



Health and Community Care Committee

23rd Meeting, 2001

Wednesday 24 October 2001

The Committee will meet at 9.30 am in the Chamber, Assembly Hall, The Mound, Edinburgh

1. **Item in private:** The Committee will consider whether to take item 3 in private.
2. **Community Care and Health (Scotland) Bill (Stage 1):** The Committee will take evidence from—

Pat Dawson, Head of Policy and Anne Thomson, RCN Officer, Royal College of Nursing

Helen Chambers, Policy & Parliamentary Affairs Manager, John Wilkes, Director and Isobel Allan, Carer, Carers National Association

Dr. Bill Reith, Chairman, Dr. Iona Heath and Dr George Dyker, Royal College of General Practitioners

Jess Barrow, Head of Policy and Public Affairs and David Brownlee, Information Officer, Age Concern Scotland

3. **Reports:** The Committee will consider a reporter's report on Organ Donation.

Jennifer Smart
Clerk to the Committee
Room 2.5
email jennifer.smart@scottish.parliament.uk

The Following papers are attached for this meeting:

Agenda Item 1

Written Submission from Age Concern Scotland (Witness)	HC/01/23/1
Written Submission from Carers National Association (Witness)	HC/01/23/2
Written Submission from Royal College of General Practitioners (Witness)	HC/01/23/3

Written Submission from Royal College of Nurses (NOT YET RECEIVED) (Witness)	
--	--

Agenda Item 2

Report from Dr. Richard Simpson MSP, on Organ Donation

HC/01/23/4



Community Care and Health (Scotland) Bill

**Age Concern Scotland's submission to the
Health and Community Care Committee
of the Scottish Parliament**

16 October 2001

**Age Concern Scotland
113 Rose Street
Edinburgh
EH2 3DT**

Community Care and Health (Scotland) Bill
Age Concern Scotland comments

Community Care and Health (Scotland) Bill
Age Concern Scotland comments

Part 1

COMMUNITY CARE

Section 1. Regulations as respects charging for community care

Age Concern Scotland does not believe that it is appropriate for the implementation of free personal care to be dependent upon regulations by Scottish Ministers. We would like to see the right to free personal care at the point of delivery, and the definition of personal care as defined in the report 'Fair Care for Older People' laid down in statute.

Leaving these two key points to be implemented by regulation rather than by statute opens up the possibility of these fundamental principles being reversed by future Scottish Ministers without the full scrutiny of Parliament.

If the Parliament wishes to stay true to its promise to deliver free personal care, it is of the utmost importance that both the definition and the right to care are laid down in statute.

With a clear definition of personal care set in statute, the definition of other aspects of social care will be clearer, and regulations set by Scottish Ministers will apply. We welcome the regulation of charging for other social care services, and anticipate that this will lead to consistency and fairness in charging, and an introduction of a national baseline of charging.

Section 1 subsection (2)(b)

We would welcome a clearer definition of 'reasonably practicable', and would recommend that the capital limits for the provision of local authority help with residential care purposes are extended for social care purposes, as a baseline for local authority charging structures whether residential or home based.

Section 2. Accommodation provided under the 1968 Act

We welcome the inclusion of this section, and feel it is appropriate for the definition of 'Accommodation' to be left to the discretion of Ministers. We anticipate that if an appropriate definition is used it will enable Attendance

Community Care and Health (Scotland) Bill
Age Concern Scotland comments

Allowance to continue to be paid to residents of residential and nursing home accommodation.

Section 3. Disregarding of resources when determining whether to make available assistance by providing residential accommodation

This section is designed to remove doubt over whether a local authority can refuse to arrange accommodation because of capital (or notional capital).

We are aware of significant problems that exist in relation to current legislation and case law, which we would like to see this part of the Bill address. The first of these is the issue of notional capital. Too often older people and their families are caught up in lengthy and difficult legal disputes because of a local authority's interpretation of the notional capital of an older person. We believe that this Bill offers an excellent opportunity to define the concept of notional capital, and to specify when and in what circumstances it should be considered as part of an older person's assets. We do not wish to support the practice of giving away property with the sole intention of avoiding care fees, but we want to see an end to the draconian practice of including as notional capital the value of assets given away over a decade ago. We suggest that a reasonable time-limit is enshrined in statute, up to which time each case is considered on its merits, but beyond which disposal of assets cannot be considered as notional capital.

