

PAYING FOR CARE IN WALES

REPORT OF THE STAKEHOLDER ADVISORY GROUP

June 2009

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Chapter 1: The Advisory Group's Remit

This chapter sets out the remit and terms of reference of the Paying for Care in Wales: Stakeholder Advisory Group, and its way of working. It also sets the context for the group's work, including the wider issues around paying for care and the Welsh Assembly Government's consultation on options for reform.

1. Remit, membership and terms of reference

1.1. The Paying for Care in Wales: Stakeholder Advisory Group was established at the request of Gwenda Thomas AM, Deputy Minister for Social Services, to advise Welsh Assembly Government Ministers on the effective delivery of a consultation and engagement exercise in Wales about establishing fairer and more sustainable arrangements for paying for care.

1.2. Its remit was to:

- help shape the engagement process so that it is effective in obtaining input from the full range of stakeholders – from representative groups to individual members of the public of all ages and backgrounds;
- represent the consultation and change process to members' own stakeholders, ensuring that key messages are articulated and heard at all levels of the consultation;
- help to identify and refine the main policy issues for debate, commenting on emerging policy proposals and representing the views of members' own stakeholders;
- produce a report, with conclusions and recommendations about what policy proposals the Welsh Assembly Government's "Green Paper" on paying for care should contain; and
- help ensure that the Welsh Assembly Government's resultant "Green Paper" proposals are based on robust and relevant statistical data, which has been analysed appropriately and presented clearly.

1.3. Membership of the group consisted of representatives from the following sectors:

- older people
- disability, including learning difficulty
- carers
- social care providers
- local government
- NHS
- housing
- research

- 1.4. The Children's Commissioner for Wales and the Commissioner for Older People Wales were represented as observers, and the Equality and Human Rights Commission provided independent strategic advice to the group.
- 1.5. Invitations were sent to the Wales TUC, Funky Dragon and the Chamber of Commerce in Wales, but these organisations did not field representatives.
- 1.6. The group was chaired by Steve Milsom, Acting Director of the Older People and Long-term Care Policy (OPLTCP) Directorate at the Welsh Assembly Government. OPLTCP also provided the secretariat.
- 1.7. A full list of attendees is at Annex A.

2. The process

- 2.1. The Advisory Group met four times between January and April 2009. Meetings were held in Cardiff, Llandrindod Wells, and Swansea (with a telephone conference facility to North Wales).
- 2.2. The first meeting was addressed by the Deputy Minister and by Alexandra Norrish, Head of Social Care Policy at the Department of Health, who gave an overview of the wider UK context for reform of paying for care. Members also considered the key findings from the two national (Wales) stakeholder consultation events. The second meeting considered the principles underpinning the group's work, and workshop-style discussions were held on the questions set out in the consultation document 'Paying for Care in Wales: creating a fair and sustainable system'. The third meeting looked in detail at various models for reform, and at options for transition to any new system. It also considered the emerging findings from the public consultation. The fourth and final meeting drew together the group's draft conclusions and recommendations.
- 2.3. The group considered various papers and documents, including research findings and major policy reports. A full list of these is at Annex B.
- 2.4. The group's discussions were recorded by the secretariat, which also attempted to summarise the group's emerging conclusions and prepared the final report. The final version of this report has been commented upon, and endorsed by each member of the Advisory Group. A full set of minutes and papers may be accessed by contacting the OPLTC Policy Directorate on 029 2082 3049 or e-mailing: payingforcare@wales.gsi.gov.uk.

3. The paying for care debate

- 3.1. In May 2008, the UK Government announced its intention to reform the care and support system in England, and launched a major consultation on options for reform. In November 2008, the Welsh Assembly Government launched its own consultation document, 'Paying for Care in Wales: creating a fair and sustainable system'.
- 3.2. The debate about paying for care is part of the Assembly Government's wider strategy for social services, which was set out in 'Fulfilled Lives, Supportive Communities' (June 2008). This set the direction for modernisation of social services, and included a commitment to a fundamental Review of funding needed for social services over the next 15 years. The debate about paying for care will tie into the funding review and the broader implementation programme for 'Fulfilled Lives, Supportive Communities'.
- 3.3. The Assembly Government has stated that it believes that the time has come for a radical re-think of the entire system of paying for care. The rationale for this conclusion was set out in the consultation document 'Paying for Care in Wales', and reiterated by the Deputy Minister in her opening address to the Advisory Group. The Assembly Government expects the impact of demographic change and higher expectations of public services to lead to a considerable 'funding gap' for social care within the next 10-15 years.
- 3.4. The Assembly Government has said that it has no fixed position on this issue, and has taken a collaborative and open approach to debating the key principles around paying for care. It has, however, emphasised that any new system must deliver the following objectives:
 - promote independence, choice and control for everyone who uses care and support services;
 - ensure that everyone can receive the high quality care and support they need;
 - be affordable to government, individuals and families in the long term; and
 - be fairer and more equitable.
- 3.5. The debate in Wales also needs to be set within a wider UK context, for two main reasons. First, the current charging arrangements are closely tied to England through primary legislation. Second, any changes that involve taxation, national insurance or the welfare benefit system (all non-devolved areas) will need to come within the scope of the UK Government's Green Paper. Decisions about options for future Assembly legislation cannot be taken in isolation from these factors.
- 3.6. The Assembly Government has also made it clear that all the different types of care need to be considered as part of this debate: home and day care; residential and nursing care; and continuing health care.

4. Consultation and engagement in Wales

- 4.1. The Paying for Care in Wales: Stakeholder Advisory Group is part of a wider programme of engagement being undertaken by the Assembly Government. The programme has consisted of:
- a national consultation exercise, based around the 'Paying for Care in Wales' consultation document and website;
 - two national stakeholder events in December 2008 and January 2009;
 - local consultation with existing forums and networks; and
 - the Stakeholder Advisory Group.
- 4.2. Further details of the consultation and engagement programme, including reports of the stakeholder events and the public consultation, can be found at <http://www.payingforcareinwales.net>.
- 4.3. The following chapters of this report set out the conclusions and recommendations of the Stakeholder Advisory Group on Paying for Care. They cover:
- Principles to underpin work in this area
 - The wider context for this work
 - The consultation questions
 - Who should contribute more in the future?
 - What are the roles of individuals, families and everyone in society?
 - Should the rules for assistance operate locally or nationally?
 - Should everyone get the same level of help?
 - Models for a reformed system
 - Transition.

Chapter 2: Principles and Context

This chapter explains the principles adopted by the group for its own consideration of these options and for devising its conclusions and recommendations. It then deals with contextual issues including the Social Services Strategy for Wales, the importance of prevention and re-ablement, social care funding, working with the UK Government and the importance of robust evidence.

