IN THE LONG-TERM *WHO CARES?*

The future of long term care for older people in Manchester.

A Resource Pack

Manchester Older People's Network

MANCHESTER OLDER PEOPLE'S NETWORK

The Manchester Older Peoples' Network was developed by the **Manchester Alliance for Community Care** and members of the Manchester Elders Forum in 2001. It is a partnership between older people (55yrs+) and the voluntary and community sector, and acts as a vehicle for older people to contribute to the planning, development and delivery of services in Manchester.

Though the work we do has a local focus, the Network has developed effective working relationships with regional and national organisations that speak out on all issues affecting the lives of older people.

The Network has been successful on a number of levels, mainly through the work it has done in partnership with the **Community Health Councils** and the **Primary Care Trusts**.

THE FUTURE…

Previously, the Network has brought together older people with representatives from voluntary and community sector groups in a single Steering Group. However, older people who have been involved felt that while they were able to collectively prioritise issues that were important to them, they then experienced difficulties having their voice heard where others set the agenda.

It is proposed to meet as a Steering Group solely of older people. This group will prioritise the work of the Network and co-ordinate where and how its input is delivered.

The Voluntary and Community sector membership of the Network will support the Steering Group by:

- Developing user involvement in their own organisations
- Support involvement for older people in existing and evolving planning mechanisms.
- Providing a focus for the promotion of good practice and facilitate the sharing of information.
- Working in partnership with older people in participating in a range of local and regional planning and decision making bodies.

"The views of older people should be heard directly, not through a third party.

We want to ensure that older people themselves influence policy and planning, and not the other way round!"

*"The Network aims to harness the **skills**, **experiences** and **abilities** of older people, to influence the planning and delivery of public and independent services that have an impact on the lives of older people."*

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INTRODUCTION

The problem with asking people to think about long-term care is that it's something people don't actually *want* to think about until they have to. As a subject it can be dry, depressing and conjures up visions of our future selves that we prefer not to imagine. Sickness and disability can, if we let it, cause such a massive change to a person's lifestyle that he or she wouldn't recognise him or herself anymore.

That's the bit we have to change - it doesn't have to be a bleak picture.

In July we sat down at the Mechanics Institute to try and look closely at this picture. People had different stories to tell and different hopes and fears. One thing they all agreed on: when it's done right, long term care doesn't just mean "nursing care" or "personal care" - it's about dignity and respect.

Rather than simply report on the meeting, we felt it would be more useful to provide a resource for people to consider these issues further - and hopefully to get involved in the development of more "user-friendly" approaches to care. So this is intended as the start of a process rather than a look back to an amiable afternoon in July.

Who cares? We do!

Mike Wild, September 2003

ACKNOWLEDGEMENTS...

Joan Hall, Jo Purcell and Professor Norma Raynes - our three speakers at the Mechanics Institute on 9th July 2003. And of course, Pat Leahy who, as Chair, ensured we hit the right note.

Mary Duncan from MACC / MOPN, Nik Barstow, Pip Cotterill and Pat Leahy from Central Manchester Healthwatch for...well, "pulling the whole thing together" is a fairly good description! Photos by Mary Duncan.

All those who attended the event - and thanks those who facilitated the discussion groups, took notes.

This report is dedicated to all those who contributed to the Community Health Councils in Manchester over the last 26 years.

CONTENTS

CONTEXT

1: National Policy

The current system of long-term care is one which has emerged from Aneurin Bevan's conception of the **welfare state** which promised to support people "from the cradle to the grave".

Over the years, new models and systems have developed as successive Governments have sought to meet the needs of an increasing population, particularly now that advances in medicine and general healthcare mean people are living longer.

Current methods of delivering long term care are:

- Care provided by relatives or friends
- Care services at home
- Care services in sheltered housing
- Day care
- Residential care
- Nursing care

A "care package" may include several of these elements working together. For example, a person living in sheltered housing may have care services coming in as well as periodic stays in a local residential home.

As can be seen from the list (right) the current system has evolved from an ever increasing amount of legislation, not to mention guidance issued by the Department of Health.

SCOTLAND

In 2002, legislation came into force in Scotland granting **free care** to older and disabled people. The Scottish Parliament had made a major break with the NHS in England in declaring that both personal and nursing care would be free of charge at the point of need. While the effect of this is still being assessed (particularly in how it affects people's eligibility for welfare benefits), few would disagree that it represents a significant step towards a more **equitable** system of access to care and support.