The second issue of concern to us is the practice of some local authorities to simply provide information to people assessed as needing care but who would be self-funding because of their assets. In addition, the recent MacGregor case has highlighted the need of local authorities to meet someone's assessed care needs immediately without regard to the local authority's resources. We would like to see a legal obligation on local authorities to ensure that an individual's assessed care needs are met, regardless of either the individual's or the local authority's resources.

Section 4. Accommodation more expensive than usually provided

While we welcome the extension of the third party payment system to allow residents to make extra payments to enable them to be placed in a more expensive home, we do not want to see a situation where this happens as a

Community Care and Health (Scotland) Bill
Age Concern Scotland comments

matter of course. Topping up of fees should only occur when someone chooses to go to a more expensive home. It should be a matter of choice. We are concerned that this concession will allow local authorities to pay less than the actual, reasonable cost of a care home place, and will also allow private homes to put up prices unreasonably. A solution to this problem would be to allow topping-up of fees, whether by a third party or by the individual concerned, only where that person has been offered a reasonable choice of alternative accommodation where topping-up would not be necessary. This would ensure that local authorities paid rates adequate for the purchase of services, that private homes had an incentive to keep prices reasonable, and that older people would not be forced against their will into topping up because it is the only option.

Section 5. Local authority arrangements for residential accommodation outwith Scotland

The proposals in this section are reasonable, and we do not wish to make any specific comments.

Section 6. Deferred payment of accommodation costs.

Age Concern Scotland welcomes the introduction of a system of deferred payment for accommodation costs. This will enable many older people to retain ownership of the family home for the rest of their lives. This is important to those people who for whatever reason do not want to be forced into selling their home before they are ready to do so. However, the legislation does not appear to impose a duty upon local authorities to offer such schemes. It is important that all older people in Scotland have access to such schemes, and that it does not depend upon where you live. We would like to see such a duty explicit in the legislation.

While there are likely to be changes to the demand for this service as free personal care ensures that the cost to the individual is reduced, we have concerns that the funding described in the Bill may be insufficient, and that further funds should be made available to meet potential demand.

Section 7. Direct Payments

Community Care and Health (Scotland) Bill
Age Concern Scotland comments

Age Concern Scotland welcomes the proposal to extend direct payments to everyone as a right rather than an option on the part of a local authority. Coupled with the extension of direct payments to those over 65 last year, there will be a huge increase in the number of older people able to take advantage of this new right.

Existing direct payment schemes have shown the need for independent advocacy and support services to be available for users of direct payment schemes, and the existence of such schemes have been crucial to the success or failure of existing initiatives. With the ability of direct payments to be used to purchase services directly from a local authority, such support is even more important. Age Concern Scotland would like to see within the Bill provisions for Scottish Ministers to issue guidance to local authorities about the setting up and resourcing of independent advice, support, and advocacy schemes.

Section 8. Amendment of the 1968 Act: assessment of ability to provide care

Age Concern Scotland welcomes the changes that will allow carers' needs to be considered in all cases.

Section 9. Amendment of the Children (Scotland) Act 1995

Age Concern Scotland has no specific comments to make on this section.

Community Care and Health (Scotland) Bill
Age Concern Scotland comments

Part 2

JOINT WORKING, ETC

Sections 10, 11, 12,13, and 14

Age Concern Scotland welcomes the move towards joint working and joint resourcing, and has long called for better co-ordination between various bodies to improve service delivery to older people. We recognise that a single model may not be appropriate, and welcome the powers in the Bill to establish methods of joint working and resourcing, and the powers to enforce joint working where necessary. In the long run it is important to be able to monitor the outcomes for older people and other service users, and to ensure that the systems in place result in seamless, quality care.