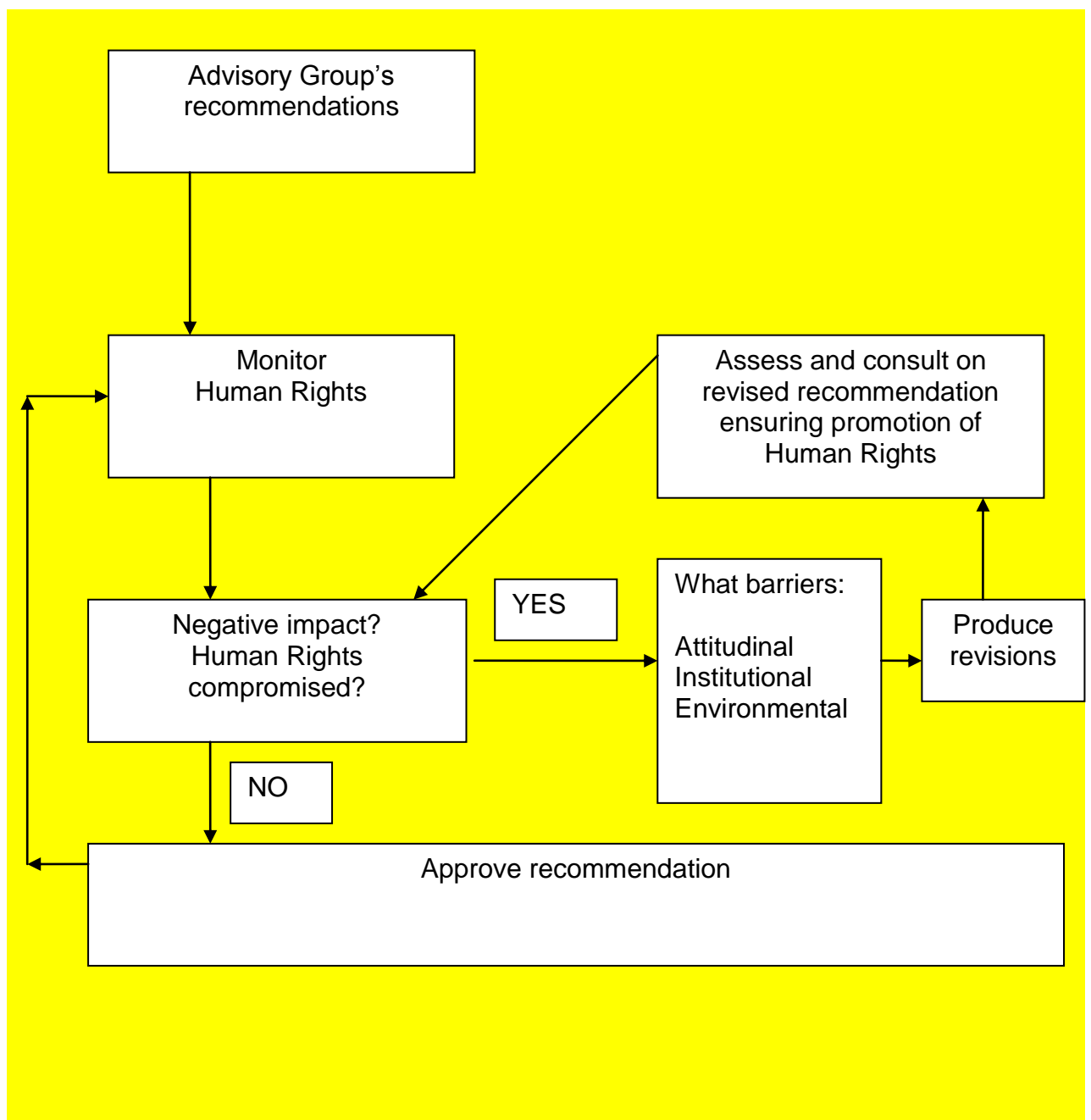
1. Principles

- 1.1 We believe that any proposals for a new system for paying for care need to be grounded in human rights and equalities, demonstrably meeting all the legal requirements on the Welsh Assembly Government in this field. They should reflect the requirements of the Human Rights Act 1998, the United Nations Principles for Older People, the UN Convention on the Rights of the Child, and the (as yet unratified) UN Convention on Rights for Persons with Disabilities. The relevant articles are attached at Annex C.
- 1.2 We have drawn up a set of principles that we commend to the Assembly Government for this purpose. These are set out at paragraph 1.3 below. We would also encourage the Department of Health to adopt the same principles to underpin their plans for reform, particularly where these would affect the UK as a whole.
- 1.3 We believe that any new system of paying for care needs to:
 - Be explicit about human rights;
 - Support the individual at the time when she or he needs the support;
 - Ensure that decisions about provision of care are made on the needs of the individual and not on the individual's financial resources or other assets or those of relatives;
 - Be simple, i.e. easily understood and operated by users and providers;
 - Promote social inclusion and independence;
 - Promote fair and equitable treatment;
 - Promote the participation and empowerment of the individual;
 - Ensure that providers are accountable and that those receiving the service can express views and complaints; and
 - Be affordable and financially sustainable, and demonstrate probity in the use of public funds.

Recommendation 1: We recommend that the Welsh Assembly Government – and the UK Government - should adopt the underpinning Principles that we propose, for the purpose of devising any new system of paying for care in Wales.

1.4 The group endorsed the following model as a filter which can be applied to ensure that this is the case.

The following model is adapted from Module 5 of the Help the Aged in Wales 'Growing Older in Wales Age Awareness and Age Equality' training manual 2007.



- 1.5 We would want to see the current system replaced by one which is clear, fair and sustainable, and which treats everyone with care needs fairly, according to their needs. We do not see any merit in a “two-tier” system, and we would want to resist the notion that a “basic” or simply “adequate” level of care should be the goal of the care system in Wales for the majority of people. People should only expect to pay additional amounts for care where this is to meet their own particular wishes and preferences, over and above the core provision they should receive automatically from the care system.
- 1.6 We would want to see the new system tackle the current problems of limited availability of services, and of rationing (which has been applied particularly by means of a continual tightening of eligibility criteria, so that only those in extreme and urgent need of care receive services). Otherwise, these two factors are likely to contribute to the continuation of a two-tier system, and to make it worse. We believe that this will lead to greater long term costs to the whole of society, not the least of which are felt by the individuals whose need remains and whose situation deteriorates whilst they wait to meet a set of eligibility criteria. We note that Care and Social Services Inspectorate Wales (CSSIW) is currently undertaking a thematic review of the statutory guidance on fairer access to care, including eligibility criteria which determine how care is made available.

Recommendation 2: Building on the ‘Fulfilled Lives, Supportive Communities’ social services strategy for Wales, we would want to see any new system for paying for care supporting the delivery of an excellent level of care for all those who need it in Wales. We would not want to see a system that excluded the less well off from receiving good care, simply because of their financial means.

- 1.7 We believe that any new system must work equally as well for younger disabled people and for children with care needs or caring responsibilities, as for older people with similar needs and caring responsibilities.

Recommendation 3: We recommend that, when devising any new system for paying for care in Wales, the Welsh Assembly Government should take into account the needs and requirements of all those for whom the care system needs to work effectively – encompassing older people, younger disabled people and children with care needs or with caring responsibilities, as well as families and other carers.

- 1.8 We recognise that there are a number of aspects of the paying for care debate that are not devolved to the Assembly Government – notably policy on taxation, benefits and pensions – but which will be crucial to any new system. It will therefore be important to ensure that the voice of Wales is properly heard in debates about these matters.

Recommendation 4: We recommend that the Welsh Assembly Government and the UK Government should work closely together to ensure that any new system reflects appropriately the wishes and needs of the people of Wales, in non-devolved policy areas as well as in devolved areas.

- 1.9 We note that there is a broader issue of the relative priority that attaches to social care funding in UK Government and Welsh Assembly Government budgets. We call on both governments to place social care higher in their list of priorities, and to devote a greater proportion of government spending to it in future. We do not agree that it should simply be accepted that there will be a sizeable deficit for social care, when huge sums of money can be found for other priorities at times of crisis.

Recommendation 5: We recommend that the Welsh Assembly Government should give a higher priority to funding social care – in particular the ‘Fulfilled Lives, Supportive Communities’ strategy – from within its own delegated budgets. We also recommend that the Welsh Assembly Government should lobby the UK Government to ensure that those aspects of social care and related issues which are funded from general taxation (such as pensions and benefits) are funded to a more realistic level.

- 1.10 We register our reservations about some of the data and the interpretation of it that has taken place to date, which has frequently drawn a relatively bleak picture of the future of social care resourcing. It is not accepted by all economists that increased longevity will automatically lead to a problem with unmet demand, and rising numbers of older people does not necessarily mean that more care and support will be needed by them – particularly if the healthy ageing agenda has a real impact. The increased cost of improving the quality of care might be overstated, and the continued development of telecare and tele-healthcare could well reduce care costs. In any case, we consider that society has a capacity for readjustment, as is illustrated by the fact that one of the biggest growth areas for employment is among older people.
- 1.11 We would want to see alternative viewpoints examined and contrasting research on demography and family structures (for example) considered, and the current assumptions challenged and tested before they could be accepted as the rationale for reform.

Recommendation 6: We recommend that the Welsh Assembly Government, working with key stakeholders in the field, should examine the existing data in this area carefully before devising clear plans for reform.

- 1.12 We are conscious that questions of paying for care are closely linked to issues of service delivery. We acknowledge the work that has already been undertaken to improve quality and availability of services. If the aims of the 'Fulfilled Lives, Supportive Communities' strategy, the Dignity in Care initiative, and the National Service Frameworks are to be made a reality, then it will be important to ensure that reform of the resourcing system dovetails with, and supports, these continuing service delivery improvements.
- 1.13 We particularly wish to draw attention in this context to the importance of continued and increasing investment in prevention, re-ablement and lower level support services. These services not only raise levels of well-being; they could be, from a financial point of view, very effective in reducing costs over the medium and longer term. They are rightly a strong theme in the 'Fulfilled Lives, Supportive Communities' strategy and they can be supported by greater use of Direct Payments, to allow people to purchase the services they themselves choose, to respond to their own needs.
- 1.14 We therefore consider that a campaign to raise public awareness about preventative measures (along the lines of the "5-a-day" healthy eating campaign) would be a worthwhile initiative, not only in Wales but also in the UK as a whole.