THE MILESTONES

1946	**National Health Service Act** *established the NHS and the principle of free healthcare*
1948	**National Assistance Act** *local councils given powers to recoup "modest fees" for residential care from people's welfare benefits*
1960s	*introduction of sheltered housing and the first regulations for private care facilities*
1984	**Registered Homes Act** *The 1980s saw rapid growth in the number of privately run care homes with fees often funded from Social Security payments*
1990	**NHS & Community Care Act** *introduced the new means-tested system using welfare benefits and personal assets to fund non-NHS care packages*
1995	**NHS Responsibilities for Meeting Continuing Healthcare Needs -** *Dept. of Health guidance issued in the wake of the introduction of means-testing seeking to clarify when the NHS should pay for care rather than Social Services.*
1997	**Royal Commission on Long-Term Care for the Elderly** *After 2 years work, its conclusion was that all care services should be free - a view rejected by the Government as too costly to implement.*
2000	**Care Standards Act** *Introduced new regulation for all providers of care services. It promised higher standards but no extra resources.*
2001	**Health and Social Care Act** *Introduced "Free Nursing Care" - NHS funding for the nursing component of the care provided in a care home.*
2003	**Health Service Ombudsman's report on Continuing NHS Care** *- found many people had been charged for care services which should have been funded by the NHS. Also supported the full implementation of the Royal Commission's recommendations.*

Many older people feel that recent Governments have broken a social contract. The current generation of older people have paid into the health and social care system all their lives through national insurance and general taxation, under the promise that the state would provide for them when needed. As with the State Retirement Pension, this has proved a more expensive promise to keep than the Government expected (or was willing to pay for) - and the "modest fees" element of the National Assistance Act was expanded into full means-testing under the **NHS & Community Care Act** in 1990.

The Introduction of guidance **Fair Access to Care Services** from April 2003 adds another set of rules which local authorities must apply when setting out who they will provide services for.

Fair Access to Care splits services into categories according to the "urgency" of the person's assessed needs:

- Critical
- Substantial
- Moderate
- Low

In practice, local authorities will only be able to provide services for those in the most urgent categories - "critical" and "substantial". Obviously this means that Social Services departments are increasingly going to be providing support to people with complex **health** needs...which seems to be a move away from the NHS.

It also begs the question what will happen to those people whose needs are categorised as "low" or "moderate"? Will they simply be left until their needs increase and become "critical"? This is both unfair to older people and a false economy.

SOME FACTS & FIGURES

Sources: Laing & Buisson, Dept. of Health & Age Concern

- In April 2002 there were approximately 381,900 people in Britain receiving care at home provided by the local authority.
- This represents roughly 65% of the total care provided by the independent sector - a further 35% is paid for privately by individuals.
- 94% of local authorities now charge for care at home.
- There are approximately 5,700,000 informal carers in Britain
- Almost a third of these carers provide over **20 hours** per week of care
- In April 2002 there were approximately 460,000 people living in care homes
  - 51% funded by local councils
  - 4% funded by the NHS
  - 45% paying from private assets and state benefits.

Prevention of poor health seems to have become less of a priority. In setting budgets and allocating resources, prevention is, with disturbing irony, rather an afterthought, though it is interesting to compare how much more seriously it is taken when addressing health issues for younger people and children. The shift has in recent years has been to focus on waiting times and emergency needs. Local and national prevention strategies are needed and in order to turn into real changes to people's lives they have to be backed up with specifically targeted resources.

The irony is of course that prevention is not only *better* than cure, it is also considerably *cheaper*.

CONTEXT

2: The Local Picture

Manchester contains some of the most deprived areas in England. As might be expected, therefore, the health of the local population is generally below average for the country.

This means there is tremendous pressure on health and social care services in the area - and less money in the local economy than more affluent (and healthier) areas.

FACTS AND FIGURES

Life expectancy in Manchester is significantly lower than the rest of England:

For women: **76.3 years** compared to 80.4 average for England & Wales

For men: **69.7 years** compared to 75.7 average for England & Wales

Source: Manchester Joint Health Unit

The last few years have seen some changes in the management structures in health services in Manchester - there are now three **Primary Care Trusts** and a separate Care Trust for **Mental Health Services.**

Limited budgets in Social Services, for example, have forced a number of difficult issues:

- historically low contract prices for domicilary care (ie care at home) agencies
- low fee levels for residential and nursing homes
- Increased charges for services - including additional costs for transport, etc.

All of these have meant that the long term care "market" in the city is growing increasingly insecure. Independent care providers have been few and far between as their biggest customer (Manchester City Council) simply hasn't been able to afford to pay them **realistic fees**. The number of care home closures has been rising sharply and **staffing problems** in the care sector stem from the fact that agencies are not able to offer attractive wage levels - to recruit new employees and retain existing ones.

FACTS AND FIGURES

General health is poorer:

- **21.5%** of the population of Manchester suffer from a **long term limiting illness.** (The national average is 18.2%)
- A further **12.5%** are in **generally bad health.** (The national average is 9.3%)

9th July 2003: A Comment from the Chair

Pat Leahy is a member of Central Manchester Community Health Council and of the Manchester Older People's Network. She is also chair of a group working across the North West looking at the involvement of older people in the work around the *National Service Framework for Older People*.