Parts 3 and 4

Age Concern Scotland has no specific comments to make on the remainder of the Bill.

Age Concern Scotland
16 October 2001

Any comments or questions should be referred to:

Jess Barrow or David Brownlee
Age Concern Scotland
113 Rose Street
Edinburgh
EH2 3DT

T: 0131 220 3345
F: 0131 220 2779
E: jess.barrow@acscot.org.uk
david.brownlee@acscot.org.uk

CARERS Scotland

Community Care and Health Bill

Briefing Paper from Carers' Perspectives

Introduction

There are currently 626,000 carers in Scotland today¹; between 15-16% of the adult population is providing care, i.e. 1 in 7 adults. Thirty-two percent of carers care for more than 20 hours a week and 15% of carers are caring for 50 hours or more.²

Recent research³ analysing demographic data predicts that by 2037 that the number of carers will rise by 60% to 992,000.

Care can range from helping with the shopping through to providing continuous care. Thirty-one percent of carers are involved in providing personal care such as washing and toileting, 27% administer medicines and 73% give other practical help. Sixty percent of carers looking after someone in their own home provide both personal care and physical care (such as getting in and out of bed, and help with stairs)⁴. The care provided is unpaid, and the value of this care to Scotland is £3.4 billion per year.⁵

The problems that carers report as obstacles to them providing care in a dignified and healthy manner are financial (depending on circumstances benefit income can be low), lack of access to support services, and lack of access to respite care.

Background to the Bill

The Scottish Executive made supporting carers a priority and committed itself in the first Programme for Government to the introduction of a strategy to support carers. The Strategy for Carers in Scotland was introduced in November 1999. There are five main aims to the strategy:

- To improve the information on help and support for carers
- To add to, and improve, the local services that help carers cope
- To introduce new laws to help carers
- To make sure that there are consistent national standards for the kind of short breaks that carers need
- To check that carers are getting the help that they need

Carers Legislation Group

Under the strategy, a Carers Legislation Working Group was established in January 2000, which reported in January 2001⁶. The recommendations of the Working Group were consulted upon in the Spring/Summer of 2001, leading to the Sections in the Bill outlined below.

The key proposals of the group were to look at a fundamental change in the status and positioning of carers as **partners in the provision of care**. This vision forms part of government social inclusion principles and needs to underpin all future legislation and guidance. It replaces traditional perceptions of carers as clients. It recognises the true role and contribution of carers in the delivery of care in partnership with statutory health and social care services.

The Working Group made 31 recommendations in total, seven of which required legislative change. These are as follows:

1. New legislation should provide for carers to continue to be treated as carers for a limited period after their caring ends, e.g. 8 weeks in line with existing rules on eligibility for Carer Premium and the UK Government's intention to allow Invalid Care Allowance to be extended for up to 8 weeks after the caring role has ended.
2. New legislation should require local authorities to provide information to carers about their rights and available support.
3. Scottish Executive to consider the case for a statutory duty on NHSScotland to identify carers, offer them information, and refer them on as appropriate.
4. New legislation should contain a right for carers to receive an assessment in their own right.
5. New legislation should place a duty on local authorities to offer carers an assessment.
6. New legislation should clarify if necessary the right of carers younger than 16 to receive an assessment, subject to appropriate provision for parental involvement.
7. The Executive should consider whether legislative change is needed to give parent carers of disabled children and 16 and 17 year old disabled children rights to direct payments to purchase care.

Provision for Carers in the Bill

There are two major provisions for carers on the face of the Bill.

Part 1, Community Care, Carers, Section 8

Amendment of the 1968 Act⁷: assessment of ability to provide care

Part 1, Community Care, Carers, Section 9

Amendment of the Children (Scotland) Act 1995: assessment of ability to provide care for a disabled child

At present, under section 12A of the 1968 Act a local authority is required if requested by the carer of an adult, to carry out an assessment of the carer's ability to care only if the authority at that time is also assessing the needs of the cared-for person for community care services. Similarly, under the Children (Scotland) Act 1995, a local authority's duty, if requested by a carer of a disabled child, to carry out an assessment of the carer's ability to care applies only when the authority at that time is assessing the needs of the cared-for child.

