

## HEALTH AND SOCIAL WELLBEING: INFORMAL CARE

<b>Issue/Problem</b>	<b>Recognising the information, support and service needs of carers</b>
<b>Evidence Base (Equality &amp; Inequalities Report)</b>	<p>18% of people in the 1997 NI Health and Wellbeing Survey indicated that they provide care for a sick, disabled or elderly person.</p> <p>Women carried significantly more responsibility than men for the provision of care, with 20% of women providing care in comparison to 14% of men.</p> <p>Informal care was highest amongst those aged 45 to 64, with approximately a fifth acting as carers. Women aged between 30 and 44 are almost twice as likely as men of the same age to be carers (25% and 13% respectively).</p> <p><i>Ref: 1997 NI Health and Wellbeing Survey cited in "Equality and Inequalities in Health and Social Care in Northern Ireland: A Statistical Overview (DHSSPS, 2004:133).</i></p>
<b>Evidence Base (Literature Review)</b>	<p>Carers are defined as people who, without payment, provide help and support to a family member or friend who may not be able to manage without this help because of frailty, illness, or disability. Carers can be adults caring for other adults, parents caring for ill or disabled children or young people aged under 18 who care for another family member<sup>1</sup>.</p> <p>Research suggests that despite a policy drive in recent years towards supporting carers in their caring role, many carers continue to feel marginalised and often believe that their own particular health and social care needs are overlooked<sup>2</sup>. Identified barriers to accessing support include:</p> <ul style="list-style-type: none"><li>▪ lack of recognition amongst some professionals of the carers' role and the needs of carers;</li><li>▪ prioritising the needs of the care recipient to the detriment of the carer;</li><li>▪ lack of training in carers' issues amongst some health and social care staff;</li><li>▪ inflexible hospital and primary care appointment systems;</li><li>▪ lack and/or cost of transport to and from health and social care facilities;</li></ul>

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- language barriers for carers who are not proficient in English, inadequacies in translation and interpretation services, lack of knowledge regarding cultural and religious practices;
- carers’ lack of knowledge and individual beliefs about health promotion;
- carers provided with insufficient knowledge about where and how to access services;
- professionals concerns with confidentiality and disclosing information to carers.

However, specific groups of carers have specific support needs. Briefly outlined are some of the difficulties experienced by women and men who provide care, young carers, older carers, carers of people with learning disabilities, black and minority ethnic carers, carers of children with disabilities; carers of people with mental health problem. Note that this is not a fully comprehensive examination of the different types of carer – it merely provides an illustration of the need to recognise “multiple identity” and its impact upon the caring role.

### *Gender and Caring*

Despite an increasing demand for elder care and childcare, changes in the population and work patterns means that few people will be available to provide informal care<sup>3</sup>. Future trends such as the growth in lone parents, falls in birth rates, higher divorce rates, the increasing number of people living alone and greater family mobility will impact upon the number of men and women available to provide care. The growing number of women in employment will also have profound implications given that it is women who have traditionally fulfilled the caring role<sup>4</sup>.

Incomes in retirement for state and private pensions are lower for those currently caring for someone in the same household, retired women carers are particularly likely to be in the lowest pension income band<sup>5</sup> and are thus more likely to experience the impact of poverty.

Other social trends such as the rise in the number of frail older people, the increased chances of living with a spouse in old age and the continuing improvements in the life expectancy of severely disabled children mean an increasing number of men are taking on the role of carer. Research suggests that older men who care for their spouses/partners often do not perceive themselves to be carers and thus do not access services they are entitled to.

### *Young Carers*

There are difficulties identifying young carers given that many do not disclose their caring role for a variety of reasons (e.g. fear of

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bullying, from being separated from parents, fear of social exclusion). It is suggested that the actual number of young carers may be substantially higher than Census figures indicate<sup>6</sup>.

It is suggested that young carers are often overlooked when the needs of the care recipient are being assessed. Often professionals carry out assessments during the day when young people are at school or fail to talk to young people regarding their caring role and subsequent needs. Many parents and young people are also reluctant to reveal to statutory services that they provide care<sup>7</sup>.

There has been an emergence of projects aimed at young carers in recent years. Research suggests that these are mainly provided by the voluntary sector and that many are short term and have limited funding.

### *Older Carers*

Advances in medical technology and higher standards of care means that older people are now living longer. There are now an increasing population of older people available to take on the role of carer.

People with learning disabilities now have a greater life expectancy than ever before and as a result there is an expanding population of older parents who are continuing to care for a son or daughter well into old age. Evidence suggests that ageing carers and their adult children with learning disabilities have a complex set of individual and joint needs. Co-operation between specialist learning disability services, generic older persons services and voluntary services is seen to be essential in cases involving older parents providing care<sup>8</sup>.