With the **draft Greater Manchester Continuing Care Criteria** in circulation and concerns about the upcoming implementation of the Community Care (Delayed Discharges) Act - better known as "Cross Charging" - members of the **Manchester Older People's Network** and **Central Manchester Healthwatch** (Community Health Council) felt it would be a good point to identify what local older people actually think about long term care and how they would like to see it develop.

We met on the afternoon of Wednesday 9th July at the Mechanics Institute in central Manchester. Of the 71 people who attended, over **50%** were older people and carers, including the Marhaba Group from Woodville Resource Centre (who came with their a Punjabi interpreter). Also among the audience were representatives from local Primary Care Trusts, Manchester Social Services, the independent sector, voluntary and community groups and, of course, our three guest speakers. Notes of their presentations and the general discussions are set out over the following pages.

The response was a good one - with many people welcoming the chance to discuss issues, some of which sprang from personal experience, with a wide range of people with a variety of perspectives.

We are grateful to **The Progress Trust** who provided funds (to the Older People's Network) for the venue and to **Central Manchester Healthwatch** who contributed to the costs of the day and the production of this report.

Pat Leahy, August 2003

Comments from members of the audience...

"It was great to have the chance to really talk about this as a topic. When you're working every day with this kind of thing, you don't really get the chance. We should have more opportunities like this."

"This is something all of us are going to have to think about sooner or later."

"It's a useful reminder sometimes to sit down and just listen to people's experiences. In fact, it's essential. How else are we ever going to improve things?"

"It was a good afternoon. I liked the way everyone was really positive. I don't know about anyone else but I certainly came away feeling like I understood it all a bit better."

"میں نے دوسرے لوگوں سے سیکھا"

"میں واقعی اس دوپہر سے لطف اندوز ہوا"

"میں آئندہ بھی اس قسم کی تقریبات میں حصہ لینا چاہوں گا۔"

JO PURCELL

As **Director of Health Development** at **North Manchester Primary Care Trust,** Jo Purcell has been involved in bringing together the new *Greater Manchester Criteria for Continuing NHS Healthcare*.

Jo discussed the issues involved in the new criteria and the current public consultation.

Jo Purcell talking to Professor Norma Raynes

- **Continuing Care** is care that is generally for people who have significant health needs or who are terminally ill.
- Continuing Care is **fully funded** by the NHS.
- It can be provided in a hospital, hospice, nursing home or in the person's own home. In the past Continuing Care was often seen as exclusively taking place in nursing homes or hospices.
- Each local Health Authority had its own set of Continuing Care criteria which were delegated to **Primary Care Trusts**. The new Strategic Health Authorities were then asked to develop criteria for their areas. In Manchester this is done by the **Greater Manchester Strategic Health Authority**. The budget management and decision making for Continuing Health Care are actually administered by the Primary Care Trusts (Manchester has three - North, Central and South).
- In February 2003 the **Health Service Ombudsman** identified that it is likely that many people had been forced to pay for their own care who should actually have been entitled to Continuing NHS Health Care funding.

  The Department of Health has therefore instructed health authorities to review their criteria and procedures in the light of this judgement.
- The new (draft) criteria for Greater Manchester aim to:
  - provide more consistency across the region
  - provide clearer review and appeals processes
  - develop closer links with local authorities' social services departments in providing support to people with continuing healthcare needs

  No matter what the criteria look like, there will still be difficult decisions to be made. Whilst new system will be more open and transparent, people may continue to feel that some decisions are unfair because they feel all long term care should be free.

The Primary Care Trust leads for Continuing Care in Manchester are:

North Manchester - Anne Hall - 0161 219 9400
Central Manchester - Chris Lamb - 0161 958 4000
South Manchester - Bernadette Starkey - 0161 611 3300
Mental Health Trust - Deborah Morris - 0161 882 1100

JOAN HALL

As Secretary of the North West Pensioners Association, Joan Hall has been closely involved with the National Pensioner's Convention's "Right to Care" campaign.