Recommendation 7: We recommend that the Welsh Assembly Government should support more effectively prevention, re-ablement and lower level support services, and that it should consider running a publicity campaign in this area to raise levels of well-being and independence among people who might otherwise become more heavily reliant on care services.

Chapter 3: Debating the Consultation Questions

This chapter summarises the Advisory Group's discussions of the consultation questions set out in 'Paying for Care in Wales: creating a fair and sustainable system':

- Who should contribute more in the future?
- What are the roles of individuals, families and everyone in society?
- Should the rules for assistance operate locally or nationally?
- Should everyone get the same level of help?

Format for the discussion

- 3.1 'Paying for Care in Wales: creating a fair and sustainable system' contained five consultation questions. The first two questions, under the heading of 'Sharing responsibility for paying for care', asked where the balance in paying for care should lie between individual service users, their families and society at large, and what kind of reform people would like to see. The final three questions, under the heading of 'Setting fair rules for financial support in the future', asked whether there should be a national or local framework for financial support; whether there should be different systems for different needs or the same for all; and if people with lower levels of income and assets should be given more financial help by the state.

A: Sharing the responsibility

Consultation Questions:

Who should contribute more for care in the future?

- Individuals who use care and support services?
- Families of people who use care and support services?
- Everyone in society?

If the current system is reformed, in which general direction should changes be made?

What role should the families of people who use care and support services play?

- 3.2 We acknowledge the huge debt that the care system currently owes to unpaid carers. Families are already taking responsibility for providing the lion's share of care, and any reform of the care system needs to take into account the non-financial contribution that families make, as

well as the monetary support that they offer to family members needing care.

- 3.3 We note that the Welsh Assembly Government is currently preparing legislation which will give greater support and recognition to carers, and we urge the Assembly Government to ensure that carers of all ages are enabled and supported by the reformed care system to:
- Continue to provide the care that they wish to provide; and
 - Take on an appropriate level of caring, to a degree which is within their capacity.
- 3.4 In devising this legislation, we urge the Assembly Government to be alert to the reality that carers will always put the needs of those they care for before their own needs – which can lead them to reject respite care where they consider that it does not fully meet the cared-for person’s needs, and to reject a carer’s assessment if they fear that it could lead either to a reduction in resources being made available to the cared-for person, or to attempts to remove the cared-for person to another care setting.
- 3.5 There are particular issues surrounding the position of children and young people who find themselves in a caring role. We need to ensure that their own best interests are taken into account, as well as those of the person for whom they are caring. We are aware that the average age of young carers is 12. They therefore would not be considered to have legal “capacity” and they should not be put in the position of attempting to judge for themselves what is an appropriate level of caring responsibility to take on. We believe that this role should be fulfilled by the relevant professionals, in the best interests of the child involved. The new carers legislation should therefore place a duty on professionals to this effect, to be supplemented by guidance from the Assembly Government.

Recommendation 8: We recommend that the Welsh Assembly Government should proceed with legislation to ensure that carers of all ages are enabled and supported by the reformed care system to:

- * Continue to provide the care that they wish to provide; and
- * Take on an appropriate level of caring, to a degree which is within their capacity.

This will require a far greater level of support to be put in place than is currently the case, in particular through providing advocacy services more widely.

Furthermore, this legislation should place a duty on the professionals involved to ensure that children and young people are not put in a position where they take on an inappropriate level of caring.

- 3.6 More broadly, it is difficult to predict with certainty what role a family would be willing and able to play in 10 to 20 years' time in providing and funding an individual's care and support needs, as all families are different. Families can split up; some live far apart; some do not wish to know; and some individuals do not want family care. We also do not know what family structures might look like in the longer term.

What role should everyone in society play in paying for care for those who need it?

- 3.7 We firmly believe that everyone in society should be responsible for paying towards the cost of care, whether or not they need care themselves at any point in their life. Care costs should be a pooled risk, in the same way that health care is, and care funding should be supported by the population as a whole - just as (for example) school education is, regardless of whether a family has children of its own. The Advisory Group believes that this is a matter of principle and fairness: that a civilized society should take care of its members when they are in need.
- 3.8 There are clear advantages to expecting everyone to pay for care through taxation and / or National Insurance. This type of system spreads the cost across the population and across an individual's lifetime, and it takes account of an individual's ability to pay, because the level of contributions (deductions) varies according to income and other means. It also means that individuals make their contributions when they can most afford it (over the whole of their working or taxpaying life), rather than having to make a block of larger payments at a stage in life when many people find it much more difficult to pay.

Recommendation 9: We recommend that any new system for paying for care should be based on the principle that the provision of social care for all those who need it is a duty of society as a whole. Care costs should therefore be a pooled risk across the whole population.

- 3.9 We considered options other than taxation, and agreed that if an insurance-type model is adopted, careful thought and planning will be needed to ensure that funds are sufficient to meet costs. The pensions example shows that people under-invest and under-save. Any system which requires people to contribute for the purposes of financing future care needs to be government backed. In the current financial climate, we do not believe that a private insurance type scheme would be feasible.
- 3.10 The next chapter of this report contains our more detailed analysis of the various options for a reformed system for paying for care, and our conclusions and recommendations about them.

3.11 Whatever system is adopted in the reform of paying for care, we consider that there is a central role for both the Welsh Assembly Government and the UK Government in ensuring that funds intended for the care system are protected; that contributions are made by, or collected from, individuals in accordance with the scheme; that funding is sufficient to provide a good level of care for all those who need it; and that the scheme is run efficiently and to the benefit of those receiving care.

Recommendation 10: We recommend that both the Welsh Assembly Government and the UK Government should play a central role in ensuring that funds for social care are collected efficiently and protected effectively; and that the scheme is well run to the benefit of those receiving care.

3.12 We also consider that both the UK and the Welsh Assembly Governments, and all stakeholders, have a vital role to play in educating the wider public about why a reformed system is needed, what it will mean for individuals, and how and when the changes will be brought in. We recognise that it will be crucial to win the support of the vast majority of the population in order for the reformed system to be successful, and that this will need skilful handling and clear explanations of the benefits of the new system.

Recommendation 11: We recommend that the Welsh Assembly Government should work with the UK Government and all stakeholders to educate the public about the reform process and to win their willingness to buy in to the changes.

3.13 We consider that, in order for any new system to win the participation of the wider public, people need to understand the “care contract” that will exist between themselves and the State in future: in particular, they will need to be given a clear understanding of what constitutes “care” – what kinds of services are included and what services might fall outside the “contract”.

3.14 We note that “care” in this context will primarily mean chargeable care; in essence, it covers residential, nursing and continuing care, and non-residential social services (i.e. statutory services provided as a result of a community care assessment, and which are currently chargeable).

3.15 We also note that the question of what constitutes care is a very complex issue, and one which the Law Commission will spend two

years examining¹. We understand that it is expected to report on its detailed agenda for reform of adult social care law in 2011, and that this will necessarily provide a definition of what “social care” means. As an Advisory Group, we would prefer to see a new definition of care used by the UK and Welsh Assembly Governments which moves away from a “medical model” of care and is based instead on a social model.

Recommendation 12: We recommend that the Welsh Assembly Government should include a working description of the main features of “care” in its forthcoming consultation document, as part of the context for its proposals for reform of the paying for care system; and that it should move ultimately to a more positive definition of care, based on the social model of disability and care needs.

What role should individuals have in contributing towards the cost of their own care?

- 3.16 In our opinion, levels of public understanding of how the care system works, and is funded, are low. This viewpoint would appear to be borne out by the responses that the Assembly Government received to its consultation exercise and that were expressed at the consultation events in North and South Wales. In our view, individuals need to learn more about the system, to be more aware of their own responsibilities regarding their potential need for care, and to prepare in accordance with the prevailing system. They have a particular responsibility to do what they can to keep healthy and safe. As previously recommended, governments have an important role in stimulating public participation in the debate, and in encouraging and supporting individuals to plan for their potential care needs. However, we would want to ensure that this does not lead to value judgements being made about individuals’ lifestyle choices.
- 3.17 We also discussed investment in prevention and re-ablement. Early intervention is crucial. ‘Fulfilled Lives, Supportive Communities’ (the social services strategy for Wales) recognises that, if people are provided with support as soon as a need for care services becomes apparent, this increases the chances of an individual retaining employment and of contributing more generally to society. It also means that costs reduce over the longer term as early intervention reduces the need for costly interventions by delaying them to a later stage. There are also practical measures that government could consider as part of the prevention agenda – for example, by extending the scope of building regulations to cover ex-council housing that is being moved into housing associations, so that these homes too are required to conform to lifetime standards.