Many older people also provide care for a spouse or partner. Older spousal/partner carers tend not to see themselves as carers (especially older men) and therefore do not access services they are entitled to<sup>9</sup>.

### *Black and Minority Ethnic (BME) Carers*

BME carers experience a range of barriers in accessing support. Often many BME carers do not identify themselves as carers and tend to see caring as part of their customary or familial role. There is a tendency for these carers to only access mainstream services as a last resort.

Additional barriers include - a lack of culturally sensitive services (e.g. reluctant to access meals on wheels if they do not provide the appropriate food); insufficient information on services provided in a range of languages; assumptions by some health and social care staff that BME carers "look after their own"<sup>10</sup>.

### *Caring for Children with Disabilities*

A recent report published by Mencap (2001) on the carers of children with profound and multiple learning disabilities highlighted a number of difficulties. These included a lack of understanding by some service providers; a lack of appropriate day care and respite care services, lack of information about their child’s diagnosis and treatment options; poorly coordinated services; rude and abrupt treatment by some health care professionals and front line staff; dissatisfaction with the assessment process; lengthy waiting lists and inadequate support to assist their children in moving from child to adult services<sup>11</sup>.

Despite diversity amongst disabled children and young people and their families a number of consistent difficulties have been identified in terms of accessing support and services. These include – parents/carers’ lack of knowledge about their child’s disability/illness; social ignorance and prejudice about disability in general; parental relationship strain and family breakdown; social isolation for both children and their carers; additional expenses resulting from special diets, clothing, adaptations etc; lack of family-based respite services<sup>12</sup>.

### *Caring for People with Mental Health Problems*

The carers of people with mental health problems have been affected by the traditional underfunding of mental health services. The difficulties in locating a hospital inpatient bed and obtaining appropriate housing are two of the most frequently cited problems for carers. Additional difficulties for carers include a need for greater access to information on issues such as - medication, specific mental health problems, the availability of new treatments, local service provision and coping strategies.

**Is the issue/problem being addressed by current or proposed strategies and policies? On what level?**

### *Strategies for Carers*

In 2001 the DHSSPS published the [Informal Carers Report](#) which explored the prevalence of informal care in Northern Ireland and examined the characteristics of both carers and care recipients. In 2001 the Department published [Valuing Carers](#) – which outlined proposals for a Strategy for Carers in Northern Ireland. Recommendations for carers in a number of areas including information and training for carers, the inclusion of carers in decision-making and future care plans, the identification of carers, provision of information on local services, a review of service provision for carers, carers’ assessments, respite services, support for carers’ groups, the employment needs of carers, training for frontline staff etc.

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Several Boards and Trusts have already produced their own individual strategies for carers many of which implement recommendations outlined in the Valuing Carers report (e.g. see North & West Belfast HSS Trust draft [“Supporting Carers”](#) Strategy).

### *PSI Working Group on Carers*

The DHSSPS is leading an inter-Department Working Group on Carers which is currently in the process of developing a strategy for carers.

### *Carers Assessment & Direct Payments*

Carers are entitled, under the [Carers and Direct Payments Act \(Northern Ireland\) 2002](#), to an assessment of their own needs and grants HSS Trusts the power to give services directly to carers (i.e. through Direct Payments). [Direct Payments](#) are provide cash payments to carers in lieu of services that would normally be arranged for them by HSS Trusts, so that carers may arrange the provision of their own services.

### *Consultation with Carers*

Many of the Boards/Trusts have organised user and carer led seminars both to inform carers of new developments and receive feedback from carers regarding gaps in service provision.

### *Northern Ireland Social Care Council*

Have established a [Carers Reference Group](#) to support the Council in fulfilling its statutory functions. The remit of the Carers Reference Group is to ensure that issues affecting family/informal carers are reflected in NISCC business.

### *Consent Guidelines for Carers*

In 2002 the DHSSPS published [consent guidelines](#) for relative and carers. These guidelines are particularly relevant for carers of people who have problems in understanding or communications (e.g. a person in the stages of advanced dementia, a person with a severe learning disability, a person who has suffered a stroke).

### *Quality Standards*

The DHSSPS has recently published a set of draft [quality standards](#) which both service users and carers should expect from Health and Personal Social Service (HPSS) organisations. Dignity, respect, independence, rights, choice and safety are central to the proposed standards. One of the key features of the standards is enabling both service users and carers to understand what quality of services they are entitled to and to provide the opportunity for them to help define and shape the quality of services provides.

### *NI Mental Health and Learning Disability Review*

The opinions and experiences of the families and carers of those with a mental health problem or learning disability form an important

part of the review. There are carer representatives on most of the review committees. The Learning Disability Committee, for example, established an Equal Lives Group with a learning disability and Carers Advisory Group. There are also reference groups of users of mental health service users and their carers<sup>13</sup>. A range of recommendations for carers of people with mental health problems and learning disabilities have been identified<sup>14</sup>.