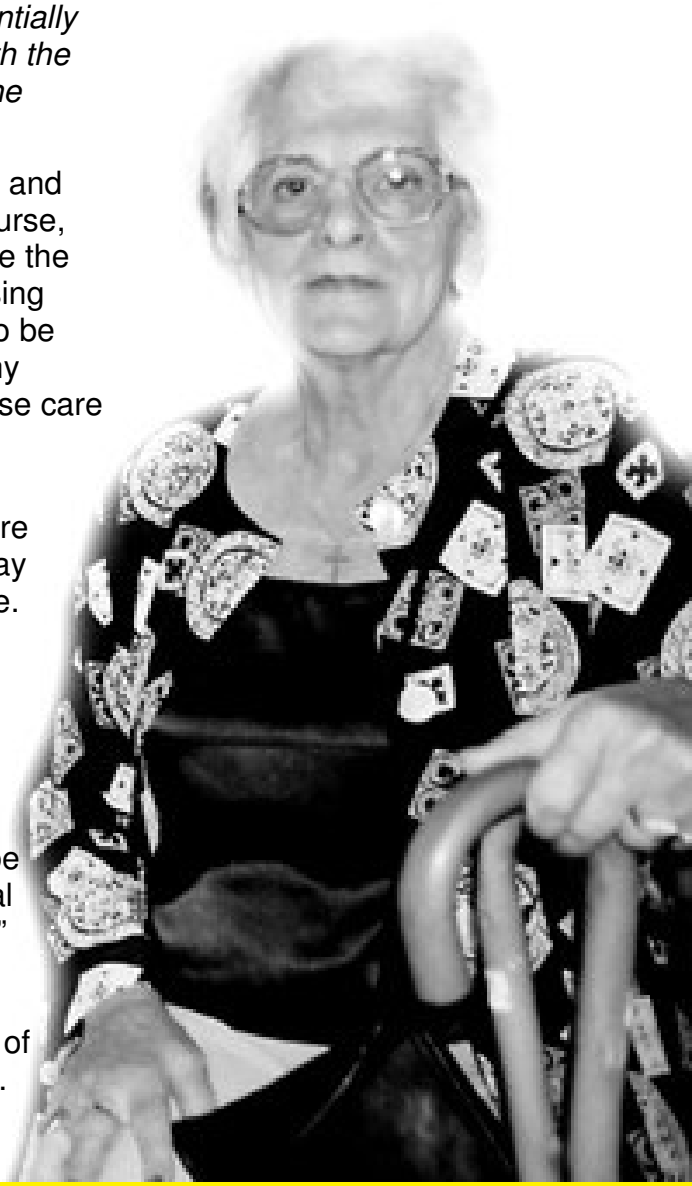
"Today's older people are paying for the neglect of past Governments that closed their eyes to the growing demands of the ageing population."

Chambers Dictionary defines a nurse as *"a person who has care of the sick, feeble or injured, especially one who is trained for the purpose."* Washing someone else, dressing someone else, toileting someone else and feeding someone else are the basic skills of nursing. For the last hundred years nurses have learned these during the first three months of training.

The National Pensioners Convention "Right to Care Campaign" believes that the recommendations of the Royal Commission should be implemented in full. It is unacceptable to charge older or disabled people for essential care. Means-testing of personal care should be ended. We worked hard, we saved, we invested our spare cash in a home to pass on to our children and now the Local Authority forces us to sell our homes in order to pay for care by trained staff.

On September 2nd the following resolution was adopted by the NPC:

"This Executive Committee agrees that in order to expose the confusing circumstances surrounding the provision of Personal and Nursing Care in England, Scotland and Wales, the NPC should give wide publicity to this fiasco and campaign vigorously to persuade the Government to raise substantially the money allocated to Local Authorities for funding both the Home Care and Residential and Nursing Homes with the money to be ring fenced."



The Government's definition of Nursing Care is artificial and narrow: it only covers the time spent by a Registered Nurse, not the care provided by Nursing Assistants who provide the majority of care to older people in what are called "Nursing Homes". This counts as Personal Care and continues to be charged for. This means the terms will not apply to many people with Alzheimers or other forms of dementia whose care is largely defined as 'Personal'.

The Institute of Public Policy Research argues that it is unfair that a heart attack or cancer sufferer gets free care in hospital while someone who develops Alzheimers may have to pay thousands of pounds for nursing home care.

Public dissatisfaction with the situation is growing. The issue topped a poll of priorities for extra NHS spending conducted by the BBC with more voters willing to pay more for free long term care for the elderly.

The artificial distinction between "Nursing" and "Personal" care should be ended.If Nursing Care is to be free, then Personal Care must also be free, for Personal Care is an intregal part of Nursing Care. The "third way" is patently absurd if it redefines nursing as non-bodily care. If ministers decide that Personal Care is not Nursing Care then the outlook for the future generation of frail, sick and dependant people in care homes is bleak. Good quality care should be provided on the basis of need, free at the time of need in all settings.

Professor NORMA RAYNES

Norma Raynes is Director of the Institute for Health and Social Care Research at Salford University.

- Responsibility for Continuing Healthcare rests with the **Primary Care Trusts** (PCTs).
- Each Primary Care Trust appoints a **Continuing Care Lead**.
- This person is responsible for promoting and developing **Continuing Healthcare services**.

*"Older people should be involved in the design, implementation and monitoring of the information about these schemes: **including** developing mechanisms for consultation."*

Accessing Continuing Care

You or your carer should request a **comprehensive assessment**. This can be made to:

- GP
- Social Worker / Care Manager
- Home Visitor
- District Nurse
- Ward Manager

They contact the Primary Care Trust's Continuing Care Lead who should then liase with you.

The assessment should take a maximum of 4 weeks to complete. The Continuing Care lead chairs the meeting of the team which applies the Continuing Care Criteria. Once this is done, services determined & planned within 3 to 10 days. This is then backed up by a review after 3 months and then further reviews annually.