¹ In June 2008, the Law Commission published its Tenth Programme of Law Reform, which included a project to review adult social care law in England and Wales. On 26th November 2008, it published its ‘Adult Social Care Scoping Report’ as the first stage of this project.

Recommendation 13: We recommend that individuals should take responsibility for planning to meet their own potential care needs in the future, identifying what steps they might need to take to meet those needs effectively. In their planning, individuals should address in particular their need to keep healthy and to maintain their well-being.

- 3.18 It could be argued that people should be encouraged or required to prepare financially for circumstances that are predictable, such as age-related care needs. However, we can see dangers in this approach. The age at which an impairment can occur is often arbitrary; and we would want to avoid any system that might encourage discriminatory decisions on the basis of genetic screening for hereditary conditions, and which could even have an impact on neonatal as well as pre-natal care. Furthermore, it can be difficult to predict far in advance how long care needs will last, and what the overall cost would be.
- 3.19 We need to recognise that people will have different financial pressures at different times of their lives (for example, repaying student loans, financing their children's education or topping up care fees for family members). This means that it is not always possible to save consistently for the future, even if you were to take the view that planning for your own care needs would be the responsible thing to do. The current financial crisis may well have an impact on the ability of individuals to accumulate personal wealth from which to fund future care costs.
- 3.20 However, we have identified one important way in which individuals can immediately do more to contribute to their likely future care costs. The Advisory Group would want to see individuals enabled to continue working into older age, past 65 if they wish, in accordance with their own preferences and circumstances. We consider that this is an important way for individuals to remain independent and to continue to contribute through taxation and National Insurance to the funding of the care system.

Recommendation 14: We recommend that government should enable individuals to continue working to whatever age accords with their own preferences and circumstances. We consider that this is an important way for individuals to remain independent and to continue to contribute through taxation and National Insurance to the funding of the care system.

B: Setting fair rules

Consultation Questions:

Should there be a national or local framework for financial support?

Should everyone receive the same level of financial help from the government?

Should people with lower levels of income and few assets be given more financial help by the state?

Should there be a national or local framework for financial support?

- 3.21 The consultation question itself can appear ambiguous, particularly when considered out of context. For the sake of clarity in this report, we record that the Advisory Group’s understanding of it is that we are being asked here not about the system for sourcing money for the care system; rather it is about how the money that is available should be distributed.
- 3.22 Furthermore, this is a question that is even less straightforward in the Welsh context. “National” could mean across Wales; it could mean across England and Wales together; or across Britain as a whole in certain circumstances (particularly since benefits and pensions are not devolved to the Assembly in Wales).
- 3.23 We would want to see a national (Welsh) system introduced for giving support for care, as opposed to a local (for example, local authority area based) system. We consider that this is the most effective way to tackle the current “post code lottery”; and is an approach that chimes with the Assembly Government’s plans for legislation that will make the system for non-residential social care charging both fairer and more consistent. However, we recognise that plans to reform the system in Wales will need to take account of those elements of the system which are not devolved to the Assembly.
- 3.24 We know that there are significant degrees of discrepancy in levels of charges across Wales (and some differences in services) in non-residential care. This is a particular problem in Wales because there are a relatively large number of local authorities, and they have a high degree of discretion. A national framework would help people to understand what they could expect, and encourage them to plan for the future. Furthermore a national system would not be susceptible to changes in local government.

- 3.25 We believe that any national framework should cover both eligibility criteria and the level of assistance to be given. To make this work, central government rather than local authorities should set the eligibility criteria and levels of service and / or payments. National eligibility levels are already in existence for Attendance Allowance and other social security benefits. Although it might be difficult to address the differing costs of provision across different parts of the country, this does not, in our opinion, outweigh the benefits of a national system. The Fairer Access to Care guidance already provides a framework for fairer access to services.
- 3.26 A Wales-wide framework of eligibility (enforced at national rather than local level as now), that guarantees a certain level of service in response to particular assessed needs, should also help address current levels of unmet need, including the needs of individuals who are not coming to the attention of social services at the moment. Much care at present is self-funded using Attendance Allowance or Disability Living Allowance (although it is recognised that neither will purchase significant quantities of care) or through personal income and savings; and a far greater amount is being provided by family and friends.
- 3.27 There is also a need for greater clarity and consistency in the assessment of care needs to address the current wide variations between local authority areas. To ensure equity in the provision of care services, it is essential that a thorough and uniform assessment of an individual's needs is carried out by people who are properly qualified to do so and who appreciate the effect their decisions will have on the quality of life of individuals and those caring for them. We believe that greater consistency can be achieved through a revised unified assessment framework that is applied uniformly and robustly; and through increased training in more consistent assessment across local authorities, related health services and Local Health Boards. It is important to ensure that the assessment and provision of care services take account of human rights issues, such as dignity and respect for family life.
- 3.28 Local authorities might wish to have the flexibility to go beyond national minimum standards, in order to respond to local concerns and priorities. We do not consider that such flexibility undermines the argument for a national framework. People have the right to choose to purchase extra services or to take advantage of additional free services if they wish. Correspondingly, it is only right that local authorities should be able to provide extra services if they so decide. The priority, however, is to ensure that the national standard is a high quality service that ensures equality of opportunity and protection of human rights.
- 3.29 We believe that establishing this kind of framework would enable Social Services Departments to move further towards a role of working with families, and advocating for them, without having to act at the

same time as “gate keeper” to the funding. We consider that this would encourage local flexibility and innovation in local level care plans.

Recommendation 15: We recommend that the Welsh Assembly Government should establish a national (all-Wales) system for giving support to those who need care, encompassing a clear eligibility framework and a consistent and considered assessment methodology to operate across Wales. It should be dovetailed with the Assembly Government’s forthcoming legislation to make the system for non-residential social care charging both fairer and more consistent.

Should everyone receive the same level of financial help from the government?

- 3.30 Everyone has an equal right to high quality care based on need, and not on the ability to pay. In the Advisory Group’s opinion, equality of this kind can only be achieved through using some form of taxation or social insurance system to pay for social care costs. (An example model is the current funding of the NHS partly through National Insurance contributions, which ensures that the majority of health services are delivered without charge to everyone at the point of need.) This equal entitlement approach is consistent with human rights principles. We would be opposed in principle to any system which linked the benefits received to the level of payments made.

- 3.31 We question the perception inherent in the current arrangements that individuals who have higher incomes and greater assets ought to be required to contribute those assets towards their care costs. There is no suggestion that individuals should use their greater earnings or assets to pay for health services (although they often do choose to pay for private medical treatment as well as making a higher level of NI contributions). We note that concerns about whether the “better off” were entitled to “free” health services might well have been raised in the early days of the NHS, but they have come to be accepted over time.

- 3.32 Likewise, we would not want to see the system reformed in such a way that it continued to require “better off” people to meet the full cost of their own care independently (whether by using their assets or by taking out private insurance or investment policies). There would be practical drawbacks - such as in defining exactly who the “better off” are, as there are peaks and troughs during the lifecycle which affect how much money an individual has. Moreover, there would be an equality impact to this proposal, as a two-tier system would be perpetuated, contrary to the principles which the Advisory Group is proposing.

- 3.33 When considering what exactly constitutes universal “high quality care based on need”, we consider that a distinction needs to be made

between what can be described as “needs” and “wants”. We use the term “needs” to mean service requirements that people cannot reasonably do without. “Wants” may be described as added luxuries, or particular personal preferences, that individuals should pay for themselves. The difference in society’s understanding of these two categories in the social care context has varied across history and cultures. Of necessity our definition of them today would rely on our current view of what constitutes the role and responsibilities of the state and what are the roles and responsibility of the individual and his or her family. Furthermore, the exact definitions of both “needs” and “wants” are tied in with the broader definition of “social care” (see paragraph 3.15).

- 3.34 Within this broad framework, we need to guard against making value judgements about individuals’ choices about the services and other activities that meet their own personal needs. As an Advisory Group, we recognise that different people have different expectations as well as different needs, and there is a need to balance the two in each individual case.

Should people with lower levels of income and few assets be given more financial help by the state?

- 3.35 There will always be a number of people who need care but who do not have a full employment history, or who have not successfully planned financially for their future (perhaps for a variety of reasons). The question of whether people in this position should be entitled to receive care services without charge and / or without having made prior contributions is a contentious one.
- 3.36 Under the current arrangements, people with lower incomes and few assets necessarily receive more financial assistance to pay for their care. Nobody would want to see people in this position deprived of the services they need, but we believe that resentment sometimes arises from a perception among some sectors of the public that people who have made an effort to “do the right thing” are perhaps losing out under the current system. People with higher incomes and greater assets ask why they should have to sell their homes when they worked hard to pay for them, or why they should save to pay for their future care when others who have not worked, or who they might consider to have been less financially responsible, will get the same services free.
- 3.37 This is a thorny issue, and we would want to guard against any suggestion of a return to the distasteful notion of “undeserving” versus “deserving” poor. We believe that a system that is based on universal participation and prior payment – such as a taxation or social insurance model - would represent a more acceptable option, in line with the underpinning principles of equality and fairness that we have proposed.