The Bill amends and adds to these provisions, and **gives carers of adults and carers of disabled children an independent right to request assessment that does not depend on whether the authority is also assessing the needs of the cared-for adult or the cared-for child. This applies to all carers.**

The main financial impact on local authorities of giving an independent right to assessment, and to extend that right to young carers under sixteen and parent carers of disabled children is likely to focus on the increased number of assessments requested and the greater level of need that these identify. It is not possible to quantify the increase at this point.

The Scottish Executive has stated that this increased demand will be met from the increasing resources provided to support carers and provide respite care (rising from £5m 1999-2000 to £20m 2003-04).

These provisions cover recommendations 4 and 6. **The extension of access to assessments for carers under the age of 16 is not specifically clarified on the face of the Bill, but is referred to in Explanatory Notes (44,147).**

Direct Payments

In response to the seventh recommendation of the Working group **the Bill provides for direct payments to 16 and 17 year old disabled children; and to parent carers of disabled children, on behalf of their children.**

Guidance

In a recent letter⁸ to the Legislation Working Group members the Scottish Executive indicates that most of the rest of the Working Group's recommendations would be taken forward in new guidance from the Executive to councils, the NHS and the voluntary sector.

Carers as Partners in the Provision of Care

The Community Care and Health Bill, and its associated guidance, has a potentially strong role to play in reframing the position of **carers as key partners in care provision**. As stated before this new concept marks an important principle that replaces traditional perceptions of carers as clients. It recognises the true role and contribution of carers in the delivery of care services.

The Executive's **Care Development Group**⁹ stated, "We endorse the vision of the Carers Legislation Working Group in treating carers as partners in the provision of care and acknowledge their importance to the care system as a whole."

Ministers and the Scottish Executive "strongly support the [Legislation Working] Group's overall vision that carers should be recognised as partners in providing care, not treated by other caring agencies as clients with needs of services."⁸

This significant recognition impacts on government social inclusion principles and the need to underpin all future legislation and guidance.

Carers Scotland's Response.

We welcome the independent right for an assessment for carers of all ages, and parent carers of disabled children.

If the "overall vision that carers should be recognised as partners in providing care" is to be realised the Scottish parliament needs to pursue placing statutory duties upon both NHS Scotland and local authorities to identify carers.

Carers cannot be treated as key partners if the statutory bodies that are supposed to be engaging with them are unaware of their existence. We do not accept that placing this intent within guidance will be sufficient. This is backed up by a recent survey¹⁰ of carers organisations across Scotland under taken on behalf of the "Joint Futures Project", a Scottish Executive funded two year initiative being carried out by Carers Scotland and the Coalition of Carers. Key findings from this survey shows that regarding NHSScotland:

- Carers and carer organisations are undervalued
- The NHS is remote, inaccessible and intimidating
- The NHS resists carer involvement
- Carer consultation is done badly

Similar experiences were reflected for local authorities:

- Consultation is done badly in many areas
- Agency structures and attitudes intimidate carers
- Carers' voices are stifled by lack of support and resources

A huge opportunity has been missed in not imposing a statutory duty upon NHSScotland to *identify carers, offer them information, and refer them on as appropriate*. Research^{10,11,12} and anecdotal evidence continues to show that NHSScotland currently serves carers poorly. They are not seen as equal and key partners in the care provision of the cared-for person. They are often ignored and sidelined.

Until NHSScotland acknowledges, and works in partnership with carers, both the health of carers, and cared-for people, will continue to be compromised. Additional pressures on NHSScotland such as 'revolving door' discharge/admittance and delayed discharge will continue to have a perspective to them that could be addressed and solved by engaging with carers. NHSScotland is already in contact with the vast majority of carers, often unbeknown to itself. Placing a statutory duty upon NHSScotland to identify and provide support would enable a sea change in the culture of NHSScotland to engage positively with carers rather than casting them in the light of a drain on services.