Each new **Strategic Health Authority** (such as the Greater Manchester Strategic Health Authority) has been charged with producing a fresh set of **Continuing Healthcare Criteria**.

The aim is to produce a single procedure which will be more inclusive and perhaps iron out some inconsistencies which have existed in the past - such as the right to advocacy services. Unfortunately, no extra resources are associated with this and health authorities may run into conflicts with the criteria used by local councils in their assessment procedures.

"Face to face communication is crucial in ensuring that the older person's care needs are properly met."

What is needed:

Primary Care Trusts need adequate **resources** to provide effective and comprehensive services.

Fully resourced **advocacy** services. With a more comprehensive appeals process.

We should lobby for the central place of older people— and for a shift to the system adopted in Scotland.

WORKSHOPS

1 - The National Issues

The format for our group discussions was to look at some fictional "case studies" around long term care. Each group took on the role of a multidisciplinary care team charged with putting together a care package for an older person. The exercises are included in the Resources section at the end of this booklet.

Over the next two pages is a summary of the issues which came up. Many of these were common to some or all of the groups and touched on both the local and national picture.

"Minority ethnic elders are treated as a separate group outside the mainstream - because of their age and also because of their race."

*"Put the **humanity** back into care work!"*

"Resources for care packages cannot be artificially divided. They need to be **jointly managed,** and funded from the same

STANDARDS

The last few years have seen the introduction of National Minimum Standards for Care Services and a new regulatory body (The National Care Standards Commission), but is the quality really improving?

The targets are being compromised by the low status (reflected in the pay) of care staff. There is a high turn over of staff and serious recruitment problems within the independent care sector.

As one participant put it - *"What does it say about how we value our old folk when you can earn more working in a supermarket than looking after someone?"*

"The efforts made to improve access to quality health and social care should be matched with *adequate funding*. The challenge for the government is to accept the reality of the word 'adequate'."

PRIORITIES

- **National standards in training for care staff and improved career opportunities for people who have completed the training.**
- **More clarity in the funding mechanisms for long-term care - it is too complex at present, making it difficult to administer and almost impossible to understand.**
- **Lobby MPs to end the distinction between "personal" and "nursing" care: it is unfair.**

"There needs to be national agreement with patient groups, service users and carers, on what activity is considered personal care and what is an NHS nursing care responsibility. The present system is not equitable – each local area sets its own criteria and the definition of terms like "substantial" or "critical" changes according to where you live."

"Care services for elderly people with mental health needs **don't get anything like the same resources as those for younger adults. All the** therapy **and** support **services just aren't available for people over**

"Surely you should be able to choose where to live? I mean, this man doesn't want to go into a care home - and he shouldn't have to unless he really wants to, even if his children think it's the best thing for him."

WORKSHOPS

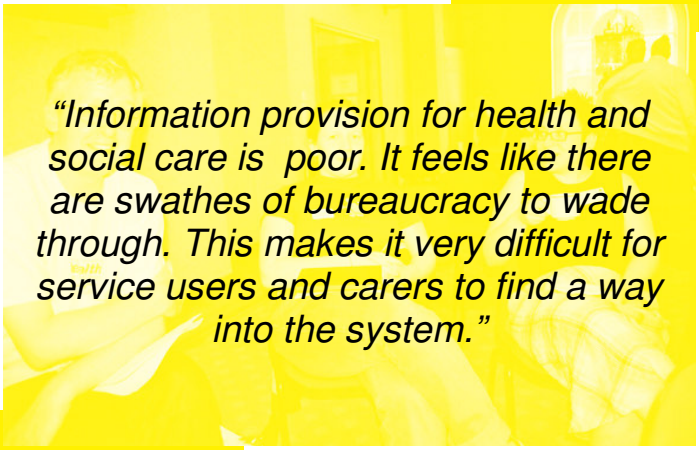
2 - Local Issues

While some of the issues raised in the groups were a direct result of government policy, participants felt that there was much which could be done by local health and social care providers to improve delivery and access to services.

One of the groups had 27 people in it - and not one of them knew how to contact Social Services: they had never heard of the "Contact Centre" and knew little about what services were provided, though they had some understanding of the role of the social worker. When asked about where they would go if they needed help/ information they agreed that they would always go to a younger member of their family or to a known voluntary organisation or group - and within those groups they would contact a known helper who they trusted.

"You need a lot of confidence to ring that number and ask for services...ask for help... do I have to call myself "vulnerable"?

"when you've tried calling 20 times and got through to a machine, you just give up."



"I don't know how you go about getting an assessment. If I was doing it regularly, I might be able to get the help we need but I have no idea what is available. It's not the sort of thing you look into until you actually need to."

ADVOCACY

Advocacy, information & advice services are needed to help people make informed choices and get their views across when trying to access services. These should be provided by independent projects/ organisations. There is no strategy in place to develop these kind of support services with the level of resources needed to ensure they are available to everyone.