*Examples of Projects/Initiatives for Carers*

- Project in Mid-Ulster, funded through the Building the Community-Pharmacy Partnership initiative, involving pharmacists and carers working together to develop a training and information pack which addresses the needs of carers on the use and administration of medicine<sup>15</sup>.
- Investments by Boards and Trusts in various projects (e.g. provision of training to carers, providing support to carers' groups, extending and enhancing respite services).
- Register for Children with Disabilities – it has been suggested that if it is implemented and maintained effectively it will be a valuable tool in planning and developing service for children with disabilities, their families and carers.
- A number of Trusts/Boards are providing input into projects for young carers (e.g. three Young Carers Projects are in operation within the SHSSB area<sup>16</sup>. Other projects for young carers in NI have been established by voluntary groups such as Barnardo's.

**Is the problem amenable to further intervention by the DHSSPS or other?**

*General Recommendations<sup>17</sup>*

- Pre and post registration training for all health and social care professionals and frontline staff to ensure that they identify and accept carers as a discrete group with their own particular health needs.
- Incentives for primary care professionals to focus on carers' health and proactively offer health checks for carers.
- Identifying and “tagging” of carers in medical records including hospital admission and discharge notes.
- Identification of a point of contact or carer support worker in each GP practice or health centre.
- Greater recognition of the needs and special circumstances of carers in the way in which appointments and electoral procedures are arranged.
- Greater flexibility and availability of respite services.
- Education for carers by health and social care professionals and/or care support workers regarding the benefits of health promotion behaviours and regular screening.
- Providing health and social care professionals with access to up-to-date information on national and local services for carers.

### *Gaps in Research<sup>18</sup>*

For a better understanding of the needs of different groups of carers, research should be commissioned in the following areas:

- Carers’ access to services in their own right, including an assessment of carers’ access to health care in different settings other than primary care (e.g. secondary and tertiary services).
- Culturally sensitive services (i.e. research into what types of culturally sensitive services are needed and how these could be implemented).
- Qualitative research regarding carers’ access to ICT, including access and use of Internet services. Findings could be used to inform e-health websites for carers.
- Research on the needs of specific user groups (e.g. young carers, older carers, BME carers, carers who are asylum seekers and refugees, carers of people who have stigmatising conditions such as HIV and AIDS, alcohol and drugs misuse or mental health problems).

### *Gender and Caring<sup>19</sup>*

- Carers who provide high level of intensive care are particularly vulnerable in the labour market which has implications for their current and long-term financial security. An increased commitment to family friendly employment policies and practices is needed to help carers balance paid work and other aspects of their lives.
- Steps should be taken to address the issues of carers low incomes in retirement. Special provisions during working life and beyond will be necessary to provide carers with incomes in retirement comparable with others.

### *Young Carers*

- Guidance to Boards and Trusts on carers’ assessments should stress the need to ensure that young carers are identified and that services are put in place to ensure that their education and development do not suffer because of their caring responsibilities<sup>20</sup>.
- The DHSSPS should make the information needs of young carers a specific consideration when looking at ways of improving information about services to carers available on the Internet<sup>21</sup>.
- The possibility of conducting an audit of initiatives for young carers should be explored. Evidence suggests that many projects may not be reaching young people given that they are reluctant to reveal that they are carers to statutory services.
- The provision of counselling and other support services through non-traditional means (e.g. telephone and internet services) should be explored.

### *Older Carers of Adults with Learning Disabilities<sup>22</sup>*

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- Services must work in partnership to identify older carers of people with learning disabilities with joint approaches developed to ensure that needs are met.
- Information systems on the number and needs of older carers of people with learning disabilities should be established. Information collected by different agencies should be coordinated and collated.
- Older families should be visited at least annually to obtain an up-to-date record of family circumstances.

*Older Spousal/Partner Carers*

- Greater attention should be given to older people who provide care to a partner or spouse, barriers to access services must be identified and addressed.

*Black and Minority Ethnic Carers<sup>23</sup>*

- Effective training on cultural diversity and ethnic monitoring to gain confidence in addressing carer assessments and professional gatekeeping issues.
- Consultation and joint working with other providers and community advocates to develop trust and acceptance of BME carers.
- Non-discriminatory approaches to service planning, care planning and carer assessment.

*Carers of Children with Disabilities<sup>24</sup>*

- A dedicated team sufficiently trained to understand the needs of children and adults with profound and multiple learning disabilities should be established. They should have the skills and experience to carry out assessments, provide and review service provision and ensure that services are co-ordinated between different agencies.
- Research should be commissioned into the additional costs of caring for children and adults with profound and multiple learning disabilities.