Similarly while it could be argued that Local Authorities are more aware of the role and profile of carers there is still much to do. The numbers of carers assessments carried out is still too low in Scotland and there is much anecdotal and other evidence to suggest that additional focus is required.

We would urge the Health & Community Care Committee to address this opportunity and to place statutory duties on both NHSScotland and local authorities.

¹ The Scottish Executive, 2001, *Men & Women in Scotland: A Statistical Profile*.

² The Scottish Executive, 1998, *Informal Carers*.

³ George, M., 2001, *It Could Be You: A Report on the Chance of Becoming a Carer*. CarersUK, London

⁴ The Scottish Office, 1995, *General Household Survey*

⁵ Nutall, S.R. *et al*, 1993, *Financing Long term Care in Britain*, The Institute of Actuaries, London.

⁶ *Report of the Scottish Carers' Legislation Working Group 2001* The Scottish Executive

⁷ The Social Work (Scotland) Act 1968 (c.49)

⁸ Otton, F. 11 Oct 2001 *Carers' Legislation - Next Steps* CLWG 1rl Oct 01 The Scottish Executive

⁹ Care Development Group, 2001, *Fair Care for Older People*, The Scottish Executive

¹⁰ "Joint Futures Project" – Coalition of Carers/Carers Scotland, 2001, Key issues to emerge from an analysis of responses from 25 local authority areas, Unpublished.

¹¹ Holzhausen, E., McGinley, A., 2001, *You Can Take Him Home Now: Research into Carers' Experience of Hospital Discharge*, CarersUK, London

¹² Henwood, M., 1998, *Ignored and Invisible: Carers' Experience of the NHS*, CarersUK, London



Royal College of General Practitioners (Scotland)

Written Evidence to Health and Community Care Committee: Community Care and Health (Scotland) Bill, Stage 1

October 2001

1. Introduction

- 1.1. The Scottish Council of the Royal College of General Practitioners (Scotland) welcomes the introduction of the Community Care and Health (Scotland) Bill and welcomes the opportunity to comment on this important piece of legislation.
- 1.2. The College in Scotland is supportive of the principles outlined in this Bill and recognise the key aim of which is to facilitate the introduction of the Sutherland report, which we have been consistently in favour of.
- 1.3. In considering the Bill, we have also examined the report of the Care Development Groupⁱ. Many of the key recommendations necessitate joint resourcing and the management of health and social care services, provided for in the draft legislation. From the group's report, we specifically welcome:
 - The opportunity to focus on enabling people to remain in their own homes as long as they wish to.
 - The need to integrate care staff and district nurses into unified and effective teams who are able to provide a co-ordinated service to patients and support for the less qualified staff.
 - The potential role of primary health care teams in the early notification of those at risk and needing preventive home care services.
 - The potential advantages of placing social workers within primary health care teams.
 - The opportunity to provide home based respite and the possibility of linking this with reassessment of the patient's needs by health and social care professionals.
 - The need for provision of medical support to care homes with input from geriatrician, psycho geriatrician and general practitioner.

- 1.4. RCGP Scotland gave written and oral evidence to the Committee during its Review of Community Care and has maintained a keen interest in subsequent developments.
- 1.5. In considering this draft legislation, we have outlined specific points we would wish to make at this stage in respect to each section.

2. Part 1: Community Care

2.1. Section 1 – Charging for Social Care

- 2.1.1. The College in Scotland fully supported the Royal Commission on Long Term Care's belief that the cost of 'personal' (nursing) care should be met by the state on the basis that community care, as an extension of primary care, is free at the point of contact.
- 2.1.2. We welcome the introduction of the legislative means to implement free nursing and personal care in this Bill.

2.2. Section 3 – Disregarding of Resources

- 2.2.1. We welcome the provision enabling Ministers to specify what resources of a person, and how much of those resources, should be disregarded when deciding whether to provide residential accommodation.
- 2.2.2. We have concerns, however, about the potential for this rule to "apply differently for different cases". Although this is presumably intended to work to the benefit of the individual, we are concerned that it might be used against them. If each case is seen as 'individual' it might undermine the creation of generally accepted practice, with each situation being dealt with individually and on its merits (presumably as seen by the local authority).
- 2.2.3. If such interpretation is correct, we think consideration should be given to an appropriate appeals process.