"Stop the care homes from closing!"
The number of care homes in Manchester has decreased by roughly 20% in the last six years. Low fee levels have made it impossible for many to remain viable as businesses.

PRIORITIES

- **An information strategy is needed which involves older people in thinking of imaginative ways to inform hard-to-reach communities about what is available.**
- **A greater emphasis on face-to-face communication**
- **Need to review the role of sheltered housing.**
- **A development programme for the provision of advocacy services. People should have a right to support in accessing services.**

Many people said that they simply could not understand the **complex funding mechanisms** for long-term care - "*Fair Access to Care*", "*Free Nursing Care*" "*Continuing Healthcare*" are all different streams - not to mention claiming welfare benefits They felt that they are **dependent** on those **care providers** to inform them about what is available. There is therefore some concern that accessing a particular service may rely on the availability of funding, without any input from the service user/carer.

*"**Sheltered housing** isn't sheltered - in most places the warden doesn't really provide any services at all and isn't accessible, yet when you move in you're given the impression that everything you need will be there when you need it. You've moved out of your own, familiar home to be somewhere safer and easier, but you still have the same problems getting services in the new place.*

"Carers are patronised and put down all the time. It's enough of a struggle as it is without having that to cope with."

PANEL DISCUSSION

The issues which had arisen in the casework were then presented to a panel - particularly focusing on issues which the groups had felt *unable* to address as these were the aspect parts of the long term care system which are, perhaps, most in need of change.

MENTAL HEALTH

The mental health needs of older people simply **aren't being recognised**.

People need to know what groups there are in their communities that can offer support if they are feeling **isolated**. Social Services should work with community and voluntary groups to help people get in touch with these services – this is the sort of **prevention** or **early intervention** that can really help.

CARERS

Carers feel very **isolated** and even some basic contact through **home visits** and **befriending** can make a real difference. **Advocacy** is important to carers too as their views can easily be overlooked.

Linda Sowden, Mike Wild, Jo Purcell, Norma Raynes, Pat Leahy, Joan Hall, David Williams

Lots of carers needs are actually very straightforward – they're about **information** on how to contact **services**, how to get **help** and where they can find **support**. Simple steps like fewer answering machines and more **face-to-face communication** would really make a

PREVENTION

Any real policy to improve long-term care needs to **tackle problems before they happen** – investment in preventative services and **earlier support** to people will give people a better **quality of life** in older age and target services more effectively.

A SINGLE PURSE

The panel recognised that a lot of the discussions were really about **money** and **'who pays?'** The real way out of the mess – and the way to get different services working together, is to have one pot from which all the money for long-term care is spent.

TEAMWORK

There is a need to make sure **all** the professionals who are involved with a person are **working together** – for example, are sheltered housing wardens ever involved when arranging a person's care services? They are an important contact for many people.

SUPPORT

Health services can get off too easily just saying that there *should* be good information and support through **advocacy** services – these things need **long-term resources**.

The voluntary sector is more than capable of building services such as advice and information – but it can't do it without support and commitment.

This could make a huge difference but, like any service, it needs **investment.**

NEXT STEPS

Where does one begin? The present situation cannot be allowed to continue - Governments not just in future but *now* will have to address the needs of the older population as it grows in size. Reading reports by MPs and the media which constantly talk about older people stuck in hospital as 'bed blockers', it's easy to get the impression that older people are seen as 'a problem' for the health service, not as people often let down by services that aren't meeting their needs. The truth is that there's probably not one single person who deliberately 'blocks' a hospital bed.

We should be celebrating the fact that people now live longer and, in general, have healthier lives as they get older. We should doing all we can to support that. But it isn't happening, despite the government saying that billions extra is going into the health service. Why?

The current system for meeting the long term care needs of older and disabled people is a **mess**. It is not driven by people's needs, it is a **bureaucratic tangle** of funding mechanisms, assessment criteria and case law which are the result of legislation, policy and guidance going back over 55 years.

Accessing care services is becoming more complex, not less. The funding system places a huge burden on service users at a time when they are, by definition, going through a crisis. It also creates extra work for consultants, nurses, care managers, accountants and administrators as they spend time and energy trying to make the system work within their own and other organisations.

But most of all, for people who need services (and those caring for them) it creates a nightmarish game of conflicting rules, arcane law and scarce information with the older person waiting to see how the dice will fall next...

Support for older people and others with longer-term care needs has been constantly 'reclassified' and shifted away from public services. It has essentially been privatised. Social care is now almost wholly provided by private sector firms who will, like any business, close services (e.g. care homes) if they can't make a profit. Should the care of older people be dictated by "market forces"?

Social Services Departments, particularly in areas with high levels of need such as Manchester, are woefully under-funded and simply can't afford to pay for high-quality care. Many have sold-off their own facilities and contracted-out their services. They now face 'fines' for not being able to move people out of hospital fast enough. 'Being fined for being broke' just doesn't make sense, and will make the problems worse by taking more money out of an already impoverished care system.