Chapter 4: Potential Models for a New System

This chapter considers the main types of potential models for paying for care in the future:

- universal state-funded care;
- a social insurance fund or National Care Fund;
- co-payment and partnership models;
- and 'self-reliance' models, such as pre-funded insurance, annuities and equity release schemes.

It considers the pros and cons of each option, and attempts to determine which models would give the best outcomes for those who need care and support services and for society at large.

- 4.1 The Advisory Group's discussion of potential models for a reformed system was informed by the background papers listed at Annex B to this report. We found a particularly useful starting point in the recent report by James Lloyd, 'Funding Long-term Care – The Building Blocks of Reform' (December 2008), although it considers only the financing of long-term care and our own remit is drawn more widely.
- 4.2 We assessed the models that we considered against the principles that we had devised (see chapter 2 and Recommendation 1), to help us to draw out issues of quality and outcomes, as well as of finance. It is important that any models that are adopted as proposals for reform are person-centred and outcome-focused.
- 4.3 The starting point for our conclusions is that we would want to see a new system that can be easily understood by those contributing to it, those using it and those administering it. In our view, openness and transparency are essential to a fair system that operates equitably. This is why we have included these elements in our proposed list of underpinning principles (see Recommendation 1, in chapter 2).

A model to support a system that maintains health, well-being and independence

- 4.4 We believe that we have a unique opportunity before us to be ambitious and radical in changing the way that care services are organised and paid for. In our view, the starting point should be restoring and maintaining the wellbeing of the citizens of Wales. Rather than prolonging a system which expects to fund a series of care interventions at points of crisis, we should be looking to establish a system that supports a broad social care model, promoting independence and wellbeing (encompassing housing, the voluntary sector, and education and family services, as well as the more traditional social care and health services).

- 4.5 It seems to us that, when an individual finds that they need care and support at a given time, they will frequently find that their health and social care needs are inextricably linked. We believe that, in those instances, health and social care services can provide better care when working well together than they could possibly do when working separately. We would want to see any new system supporting the continued integration of health and social care, whilst recognising that the position of social care would need to be safeguarded, given its relative budget and current profile when compared with the health sector. For this reason we would be cautious about the creation of a unified health and social care system, and if National Insurance were to be expanded to include a social care fund payment, we would want to see a robust mechanism put in place to ensure that this element was not liable simply to be swallowed by the NHS.
- 4.6 Drawing on our conclusions at Recommendation 12 (chapter 3) about the importance of adopting a social model, we would want to see social care in the driving seat, along with health promotion, rather than the rest of the health service; because these are the front line services for promoting and maintaining people's independence and wellbeing. The Assembly Government is in a strong position to use its sizeable health budgets to bring such a system into being; and we would prefer to see a logical, national level system put in place rather than the current patchwork of grant schemes and separate funding schemes.

Recommendation 16: We recommend that health and social care should be much better integrated, along with other related services, so that services are delivered in a more straightforward and seamless way, cutting through the bureaucracy that many service users experience at the moment.

The Welsh Assembly Government should use its pivotal position to nurture and increase the position and funding of social care within the new arrangements, recognising the fundamental importance of social care in maintaining individuals' wellbeing and independence.

Understanding how much money is needed

- 4.7 It will be difficult for any new system for paying for care to be devised independently of having a clear idea of how much resource is actually required for care, both now and in the future. We therefore believe that it is crucial for the Assembly Government's resource review for social care to be carried out as quickly as possible, in order that we have a clearer picture of the level of funding that is likely to be required in Wales for social care over the next 10 to 15 years. We call on the Assembly Government to accelerate the completion of this review.
- 4.8 The resultant information will need to be considered alongside the broader economic data that is available (see Recommendation 6, chapter 2).

Recommendation 17: We recommend that the Welsh Assembly Government should complete its review of social care resourcing as quickly as possible, in order to provide a sound basis of evidence for considering how much funding any reformed system for paying for care needs to yield.

Our preferred type of model

4.9 Our strong preference for a new model for paying for care is for one which is funded by payments from everyone in society, according to their ability to pay, primarily over the course of their working life. We recognise that the main options for achieving this would be increasing general taxation, or establishing a new social insurance fund or National Care Fund to which most people would expect to contribute.

4.10 The main arguments in favour of **universal state-funded care** (through taxation) are:

- It would be likely to be popular with the public. Indeed it seems that the majority of people believe that care is currently funded in this way – i.e. that long term care is already part of the welfare state “contract” (like the NHS).
- It is based on an established principle. Tax payers are content to cross-subsidise universal services such as education and NHS services, including continuing healthcare, even when they know that they will have no need for such services themselves.
- This model is easily understood.
- There would be minimal new administration costs, or transition costs.
- This model would buy peace of mind for everyone in society, including younger people who would know that the care needs of older and disabled friends and relatives are being taken care of.
- This model does not make an artificial distinction, in terms of paying for care, between the care needs of older and younger people.
- It is the fairest model, as it spreads the cost across the population and across an individual’s lifetime. It does away with a situation whereby older individuals often have to pay for care at a stage in life when it is most difficult for them to do so – care that the majority of them believe they have already paid for throughout their working lives. It would also relieve the financial burden on families with young children.

- This model does away with means testing and the stigma of being perceived to be ‘the undeserving poor’.

4.11 The main concerns that might be raised in connection with this model are:

- There would need to be a high degree of political consensus, particularly if it involved raising taxation or redistributing budget priorities. Many people, and especially the older generations, believe that they have already paid for this care across their working lives, through their National Insurance contributions.
- The case for increased taxation (or cuts in other areas) would need to be explained to the general public. Budget literacy in this area is generally very low.
- A much wider public debate would be needed on the implications of such an approach.
- The issue of ‘intergenerational solidarity’ needs to be addressed – i.e. we would need to ensure that an unfair burden did not fall on younger generations. Younger people are already struggling with high levels of debt, and are struggling to get on to the housing ladder.
- The level of support for vulnerable people could be determined by local politics rather than on the grounds of need, because there would continue to be no ring-fenced funding pot for social care
- There could be a risk of cuts or rationing during times of economic strain.

4.12 As part of our discussion on the potential role of taxation, we considered the question of whether it would be appropriate in this country to tax only those people aged 40 to 60 for the purpose of funding social care (as in Japan). However, we consider that this suggestion raises fundamental questions of age equality and discrimination, and is not in accordance with the principles set by the Advisory Group. Because of this, we did not consider it further.

4.13 Under a **social insurance** model, individuals would make ear-marked contributions to a social insurance fund, tied to employment and paid via the pay roll. Contributions could be compulsory or voluntary, or “soft compulsory” (for example, by auto-enrolment). Everyone would be entitled to a “benchmark” level of care regardless of contribution. It could be restricted to the current cohort of people of working age, or extended to include current older people who pay income tax.

4.14 An alternative would be to establish a **Care Fund**. Under this model, people with wealth above a certain threshold could opt to insure themselves for a benchmark level of care. Premiums could be single level, progressive (means tested), lump sum, by instalments, or paid after death through equity release schemes.

4.15 The main arguments in favour of these models are:

- Its pragmatism, and the sense that people would have a feel for what they were paying into.
- In some ways this is similar to National Insurance, and in the same way it would act as a “national guarantee”.
- It could be ring-fenced, in a way that general taxation could not be.
- It is based on affordable levels of contributions, spread across the years of working life.
- A social insurance fund would have low administration costs, by using employers’ payroll systems.
- It has been suggested that a social insurance fund would be self-funding and sustainable after several decades.

4.16 The arguments against these models are:

- Social care would be singled out in a way that other services, funded through general taxation, are not. Why single out one aspect of life in this way? Why not, for example, have an education or a leisure fund?
- Introducing this model would not settle arguments over what exactly should be paid for from it. There would continue to be separate pots for health and social care, and the current disputes over boundaries and funding would continue. A system of separate funding pots encourages a focus on finance rather than on meeting care needs. In our view, merging social care and health funding, possibly within National Insurance, would help resolve these issues.
- The National Care Fund model would not address the long-term care needs of working age people.
- There might also be patchy rates of participation in a National Care Fund, if contributions were voluntary. Auto-enrolment may be difficult to understand and administer.