2.3. Section 4 – Accommodation more expensive than usually provided

- 2.3.1. We welcome the provision for the regulation of how, and in what circumstances, third parties or residents themselves can make top-up payments. Clarification in this area will be useful and should ease the significant problems that arise from the current provision.

2.4. Section 5 – Local authority arrangements for residential accommodation outwith Scotland

- 2.4.1. This section seems to allow social work departments to 'call on' the health authority to provide services within the NHS if it is felt to be better for the individual. This clearly makes sense.

- 2.4.2. It is our view, however, that the more significant problem is the other way round, with individuals being cared for in hospital who would be better cared for in a residential setting. There is a considerable problem of bed blocking and the consequent effect on NHS resources. There seems to be little or no incentive for local authorities to resource care in the community rather than in hospital, where the cost to the NHS is huge. Other sections of the Bill do seem to allow for easier transfer of resources between authorities, although we feel this particular point would benefit from more explicit provision.

2.5. Section 6 – Deferred payment of accommodation costs

- 2.5.1. Provisions in this section, which allow people to defer the sale of their property to pay for the care they receive is welcomed by the College in Scotland and should be reassuring to the elderly.

2.6. Section 7 – Direct payments

- 2.6.1. The College in Scotland welcomes the expansion of direct payments to all community care client groups, particularly where it reaches people in more deprived sections of the community.
- 2.6.2. This move is not without implications and will require additional resources to counterbalance the increased number of direct payments being made.
- 2.6.3. We welcome the provision that services can be bought from individuals as well as local authorities. However, this may put local authorities in a difficult position, deciding whether or not to make a payment to an individual, but also then as a key provider of that service. Might there also be pressure on individuals to purchase from that local authority?

3. Part 2: Joint Working etc

3.1. Joint Working

- 3.1.1. We believe that joint working is the key to the delivery of high quality, seamless care for the people of Scotland. Continuity of care across providers is essential, and the GP can often play a pivotal role in guiding the patient through their health and community care journey.
- 3.1.2. We would support joint working initiatives, based around the patients' needs and the provision of a high quality service. This may include integrating care staff and district nurses into a unified and effective community team, or placing social workers in the primary care context.
- 3.1.3. To facilitate such arrangements, it is essential that resources can flow from NHS bodies to local authorities and *vice versa*. We would therefore welcome the provisions in Part 2 for this and would hope that this will encourage creative thinking around the provision of services.

- 3.1.4. There also exists an urgent need for the simplification of planning and monitoring systems so that organisations are only required to produce documents of proven utility.

3.2. Staff

- 3.2.1. We would support the opportunity for career and professional development through the provisions for staff transfers. That said, staff would need to be adequately trained and account must be taken of the impact on existing staff to cope with the absence of a trained member of the team.
- 3.2.2. We have long-standing concerns about the recruitment and retention of care staff and would strongly recommend further consideration of these issues when implementing the provisions of the Bill.
- 3.2.3. As far as staffing in other professions are concerned, there remains a shortage of practitioners across the board and a crisis of morale among general practitioners in particular. Issues surrounding training, status and remuneration are all pertinent factors, which must be addressed in considering the delivery of high quality services.

4. Part 3: Health

4.1. Section 15 – Health Boards' Lists

- 4.1.1. The provisions under Section 15 extending the medical list system to cover all GPs working in the NHS in Scotland have the full support of the College in Scotland.
- 4.1.2. From a practical point of view, there will need to be a significant amount of publicity directed at non-principals and practices to ensure that only those on the list are employed.
- 4.1.3. We would also urge that the mechanism for registering non-principals, particularly on boundaries of health boards, is as uncomplicated as possible. The concern is that locum cover will be difficult to obtain, especially in emergency situations.

ⁱ *Fair Care for Older People*, Care Development Group Report, September 2001