Assessment. The Support Worker wrote to the manager of the appropriate team challenging this decision but still an Assessment was not forthcoming. Mrs H's daughter became increasingly upset and as the months passed her mother was coping with increasingly demanding behaviour at home. After an inadequate response to her complaint, the Support Worker assisted Mrs H in making a complaint to the Local Government Ombudsman. Social Care and Health are now funding 12 hours Direct Payments per week individual support for Mrs H's daughter. They have also apologised for malpractice and offered compensation to Mrs H and her daughter.

**Mr Z and Mrs Z** have cared for their niece, R, since she was a child. Both Carers are in their late seventies. Mr Z has limited mobility and chronic health problems. For decades, Mr and Mrs Z attempted to meet their niece's needs with no help from outside agencies. The family were not known to Social Care and Health. Three years ago, through one of their events, **DCCS** made contact with them and established a trusting relationship. This was enhanced when the Support Worker assisted Mr Z in making a successful Attendance Allowance application. Last year, a crisis ensued as R developed severe mental and physical health problems. These problems came to a head rapidly. R became severely withdrawn and distressed, would not eat or drink and wouldn't leave her bedroom. Mr and Mrs Z were devastated. However, they had dedicated their lives to meeting R's Care Needs and were frightened that through gaining outside support R would be taken in to care. They therefore contacted **DCCS** rather than Social Health and Care in the first instance. The **DCCS** Manager visited discussed matters with them and gained their permission to alert Social Care and Health about the crisis. R was admitted to a local hospital for medical investigations The Care Coordinator was then able to gradually introduce home care for R and has prioritised visiting the family regularly. Long- term support has therefore been established following the **DCCS** intervention.



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