*Carers of People with Mental Health Problems<sup>25</sup>*

- All statutory community and primary mental health services must involve carers and families in the development, delivery, monitoring and evaluation of services.
- Care plans embracing risk assessment should be provided for all people with complex needs, based on a multi-disciplinary approach and when required a multi-programme approach. Risk assessment should include accommodation needs. Where appropriate, carers, must be involved in care planning.
- The needs of carers and families of individuals with bipolar disorder must be considered.
- Carers, families and friends of individuals with mental health problems should be provided with relevant information in clear

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and simple formats.

- The needs of carers, children and other relevant family members, should be identified during the assessment process.
- Agencies should afford carers equal status with other providers of care.
- Carers should be offered an annual assessment and a written care plan.
- Trust should make available dedicated carer and family workers.
- Trusts should ensure that a range of support services in the form of helplines, self-help groups, directories of services, help with social security benefits and respite opportunities, is provided for carers and families.

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<sup>1</sup> DHSSPS (2002) *Valuing Carers: Proposals for a Strategy for Carers in Northern Ireland*. Belfast: DHSSPS.

<sup>2</sup> Arskey, H., Jackson, K., Wallace, A., Baldwin, S., Golder, S., Newbronner, E. & Hare, P. (2003) *Access to Health Care for Carers: Barriers and Interventions. Report for the national Co-ordinating Centre for NHS Service Delivery and Organisation R&D*. [www.sdo.lshtm.ac.uk/pdf/access\\_arksey\\_report.pdf](http://www.sdo.lshtm.ac.uk/pdf/access_arksey_report.pdf)

<sup>3</sup> Mooney, A., Statham, J. & Simon, A. (2002) *Informal Care and Work After Fifty*. Joseph Rowntree Foundation Findings. York: Joseph Rowntree Foundation.

<sup>4</sup> DHSSPS (2002) *Valuing Carers, Op Cit*.

<sup>5</sup> University of York Social Policy Research Unit (2001) *Informal Care Over Time. Research Works*. York: University of York.

<sup>6</sup> Princess Royal Trust for Carers. “*Shocking New Figures on the Number of Kids Caring*”, Press Release, 1 September 2004.

<sup>7</sup> Banks, P., Cogan, N., Riddell, S., Deeley, S., Hill, M. & Tisdall, K. “Does the covert nature of caring prohibit the development of effective services for young carers? *British Journal of Guidance & Counselling*. Vol. 30, No. 3, 2002.

<sup>8</sup> Hubert, J. & Hollins, S. Working with elderly carers of people with learning disabilities and planning for the future. *Advances in Psychiatric Treatment*. vol. 6, 2000, p41-48.

<sup>9</sup> Neno, R. Spouse caregivers and the support they receive a literature review. *Nursing Older People*. Vol. 16, Issue 5, p14, 2004

<sup>10</sup> Welsh Assembly Government (2004) *Challenging the Myth: “They Look After Their Own”*. *Black and Minority Ethnic Carers*.

<sup>11</sup> Mencap (2001) *No Ordinary Life: the support needs of families caring for children and adults with profound and multiple learning disabilities*.

<sup>12</sup> Kelly, B. Monteith, M. (2003) *Supporting Disabled Children and their Families in Northern Ireland: A Research and Policy Review*. National Children’s Bureau.

<sup>13</sup> Information extracted from the Review of Mental Health and Learning Disability Website [www.rmhdni.gov.uk/](http://www.rmhdni.gov.uk/)

<sup>14</sup> See Adult Mental Health Report and Equal Lives Report.

<sup>15</sup> DHSSPS (2003) *Making it Better: A Strategy for Pharmacy in the Community*. Belfast: DHSSPS.

<sup>16</sup> see <http://www.southernareacsp.n-i.nhs.uk/YCarers.htm> for further details of these Projects.

<sup>17</sup> Recommendations extracted from Arksey et al (2003)

<sup>18</sup> Arksey et al (2003) *Op Cit*.

<sup>19</sup> Recommendations extracted from University of York Social Policy Research Unit (2001) *Op Cit*.

<sup>20</sup> DHSSPS (2002) *Valuing Carers Report*

<sup>21</sup> *Ibid*.

<sup>22</sup> Recommendations extracted from Foundation for People with Learning Disabilities (2003) *Good Practice Guidelines in Supporting Older Family Carers of People with Learning Disabilities*.

<sup>23</sup> Welsh Assembly Government (2004) *Op Cit*

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<sup>24</sup> Mencap (2001) *Op cit.*

<sup>25</sup> Recommendations extracted from Review of NI Mental Health and Learning Disability (2004) *A Strategic Framework for Adult Mental Health Services. Consultation Document.*  
[www.rmhdni.gov.uk/amh\\_committee.asp](http://www.rmhdni.gov.uk/amh_committee.asp)