This artificial divide between 'health care' and 'social care' - where social care is charged for or means tested - has meant that millions of older people face a future of little support

When the current Government was first elected, it set up a Royal Commission on Long Term Care to look at the problem. The Commission recommended that, like health care, social care was a fundamental service which should be free to those who need it. The Government's response was a legalistic, mean-spirited arrangement where some nursing costs in care were met ... and nothing changed.

The National Pensioners Convention's **Right to Care** campaign has four simple demands. The 9th July Conference backed them and agreed to campaign for them:

- **The recommendations of the Royal Commission on Long Term Care should be implemented in full.**
- **It is unacceptable to charge older or disabled people for essential personal care. Means testing for personal care should be ended.**
- **The artificial distinction between nursing and personal care should be ended**
- **Good quality personal and nursing care should be provided on the basis of need, free at the point of use in all settings** (i.e. at home, in care homes, in hospital)

SPREAD THE MESSAGE!

On the following page is a sample letter summarising the points made at the event on 9th July.

We would encourage anyone who wishes to see changes to the current system to send such a letter to local **MPs** and **Councillors** and managers of health and social care services.

We hope you will support this work. We intend to continue to raise these issues wherever and whenever we can. In the **New Year** we hope to hold a follow-up to the event in July. Our aim is to look in more depth at the **hospital discharge** end of the long-term care spectrum. In January this year the Government issued a new **Hospital Discharge Workbook** offering detailed guidance on good practice for local health and social care authorities. As the shadow arrangements for "**cross charging**" will be coming into effect during October, this will be an appropriate time to look at the issues faced by older people passing through hospital.

In the meantime, we aim to circulate the views of people from the event in July to local and national bodies and campaigning groups.

If you would like to get involved or be kept informed about this work, contact the **Manchester Older People's Network** (see "Resources" over the page).

Dear

As you will know, many people are of the opinion that the current system of long-term care is not providing the level and quality of care needed by many older people. I am writing to you to as I feel it is time for a fresh look at the ways we respond to people in need of support.

At an event held in Manchester on 9th July this year, the following points were agreed:

- Funding for care services should come from a single, centrally managed source.
- People should get information about care services, and what they are entitled to, face-to-face.
- Personal support in accessing services is essential - this means information and advocacy. There should be a strategy for developing local advocacy services so that people can receive support
- Prevention and health promotion should be further up the agenda - backed by planning and investment.
- Standards in training for care staff and the resources to recruit and retain good quality staff are needed. This should be part of a process of identifying what the real costs of care are. Nationally, we should be building towards realistic payment for care services which would enable staff wages to reflect the value of their work.
- There needs to be an urgent review of the roles of the various forms of long term care. Are they providing what we expect? Is sheltered housing really a supported environment?
- There must be equality of access, standards and providing of services - why are some services only available to certain sections of the community? Why, for example, should older people with mental health needs not have access to the same resources as adults of working age?

Above all the distinction between personal and nursing care should be ended.

In its watered-down response to the Royal Commission on Long Term Care, the Government effectively continued the trend of unravelling this cornerstone of the welfare state.

The current system is a bureaucratic mess of national legislation and guidance, local policy and practice. It is a tangle of funding mechanisms and assessment criteria which seem to put administration and budget monitoring before the needs of people.

I would welcome your views and would be interested to hear what steps you are intending to take to address these issues.

Yours sincerely,

RESOURCES - 1

Manchester Statutory Bodies

Manchester Social Services
PO Box 536, Town Hall Extension, Manchester, M60 2AF
Telephone: 0161 255 8250 www.manchester.gov.uk/ssd

North Manchester Primary Care Trust
Newton Silk Mill, Holyoak Street, Newton Heath, Manchester M40 1HA
Tel: 0161 219 9400 www.northmanchesterpct.nhs.uk

Central Manchester Primary Care Trust
Mauldeth House, Mauldeth Road West, Chorlton, Manchester M21 7RL
Tel: 0161 958 4000 www.centralmanchesterpct.nhs.uk

South Manchester Primary Care Trust
South Manchester PCT - 1st Floor, Home 4, Withington Hospital, Nell Lane, West Didsbury, Manchester M20 2LR Tel: 0161 611 3300 www.smanpct.com

Manchester Mental Health and Social Care Trust
Chorlton House, 70 Manchester Road, Chorlton-cum-Hardy, Manchester, M21 0UN

Greater Manchester Strategic Health Authority
Gateway House, Piccadilly South, Manchester M60 7LP
Tel: 0161 236 9456 www.gmsha.nhs.uk

There are new **Patient and Public Involvement Forums** for each Primary Care Trust and NHS Trust. This is the new structure to enable people to have a strong voice on issues about health and health services. For more details contact Manchester PPI Network Partnership on 0161 912 1157 or email ppinetwork@masthaz.freeserve.co.uk

If you would be interested in joining a forum, call **0845 120 7115** (minicom 0845 120 7113)

Government

Department of Health
The National Service Framework for Older People is available at
www.doh.gov.uk/nsf/olderpeople/index.htm

Royal Commission on Long Term Care for the Elderly
www.royal-commission-elderly.gov.uk

Parliamentary and Health Service Ombudsman -
Special report: NHS Funding for Long Term Care of Older and Disabled People
www.ombudsman.org.uk

Audit Commission – the independent body which assesses and reviews public services. Amongst the many reports they have produced is the *Forget-Me-Not* study of services for people with dementia (updated in 2002).

