

Implementation of 'Valuing Carers'

Northern Health and Social Services Board

Progress Report May 2004



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***Carers Week
14-20 June 2004**

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***There are
6 million carers in
the UK**

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***Carers save the
UK Treasury
£57 billion every
year**

***3 in 5 people will
become a carer
at some point in
their lives**

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***In the UK, 4
million carers
work full-time or
part-time**

***Logos and boxed data provided courtesy of the
Carers' Week, 2004 website: (www.carersweek.org)**

Executive Summary

This report provided an interim evaluation of progress made in the Northern Health and Social Services Board area on the implementation of 'Valuing Carers' (DHSS&PSNI 2002).

The report reviews a suite of investments made in pilot projects by the Board that are due for final evaluation in March, 2005. The projects include:-

- A Family Carer Training Project that aims to offer and deliver training to Carers
- A Carers Information and Support Project that aims to develop and support Carers' Groups and to offer information and support to individual Carers
- Enhanced respite care provision in both community Trusts

Good progress has been made in implementing these Projects although there have been some difficulties, specifically in recruiting and retaining suitable staff. Further work remains to be done on the wider issues of separate Carers' Assessments and in maximising the potential impact of Direct Payments for Carers.

A final evaluation report will be provided in the spring of 2005.

1.0 Background

1.1 In 2002, the Department of Health, Social Services and Public Safety (DHSSPS) published a regional strategic plan entitled 'Valuing Carers' aimed at improving the support provided to informal Carers.

1.2 The document highlighted a number of strategic drivers, not least the anticipated decline in the population of people of working age compared to the number of pensioners (the document stated that this ratio is five to one at present but projected three to one by 2031).

1.3 Some of the main points in this document were as follows:-

- It is estimated that there are 250,000 informal Carers in Northern Ireland with a Carer living in 18% of all households. This equates to approximately 60,000 informal Carers in the Northern Board area.
- While it is estimated that the gross numbers of people requiring the support of a Carer will increase year on year, a number of factors are likely to combine to cause a potential decline in the numbers of people available to assume caring roles.
- A substantial percentage of people in receipt of a domiciliary care package are also dependent on an informal Carer or Carers.
- A typical profile of a Carer shows that they are a highly diverse group, with only small differences in gender for those providing more than 20 hours care per week.
- While a third of Carers are in full-time employment, almost a half were economically inactive (this figure increased sharply for those Carers living with their dependant).
- Half of those Carers living with their dependant had a long-standing illness themselves.

- Compared to people who do not have caring responsibilities, Carers are more than twice as likely to report that they are suffering a great deal of worry or stress.

1.4 'Valuing Carers' proposed a number of priority actions. Those with relevance to the Northern Health and Social Services Board were as follows:-

Information

- The provision by GPs and other clinicians of better information about medical conditions and services provided
- The inclusion of Carers in hospital assessments and discharge plans
- The prioritisation of Carers' needs by Local Health and Social Care Groups (LHSCGs)
- The development by Trusts and Carers organisations of handbooks for Carers about local services
- The provision of internet based information

Training

- The provision by Trusts of appropriate assessment of Carers' training needs and the delivery of suitable training

Support Services

- A review (to include Carer representation) by Boards and Trusts of their service provision for Carers including a specific review of respite provision
- The routine provision by Trusts of information about the right to a separate assessment of a Carer's needs and arrangements for separate recording of such assessments
- The provision of encouragement and support by voluntary sector organisations to locality and disability specific respite groups

- The provision of training for front-line staff in handling complaints and for advocates acting as guides in the complaints process
- The identification and support of older Carers (over 65s)
- The provision by Trusts of a Carer Liaison or Co-ordinator post

Help for Young Carers

- The identification of Young Carers' needs with particular reference to ensuring their continuing education and development

2.0 Summary of Investments made in 2003/04 by the Northern Health and Social Services Board

2.1 The following recurrent investments were made by the Board during 2003:-

- ExtraCare; £49,741 over two years for a pilot project providing training to Carers
- Carers Northern Ireland; £66,658 over two years for a pilot project employing two Information and Support Workers
- Homefirst Community Trust (Homefirst); £55,350 in-year for the provision of respite care to support Carers
- Causeway Health and Social Services Trust (Causeway); £18,450 in-year for the provision of respite care to support Carers

2.2 In total this represents an investment over the two year period of £190,199.

2.3 These investments were made on a pilot basis and it was agreed at the time that they would be subject to formal review after two years. This paper provides an update to the Board by way of a brief interim progress report.

2.4 It is also worth noting that these additional investments occurred in the context of a number of other specific initiatives, projects, pieces of legislation and/or schemes, specifically designed to:-

- Assess the needs of Carers
- Assist and support them
- Provide them with respite care

2.5 Two examples of such schemes are provided later in this report, namely;

- Causeway Share the Care Scheme
- The work of the Northern Area Children and Young People's Committee Sub-Group on Children in a Caring Role

3.0 Progress to Date

A) EXTRACARE

3.1 The Family Carer Training Project aims to provide intensive, individualised support and guidance based on assessed need and delivered in a way which is tailored to suit individual Carers. This support and guidance is intended to enable Carers in their role, to enhance safety and to encourage skilled participation in the caring process.