4.17 In our view, there is not one obvious solution for a reformed system to pay for social care. If additional money were to be collected through

taxation, for example, there would be no certainty that it would be used to fund social care – and even if it was used in this way initially, there could be no long-term guarantees. We are aware that social care does not currently have the level of public support that education or the NHS do, for instance, and this would be likely to affect the level of political commitment to maintaining levels of public funding for social care from general taxation, as at present.

- 4.18 If there was an attempt to broaden the remit of the current National Insurance arrangements to include social care, we recognise that flaws in the current NI system could be perpetuated – in particular, the siphoning off of “surplus” funds for purposes that do not immediately seem to be relevant to health (or social care). Furthermore, contributions would presumably be collected from employers as well as from employees, so that there would be economic implications for business in being expected to meet some of the costs of the social care funding gap through employers’ contributions. We would have particular concerns about the potential impact on small businesses of employers being expected to make additional contributions to the National Insurance scheme.
- 4.19 The particular benefit of establishing a specific, new fund, such as a National Care Fund, would be that money for social care would be ring fenced, and people would know exactly what they were paying for and why; whilst the benefit of collecting the money via taxation (or National Insurance) would be that it would reinforce the message that social care was not a separate, “special interest” type of service, but was integral to the business of government and fully a part of the responsibilities of society in the same way as other major policy areas (like education or transport). In both cases, there would be the significant benefit that means testing would no longer be required, doing away with the stigma and indignity that many people feel about going through this process.
- 4.20 We believe that these issues need to be tackled on a pan-UK level, with the governments of all four nations working together to get the framework right. We would want to see governments taking a radical and courageous approach to finding a system that is sustainable, that accords with the principles that we have recommended (see Recommendation 1, chapter 2), and that safeguards funding for social care at a level that truly meets need. Our initial thoughts are that, of all the possible models we have considered, a fundamentally reformed National Insurance Fund, covering both health and social care, might be the way forward. However, it would need to be more clearly focussed on promoting wellbeing and independence for individuals than the current NI scheme is, and it would need to be more effectively protected from being “raided” for resources by other areas of government.

Recommendation 18: We recommend that any reformed system should be funded by payments from everyone in society, according to their ability to pay, primarily over the course of their working life. We consider that the framework for this system needs to operate at an all-Britain, or all-UK, level.

We urge the Welsh Assembly and UK Governments (with the other relevant administrations) to think radically about reform on these lines, drawing on the expertise and advice of a wide range of stakeholders.

Our initial thoughts are that, of all the possible models we have considered, a fundamentally reformed National Insurance Fund, covering both health and social care, might be the way forward. However, it would need to be more clearly focussed on promoting well-being and independence for individuals than the current NI scheme is, and it would need to be more effectively protected from being “raided” for resources by other areas of government.

- 4.21 If some kind of social insurance Fund is established, we consider that contributions should be compulsory for all people in paid work, to ensure that people are not tempted to skip or postpone their payments. If the National Insurance Fund scheme is to be broadened to collect contributions for social care, we ask that maximum levels of income (after which further contributions are not taken) should be looked at again to ensure that that level is not set too low, penalising (proportionately) those on lower incomes.
- 4.22 It would be important for any social insurance Fund to build in a compensatory mechanism to cover people who for some reason had an interrupted career history. Nobody should be excluded from receiving a decent level of care in accordance with their needs because they were unable to pay sufficient tax or NI contributions – if, for example, they have caring responsibilities, are sick or disabled, or are unemployed. In these cases, Government should cover any NI contributions.

Recommendation 19: We recommend that contributions should be compulsory, and that they should be proportionate to the individual’s level of income.

- 4.23 Within the already developing concept of time banks and volunteering, we would welcome consideration by government of creative options which enable communities to some extent to support themselves – for instance through a “caring credits” scheme, which would give people undertaking caring tasks a form of “bankable” credit, which could be cashed in when they needed care themselves; or alternatively through supporting a version of mutual societies that could help communities to plan and arrange care. (Issues around vulnerability and potential

manipulation would obviously need to be addressed in working through these ideas.)

Recommendation 20: We recommend that governments should look into creative, community based responses such as “caring credits” and “mutual society” approaches.

Co-payment models

4.24 Under this type of model, the State would fund a universal, capped amount towards care, either as a standard proportion of the cost, or as a fixed cash amount. Individuals would then make up the amount either “out of pocket” or from insurance. Co-payments could be proportional to individual means.

4.25 The partnership model is a variant on this, under which everyone who needs it receives a basic level of free care (to a low benchmark). The State would match individuals’ contributions proportionately, to a maximum at a second benchmark level.

4.26 We could see only one main argument in favour of this option:

- It would encourage personal responsibility, and reward those who had saved. Everyone would get something out of the system.

4.27 The arguments against it include:

- It would fall down on the grounds of equality and human rights. The relevant Human Rights Act articles are those around dignity, respect, life and domicile (to live in a setting of one’s own choosing).
- It could lead to a two-tier service, depending on what people could afford to pay. This, in turn, might lead to a diminution of the hard work that has been put into getting real quality standards in social care, and in building up the social care workforce. We would want to avoid at all costs anything that undermines these gains, and that pushes down the quality of care.
- It might have negative implications for people in Supported Living settings or living with their parents.
- This model does not consider the length of time an individual might need care for. Needs could become more complicated; and it could not be known in advance how long the cost to the individual would need to be borne. Depending on how the individual’s payments are made (through insurance schemes or from assets/ savings), this could leave the individual with no choice but to scale down the level of care and support as needs increase or the money runs out.

- Fixed cash amounts would not take account of regional variations in the actual cost of care.

4.28 We also believe that there is little merit in expecting everyone to pay only a fixed proportion of the cost of care, such as 5% or 10%. A major disadvantage of this model is that it does not consider the length of time an individual needs care, or the potential for needs to become more complex (and therefore more costly to meet). We think that it is preferable, therefore, to spread the entire cost over the population as a whole.

4.29 In our view, it would be difficult to devise a model based on principles of co-payment or partnership which was compliant with human rights legislation, or with principles of equality and fairness. We would be concerned that an unacceptable “two-tier” service would develop under such a regime. We therefore recommend that such an approach be treated with great caution.

Recommendation 21: We are unable to support any model based on principles of co-payment or partnership. We consider that an unacceptable “two-tier” service would develop under such a regime and that it would be difficult to devise such a model that was compliant with human rights legislation, or with principles of equality and fairness.

Models of “self reliance”

4.30 We would also be concerned about any reformed system which relied on individuals (or the majority of individuals) taking the lead in organising their own arrangements for paying for care - for instance through personal insurance schemes or annuities, or equity release schemes. We considered private sector insurance schemes, which are a form of pre-funded insurance (i.e. bought prior to needing care), which would pay out if care is required, proportional to need. Alternatives on the same theme include immediate need annuities and deferred needs annuities. We also looked at care-linked annuities, which could be purchased with pension savings and give a guaranteed income until the person’s death. Sometimes this is linked to the individual’s level of care needs.

4.31 In our view, people with lower levels of personal wealth would be unlikely to receive as good a service as wealthier people, and people with pre-existing conditions or genetic propensities could find it very difficult to get insurance, or their premiums might be too high. Furthermore, we have some doubts that private insurance companies would be sufficiently well informed about disabled people’s needs to be able to provide them with appropriate services.

Recommendation 22: We have serious concerns about the suitability of systems which would rely on individuals (or the majority of individuals) taking the lead in organising their own arrangements for paying for care - for instance through personal insurance schemes or annuities. We feel that some people may not get the coverage or services they need and that some would not be able to afford to make the necessary arrangements.

- 4.32 A further alternative is **equity release**, provided by the private sector or by the State (local authorities). This would enable homeowners to realise part of the value of their home as income and/ or a cash lump sum. This money could be used as an “out of pocket” payment to fund care costs, rather than using income or savings.
- 4.33 It is our opinion that equity release schemes also raise clear problems. The current financial climate raises serious questions about what the market is capable of delivering, and patterns of property ownership and inheritance might well change in the next twenty years, making it difficult to predict a way forward. Moreover, the quality of current equity release schemes is poor, and better products would need to be developed to make this an attractive and viable option even for those who wished to use it. There are also issues about the point at which point equity might be tapped into, especially where older people decide to downsize and / or rent. People might also try to manipulate the system (or be manipulated), so the existence of a formal requirement to participate in equity release schemes might act as a disincentive to getting individuals to contribute to the cost of their care, in the same way that the current system proves to be a disincentive on the grounds that people want to preserve their inheritance.
- 4.34 Equity release also raises a fundamental issue of whether it is right to tell people what to do with their own money and assets. Having equity release as an option is different to enforcing it; and, in our view, people need to be able to choose. Some parents, for example, choose to remortgage in order to help their children buy their own house or with the costs of higher education. Other homeowners might choose equity release to “top-up” their care. There are only a limited number of times that equity can be used up. Moreover, we believe it would be wrong to force individuals into equity release in order to be able to access their basic entitlement of care.
- 4.35 The arguments we can see in favour of equity release schemes are:
- These schemes, if made available for those who could afford them, could help reduce the overall costs on the State, allowing the State to help those with less means.
 - For some people, these could be good alternatives to the current system.