RESOURCES - 2

Voluntary Organisations and Campaigns

Help the Aged - as well as providing a range of information and advice and other services, Help the Aged is running several national campaigns:

- **Age Discrimination** – seeking to challenge ageist attitudes not just in health and social care but in all walks of life.
- **Speaking Up for Our Age** is a national programme to give older people "the chance to make their voices heard on the things that matter to them". The organisation is supporting the development of Senior Citizens' Forums throughout the UK to work together, to influence a wide range of local and national issues that impact on older peoples' lives.
- ***Older People and Regional Assemblies*** is a guide produced by Help the Aged which looks at the involvement of older people in elected Regional Assemblies. These will be responsible for strategic planning and scrutiny of local and regional bodies including Regional Development Agencies. They will address all key areas of interest to older people and not just the traditional areas of health and social care.

For further information, contact:
Annie Thompson - Speaking Up for Our Age Officer
Neil Mosely - Regional Planning Officer
Help the Aged, Northern England Office
92 Lee Lane, Horwich, Bolton BL6 7AE
Tel 01204 667267 Email neil.mosely@helptheaged.org.uk

www.helptheaged.org.uk

Age Concern England is also campaigning for the full implementation of the recommendations of the Royal Commission on Long Term Care. They produce factsheets which advise on the various funding mechanisms for care services.

- ***Maximising User Participation*** is a training programme developed by Age Concern's Involving Older People Partnership. For further information email: steeles@ace.org.uk

www.ageconcern.org.uk

The **Alzheimer's Society** is also campaigning for more funding for long term care. Details of their "Fair Rate for Care" campaign can be found on their website:
www.alzheimers.org.uk

Counsel and Care – information and advice on issues affecting older people
Counsel and Care, Twyman House, 16 Bonny Street, London, NW1 9PG
The run an advice line on 0845 300 7585 (charged at local rate)
www.counselandcare.org.uk

The **Relatives and Residents Association** provides advice and support for those living in or considering long-term care and their relatives.

24 The Ivories, 6-18 Northampton Street, London, N1 2HY Tel: 020 7359 8136

RESOURCES - 3

Other Campaigning Groups

The **"Right to Care Campaign"** being supported by the National Pensioner's Convention is also supported by UNISON. More information about the campaign is available at:
www.unison.org.uk/righttocare/index.asp

The Better Government for Older People Programme was developed to: "improve public services for older people by better meeting their needs, listening to their views and encouraging and recognising their contribution." BGOP is part of the UK's "Modernising Government Agenda". The BGOP Network provides an online forum for communication between the teams of people engaged in the work of the programme.
www.bgop.org.uk

The Older Peoples' National Service Framework Network exists to support older people in being involved with the "National Service Framework for Older People" - which aims to improve the quality and accessibility of NHS services for older people. The work is done by "Local Implementation Teams" in each area which *should* include older people as members. The network was formed when it was identified that the involvement of older people in the NSF across the region was patchy at best. It is based at:

Age Concern Wirral,
42-44 Market Street, Birkenhead, Wirral CH41 5BT
Tel: 0151 666 2220

Policy and Research

The King's Fund – Recent publications include *Auditing Age Discrimination* and *Fair Deal For Old People: Public Views on the Funding of Long Term Care.*
King's Fund, 11-13 Cavendish Square, London W1G 0AN
Tel: 020 7307 2400 www.kingsfund.org.uk

Joseph Rowntree Foundation – another social policy organisation which has a long history of research into older people's issues
Joseph Rowntree Foundation, The Homestead, 40 Water End, York,
North Yorkshire, YO30 6WP www.jrf.org.uk

Laing and Buisson are market analysts who specialise in the health and social care sectors. Earlier this year they published a report entitled *Care of Elderly People – Market Survey 2003*. www.laingbuisson.co.uk

We apologise that so many of these references are internet based as we recognise that not everyone has access to the internet – however, all the material above is free to read online but purchasing printed copies is usually quite costly. If you do not have internet access and would like to read any of the documents, please contact the **Manchester Older People's Network**.

Manchester Older People's Network
c/o MACC, Swan Buildings, 20 Swan Street, Manchester, M4 5JW
Tel: 0161 834 9823
Fax: 0161 832 2352 **email:** mary@macc.org.uk

Produced for Manchester Older People's Network
October 2003