3.2 Following detailed assessment, which includes self-assessment, each Carer receives a unique Training and Development plan that details the inputs to be given. This could include knowledge and understanding of specific illnesses and conditions, stress management techniques, back care and manual handling training, health and safety in the home, guidance on specific personal care tasks, the management of challenging behaviour, benefits and welfare advice or advice on the role of other agencies.

3.3 Up to the 31 March 2004, it was intended that the scheme should provide inputs to 50 cases referred from both Trusts on a two thirds to one third ratio between Homefirst and Causeway Trusts respectively.

3.4 In practice, because of recruitment and retention difficulties and a slow start to uptake of the scheme (the first referral from Homefirst was received on 7 July 2003 and from Causeway, on the 15 August 2003), it was agreed between the Board and ExtraCare to revise this target downwards to 25 cases.

3.5 Referrals to the scheme have largely been from Community Teams for older people and Dementia Teams with one referral being received direct from one of ExtraCare's domiciliary schemes.

Table 1: Source and Volume of Referrals

Source of Referrals	Referrals Received	Referrals Actioned
Causeway	12	9
Homefirst	13	11
Total	25	20

3.6 As shown above in Table 1, some Carers, although referred for help and assistance, did not actually receive it. There was a variety of reasons for this including the death of the person being cared for, inappropriate timing of the referral (i.e. it did not suit the Carer), changed circumstances and, in one case, a Carer who it transpired was only interested in respite care.

3.7 Feedback on the Project has been collected from both Carers and referral agents. This is systematically collected from each Carer on completion of the training and support package and has revealed very positive comments. Most comments are about the benefits gained in terms of practical knowledge or emotional support while others have praised the individual contribution of the Project Worker. ExtraCare are now in the process of completing a three month post-intervention follow-up study and will share the results in due course. Feedback from referral agents has been slower in coming forward but is similarly positive.

3.8 Developmental challenges for the second half of the Project are:-

- Ensuring retention of the Development Officer, thus providing continuity of service
- Improving uptake of the service by referral agents
- Achieving a second year target of 50 referrals

3.9 Board and Trust officers will continue to monitor the scheme and an external evaluation will be completed by Carers' Northern Ireland before 31 March 2005.

B) CARERS' NORTHERN IRELAND

3.10 The aim of the Carers' Support Project is to identify and meet the information and support needs of Carers, as identified in 'Valuing Carers', across the Northern Board area.

3.11 The key objectives of the project are to:-

- Develop support for Carers' groups
- Produce and distribute local A-Z information guides for Carers
- Provide access to an enquiry service to advise on individual information needs
- Develop an information outreach programme
- Provide formal opportunities for networking amongst all agencies
- Offer training and support for mentors to support Carers in raising complaints
- Support the involvement of Carers in service planning and development

3.12 The Project has been somewhat hampered in its first year by staff recruitment and retention difficulties. The two Project Workers were appointed in June/July of 2003 but one of these suffered ill-health during her probationary period and subsequently left the post in December, 2003. The replacement worker took up post in April, 2004. As this post covers both the Antrim/Ballymena and East Antrim LHSCG areas, project objectives in these areas have not been fully progressed.

3.13 Most success in supporting Carers' groups has been achieved in the Mid-Ulster and Causeway areas. Three existing Carers' groups have been sustained and developed (Coleraine, The Glens and Mid-Ulster). Activities, supported by the Project Worker, have centred on attracting local media coverage (press and radio), holding information evenings, sorting out committee structures, roles and functions, developing information leaflets and social functions and arranging access to alternative therapies for Carers.

3.14 A group based in Whitehead has struggled with poor attendances and a lack of focus but it is hoped to re-launch it this year in the Carrickfergus area. The Antrim group has been hampered by illness among key members and it is hoped to re-launch this during Carers' Week 2004 (14 June to 20 June). A group in Larne is in existence but has not yet secured a funding base. In addition, it wishes to retain an independent identity from Carers' Northern Ireland but continues to receive assistance and support from the Project.

3.15 Work is in hand to develop new Carers' groups in Cookstown, Draperstown, Ballymoney and Whiteabbey.

3.16 Revised versions of the Carers' A-Z Directory of support agencies have been produced for the Causeway and Homefirst areas. These are now on their second print run and are being distributed through Carers' groups, HSS Trusts, local pharmacies and voluntary organisations.

3.17 The Project Workers are handling approximately 20 telephone queries per-week, usually social security benefit and community care issues. A number of enquiries relate to Direct Payments. With the consent of the caller, a full information pack is

posted, including details of local groups, a year's free membership to Carers' Northern Ireland and a Carers' Emergency Card detailing contact details to be used in the event of an accident or health crisis.

3.18 A number of events were sponsored during Carers' Week, 2003 including a coffee morning, a day trip for Carers, a luncheon attended by the Chairman of the Northern Board and a musical evening. Carers' Rights Day (5 December 2003) was marked by a range of activities including public library displays, presentation to Age Concern lunch clubs and the distribution of information packs to voluntary organisations and to every GP in the Causeway area.