4.36 In our opinion, some of the main arguments against are:

- Like the other “self reliance” models, equity release schemes depend on tapping into individuals’ accumulated personal wealth. Those with low incomes would not be able to afford to make use of such options, and where the less well off did have some property wealth, we would need to remember that equity release relies on owner-occupation as a model, and owners are still responsible for (the cost of) maintenance on the properties during their lifetimes. In general, equity release schemes would also raise less finance in Wales because of relatively low house prices.
- In our view, these schemes would be at the mercy of financial uncertainty; there is anecdotal evidence of unreliability; and they operate at high cost to the user. We wonder how the system would work if there was a spouse, child or other dependant relative living in the house. They are currently geared up for large sums of money to be released, which limits their overall effectiveness if smaller amounts are needed periodically. Further research would be needed, and robust guarantees put in place, if this was a serious option.
- Promoting expensive equity release schemes might actually encourage people to go into residential care because it could be cheaper than care in one’s own home. It could thereby reduce independence rather than promote it, taking us in a contrary direction to that set out in ‘Fulfilled Lives, Supportive Communities’.
- At the level of principle, this model is at odds with welfare state values, and what we value as a society; and we believe that going down this route would be unlikely to produce a political consensus. We should also remember that equity release might be offensive to some faith groups as a form of usury.

4.37 We do not consider that people should be encouraged to take up the equity release options that are currently on offer. Group members with knowledge of existing schemes have evidence of negative outcomes of various kinds; and in the current financial climate, notions of “equity” delivered by rising property prices are in any case being challenged.

4.38 There is a recognition within the Advisory Group that, where it does exist, equity might not necessarily be available to pay for care. In many families, it is being tapped for various purposes already, in particular to fund higher education or homes of their own for offspring; and we feel that families should retain their autonomy in determining how best to allocate their wealth among family members. There does not appear to us to be any particular logic to attempting to designate care funding alone (as opposed to any other area of spending) as the appropriate beneficiary of property wealth. Looking at the position of Wales’ current younger generations, for whom property purchase is

often a challenge, we feel that patterns of property ownership and of inheritance may well change significantly over the next 20 years in any case.

- 4.39 We consider that equity release would potentially be a complex, as well as an unfair, system if it were to be introduced on a compulsory basis. The Group notes that there is a parallel in the way that some continuing care decisions (which have involved people giving up their homes) are being challenged, causing distress to families and significant bureaucratic burdens and costs to the reviewers.

Recommendation 23: Whilst we recognise that equity release remains an option for certain individuals at the moment, we recommend that is not a suitable mechanism for addressing the social care funding gap in Wales in the long term. Equity release should not therefore form a major plank of any new system for paying for care.

Chapter 5: Transitional Issues

This chapter considers options for transitional arrangements leading up to the introduction of any new system of paying for care, including actions currently being taken by the Welsh Assembly Government and further suggestions from the Advisory Group.

- 5.1 We note that the earliest it would be feasible to have new primary legislation in place would be 2012 after the Law Commission is due to complete its review of the legal framework of adult social care. We would therefore want to see transitional arrangements in place, that will need to be consistent with the system we will be moving to ultimately, with clear information about how long the interim arrangements will last and when the new system will be introduced.
- 5.2 Whatever transitional arrangements are put in place should cover all types of care, so that people are not pressured into making choices for financial reasons. The arrangements will therefore need to cover non-residential care and support for unpaid carers, as well as residential care. It will be important for all this to be explained clearly and comprehensibly to the general public.
- 5.3 We discussed options for transitional arrangements which included consideration of the Joseph Rowntree Foundation paper, 'Options for care funding: what could be done now?'², in the context of current Assembly Government initiatives to improve the existing system of charging for care.
- 5.4 The actions already being taken by the Assembly Government in relation to non-residential charging should be seen as part of the transitional package; and they are broadly welcomed by the Advisory Group.

Recommendation 24: We recommend that transitional arrangements will be necessary, and will need to be both comprehensive and consistent with the new system to be introduced. Government(s) will need to explain them clearly and comprehensibly to the general public.

Four recommended transitional actions

- 5.5 Our discussions of various options have led us to recommend four transitional actions for the Welsh Assembly Government:
- 5.6 The first is to **invest more funding in local authority social services**, thereby demonstrating the benefits of better funded social care and encouraging people to “buy in” to the longer-term reforms. In

² 'Options for care funding: what could be done now?', by Sue Collins (Joseph Rowntree Foundation, March 2009).

particular, we would want to see this uplift of local authority social services used to support increased independence and new models of care. This would be a good opportunity to show the benefits of better funded social care. Furthermore, we believe that this would be economically beneficial, as we believe that money invested in social care will work itself back into the economy more quickly than money invested into, say, the financial sector.

- 5.7 Second, we believe that the Assembly Government should **undertake an awareness-raising campaign** as part of its consultation exercise on its forthcoming Green Paper. This should give the public better information about the current system and about what might happen in the future. By doing so, it would encourage people to take action themselves, now, so that they experience the best possible outcomes in the period leading up to implementation of the reforms. (This links back to our previous recommendations 11 and 13, about the need for better information and about individuals' responsibilities.) In paragraph 5.10 below, we go on to discuss the (limited) role that we see for private insurance schemes during this transitional period.
- 5.8 Third, we would want to see the Assembly Government following through on its commitment to make charging for non-residential social care fairer by **putting additional resources into the implementation of the forthcoming Assembly Measure**. We believe that it is important to reduce the impact of charging for non-residential care as far as possible, as well as reducing the disparities between the way that charging is applied in various parts of Wales.
- 5.9 Fourth, we would want to see the Assembly Government **act now to bring about closer working between health and social services** within the current policy framework, rather than waiting perhaps 10 to 20 years for the reformed system to come on line. In our conclusions leading up to recommendation 16, we noted that the legal mechanisms are already in place to enable this to happen. In our view, government could encourage pilots of flexible models of care, especially in relation to individual budgets. For example, there is potential in direct payments to establish loose local arrangements whereby a number of people within a certain radius could co-operate in the employment of a number of care staff, each working as many hours as they required but meeting the needs of their employers/ clients.

Recommendation 25: We recommend four transitional measures to the Welsh Assembly Government:

* Increased investment in social care services;

* An awareness-raising campaign for the public about social care funding and how the current system and the planned reforms affect individuals;

* Additional resources to implement the forthcoming Assembly Measure on non-residential care charging; and

* Immediate action to bring about closer working between health and social services, perhaps through piloting more flexible models of integrated care.

Personal insurance schemes

5.10 We see a limited role for personal insurance schemes in the medium term, as a way for some groups of people to make better preparation for their potential care needs – with the incidental benefit that they would be saving the taxpayer some money, which could be redirected towards those in greater need. There might be some public reluctance to embrace private insurance arrangements, given the current financial climate and public perceptions of the financial products sector, and this would need to be tackled if such an approach were to be successful. It would also be necessary to ensure that any promotion of personal insurance schemes did not cut across the strategic direction being taken in the longer term reforms, potentially confusing the public with conflicting messages about what they need to do.

Recommendation 26: We see a limited potential role for private insurance schemes in the medium term, in enabling some groups of people to make better preparation for their potential care needs. We recommend that the Welsh Assembly Government, working with the UK Government, should take steps to encourage the development and marketing of high quality private insurance schemes.

Free personal care for all people requiring nursing care

5.11 JRF has also suggested that personal care should be made free for all people requiring nursing care, during the transitional period to the reformed system. We note that this proposal would remove inconsistencies around whether nursing care is funded by the NHS or by the individual concerned. One option would be to extend the current “continuing care” regime, under which all care home / hospital costs are paid in full, to nursing home residents, creating a more level playing field for those with nursing needs. Another option would be to impose a charge for non-care costs on everyone, including those meeting the continuing care criteria, subject to means-tested assistance under current local authority rules for those with capital below the eligibility limits.