3.19 Successful partnership working has been developed with a variety of groups including HSS Trusts, LHSCGs, the Rural Health and Well-Being Project in Draperstown and the Pharmaceutical Palliative Care Services' Steering Group. Support and advice is offered in a variety of ways to a further set of community and statutory bodies.

3.20 Key objectives for the coming year are:-

- Further development of the Carers' Advocacy and Mentoring Project which seeks to offer peer support to Carers who are experiencing difficulties with health and social care services
- Consolidation of progress with Carers' Groups in Mid-Ulster and Causeway
- A renewed focus on Antrim/Ballymena and East Antrim
- Further development of partnership approaches with a wide range of agencies, groups and networks

C) TRUST RESPITE CARE

3.21 Both Homefirst and Causeway Trusts were given a special allocation to develop respite care.

3.22 Causeway Trust chose to use their allocation to appoint a part-time Social Worker. Their aim was to develop creative respite care solutions including domiciliary based respite care. However, Causeway did not draw down their allocation of £18,450 for

2003/04 and they have recently written to the Board confirming their intention to draw down funding when the Social Worker takes up post.

3.23 Homefirst used their allocation of £55,350 to purchase 724 additional Nursing Home bed days and 658 Residential bed days. This is equivalent to almost 200 families benefiting from one weeks respite care which would otherwise not have been available.

3.24 Homefirst managers recognise that the intention of this funding was to secure a wider range of respite options and during 2004/05, they intend to use this funding to expand their domiciliary sitting service and night support services across the Trust.

3.25 Board officers will work with both Trusts to ensure that these allocations are expended in line with the recommendations of Valuing Carers, including the development of non-domiciliary respite options that go beyond orthodox offers of residential or Nursing Home placements.

D) OTHER INITIATIVES - EXEMPLARS OF BEST PRACTICE

Causeway Adult Share the Care Service

3.26 The above scheme has been in existence for eight years. It aims to provide domiciliary based respite care through the identification, recruitment and training of 'host Carers'. Until recently, the scheme was used primarily by people with a learning disability but the Trust aims to extend this to people with a physical disability or sensory impairment. Currently, there are 29 different homes accepting placements and this year, 104 people have enjoyed a respite placement. Consumer feedback is reported to be excellent and drop-outs are very rare. Investment in the scheme is currently circa £129,000 and is accounted for by staff costs and the cost of overnight placements. It remains an important objective for the Trust to consolidate what has been achieved to date.

Children in a Caring Role

3.27 The current vision for children in a caring role within the Northern Board area is that 'all agencies will identify children and young people who are living in situations where they are being required to provide care which places a level of responsibility and demand which is not in keeping with their rights as children. Appropriate supports will be provided for children in this situation and all relevant agencies will work together, at a level which ensures that these children enjoy the same life chances as all other children'.

3.28 The focus on these children is now led by the Northern Area Children and Young People's Committee through a sub-group. It has given expression to this vision by developing an Inter-Agency Policy for Young Carers, a Protocol for the identification of Young Carers and a checklist to assist in the identification process. This approach is aimed at making staff aware that some young people may have to spend a lot of time caring for another family member and showing them how they can help these young people access services which would help them to take part in all the things they might want to.

3.29 The Inter-Agency Policy, Protocol and Checklist for the identification of Young Carers has been produced and are being circulated to all partner organisations. An extension of the Barnardo's Young Carers' Scheme in throughout the Northern Health and Social Services Board area has been funded through the Children Fund and a School Age Mother (S.A.M.) Co-ordinator has been appointed within each Education and Library Board and a worker identified in each school in the area. Finally, a research proposal and literature review of the educational needs of Young Carers has been drawn up and the field work has been completed.

4. Conclusions and Next Steps

4.1 The initiatives that have been taken in the past year are significant. They represent additional investment of almost £200,000 and build on a considerable history of support by this Board to projects that directly support Carers.

4.2 In relation to the specific projects reviewed, good progress has been made on implementation. This has not been without difficulty, perhaps demonstrating that working with Carers is as difficult and challenging a task as any other area within the Health and Personal Social Services (HPSS).

4.3 New possibilities will emerge in the near future. Direct Payments for Carers are now available and the Regional Review of Mental Health and Learning Disability holds forth the possibility of ring-fenced funding for advocacy and Carer support.

4.4. The Board, together with Trust and voluntary sector partners, will continue to work towards achieving all of the objectives set out in each of the three initiatives described in this interim evaluation. In particular, close attention will be given to the issue of separate Carers' assessments. Without these assessments and the detail they contain about individual needs, it will be difficult to improve choice and to refine our wider understanding of population-level needs.

4.5 In addition, there will be growing pressure from consumers to improve the range and flexibility of respite provision so that it becomes more person centred. Carers will also wish to become more involved in decision making processes in areas such as service planning and monitoring. The Board will wish to take account of these issues as it seeks to develop Carer support in the future.

4.5 It is proposed to provide Senior Management Team (SMT) members and the Board with a final evaluation report in the early Spring of 2005.