5.12 Although we agreed that this is a logical proposal, we believe that it would only tinker with the current system and would benefit only a relatively small number of people. It seems to us not to be a priority for action in the transitional phase; and it contributes little to the broad agenda of reform of paying for care. We also fear that it might perversely increase the number of disputes between health and social

care funders (resulting in “cost shunting”), and make the current situation worse. We would not favour adopting this proposal as an interim measure.

Higher capital limits for care home fees

5.13 We considered carefully the Joseph Rowntree Foundation’s proposal that the current process of means testing should be overhauled prior to the introduction of the reformed system. In particular, JRF suggested that the upper capital limit should be raised (from £22,250 to £42,500) so as to remove a perceived disincentive to saving. In our view, this could be done within the Assembly’s existing legislative competence and might be expected to cost in the region of £14 million annually. (This figure represents the estimated amount that would need to be given to local authorities to compensate for a loss of income from this charging route.)

5.14 We do not favour this option. We believe that it does little to move the agenda forward and would therefore deliver little gain for £14 million expenditure. Our main objections to the proposal are:

- We understand the average property price in Wales to be £150,000 at present. Therefore this proposal would not benefit most home owners unless they were in residential care for four years or more. This is because by then their capital might have diminished to the extent that they might fall below the upper limit. In fact, the average length of stay in a care home is up to two years.
- There are only relatively small numbers of people in residential care in Wales (around 27,000 in care homes) and so only a few people would benefit overall.

5.15 If, however, the Assembly Government was minded to pursue the JRF proposal, we would suggest that an upper limit of £50,000 should be adopted rather than £42,000, so that there is consistency with what has been recommended by the recent Assembly Measure Task and Finish Group in respect of non-residential care charging.

Recommendation 27: We recommend that raising the upper capital limit when assessing care home charges, at an estimated cost of £14 million, would not represent best value for expenditure of this order when compared with other options for transitional action. However, should the proposal be adopted by government, we advocate that the upper level should be set at £50,000, as recommended by the recent Assembly Measure Task and Finish Group in respect of non-residential care charging.

5.16 Finally, we call on the Assembly Government to double the personal expenses allowance (currently set at £21.90 per week, to allow people

supported by local authorities who live in care homes to pay for personal items such as clothes and shoes). We do not see this as a “transition” issue, but as a matter which needs immediate remedy in its own right, as an issue of individual dignity and human rights.

Recommendation 28: We recommend that the personal expenses allowance for people in care homes should be doubled (from £21.90 per week to £43.80).

Chapter 6: Conclusions and Recommendations

This chapter sets out the Advisory Group's conclusions and makes 28 recommendations for reform. The recommendations are aimed primarily at the Welsh Assembly and UK Governments.

Underlying principles

- 6.1 We believe that any proposals for a new system for paying for care need to be grounded in human rights and equalities, demonstrably meeting all the legal requirements on the Assembly Government in this field. They should reflect the requirements of the Human Rights Act 1998, the United Nations Principles for Older People, the UN Convention on the Rights of the Child, and the (as yet unratified) UN Convention on Rights for Persons with Disabilities.
- 6.2 We have drawn up a set of principles that we commend to the Assembly Government for this purpose. These are set out in Chapter 1 of this report. We would also encourage the Department of Health and Department for Work and Pensions to adopt the same principles to underpin their plans for reform, particularly where these would affect the UK as a whole.

Recommendation 1: We recommend that the Welsh Assembly Government – and the UK Government - should adopt the underpinning Principles that we propose, for the purpose of devising any new system of paying for care in Wales.

- 6.3 We would want to see the current system replaced by one which is clear, fair and sustainable, and which treats everyone with care needs fairly, according to their needs. We do not see any merit in a “two-tier” system, and we would want to resist the notion that a “basic” or simply “adequate” level of care should be the goal of the care system in Wales for the majority of people. People should expect to pay additional amounts for care only where this is to meet their own particular wishes and preferences, over and above the core provision they should receive automatically from the care system.
- 6.4 We would want to see the new system tackle the current problems of limited availability of services, and of rationing (which has been applied particularly by means of a continual tightening of eligibility criteria, so that only those in extreme and urgent need of care receive services). Otherwise, these two factors are likely to contribute to the continuation of a two-tier system, and to make it worse. We believe that this will lead to greater long term costs to the whole of society, not the least of

which are felt by the individuals whose need remains and whose situation deteriorates whilst they wait to meet a set of eligibility criteria.

Recommendation 2: Building on the ‘Fulfilled Lives, Supportive Communities’ social services strategy for Wales, we would want to see any new system for paying for care supporting the delivery of an excellent level of care for all those who need it in Wales. We would not want to see a system that excluded the less well off from receiving good care, simply because of their financial means.

6.5 We believe that any new system must work equally as well for younger disabled people and for children with care needs or caring responsibilities, as for older people with similar needs and caring responsibilities.

Recommendation 3: We recommend that, when devising any new system for paying for care in Wales, the Welsh Assembly Government should take into account the needs and requirements of all those for whom the care system needs to work effectively – encompassing older people, younger disabled people and children with care needs or caring responsibilities, as well as families and other carers.

Context

6.6 We recognise that there are a number of aspects of the paying for care debate that are not devolved to the Assembly Government – notably policy on taxation, benefits and pensions – but which will be crucial to any new system.

Recommendation 4: We recommend that the Welsh Assembly Government and the UK Government should work closely together to ensure that any new system reflects appropriately the wishes and needs of the people of Wales, in non-devolved policy areas as well as in devolved areas.

6.7 We note that there is a broader issue of the relative priority that attaches to social care funding in UK Government and Assembly Government budgets. We call on both governments to place social care higher in their list of priorities, and to devote a greater proportion of government spending to it in future. We do not agree that it should simply be accepted that there will be a sizeable deficit for social care, when huge sums of money can be found for other priorities at times of crisis.

Recommendation 5: We recommend that the Welsh Assembly Government should give a higher priority to funding social care – in particular the ‘Fulfilled Lives, Supportive Communities’ strategy – from within its own delegated budgets. We also recommend that the Welsh Assembly Government should lobby the UK Government to ensure that those aspects of social care and related issues which are funded from general taxation (such as pensions and benefits) are funded to a more realistic level.

- 6.8 We register our reservations about some of the data and the interpretation of it that has taken place to date, which has frequently drawn a relatively bleak picture of the future of social care resourcing. It is not accepted by all economists that increased longevity will automatically lead to a problem with unmet demand, and rising numbers of older people does not necessarily mean that more care and support will be needed by them – particularly if the healthy ageing agenda has a real impact. The increased cost of improving the quality of care might be overstated, and the continued development of telecare and tele-healthcare could well reduce care costs. In any case, we consider that society has a capacity for readjustment, as is illustrated by the fact that one of the biggest growth areas for employment is among older people.
- 6.9 We would want to see alternative viewpoints examined and contrasting research on demography and family structures (for example) considered, and the current assumptions challenged and tested before they could be accepted as the rationale for reform.

Recommendation 6: We recommend that the Welsh Assembly Government, working with key stakeholders in the field, should examine the existing data in this area carefully before devising clear plans for reform.

- 6.10 We are conscious that questions of paying for care are closely linked to issues of service delivery. We acknowledge the work that has already been undertaken to improve quality and availability of services – particularly as part of the ‘Fulfilled Lives, Supportive Communities’ strategy; through the Dignity in Care initiative; and by means of the National Service Frameworks, for example. It will be important to ensure that reform of the resourcing system dovetails with, and supports, these continuing service delivery improvements.
- 6.11 We particularly wish to draw attention in this context to the importance of continued and increasing investment in prevention, re-ablement and lower level support services. These services not only raise levels of wellbeing; they are, from a financial point of view, very effective in reducing costs over the medium and longer term. They are rightly a strong theme in the ‘Fulfilled Lives, Supportive Communities’ strategy. We therefore consider that a campaign to raise public awareness about

preventative measures (along the lines of the “5-a-day” healthy eating campaign) would be a worthwhile initiative, not only in Wales but also in the UK as a whole.

Recommendation 7: We recommend that the Welsh Assembly Government should support more effectively prevention, re-ablement and lower level support services, and that it should consider running a publicity campaign in this area to raise levels of wellbeing and independence among people who might otherwise become more heavily reliant on care services.

Consultation Question: Who should contribute more for care in the future?

Families

6.12 We acknowledge the huge debt that the care system currently owes to unpaid carers. Families are already taking responsibility for providing the lion’s share of care, and any reform of the care system needs to take into account the non-financial contribution that families make, as well as the monetary support that they offer to family members needing care.

6.13 We note that the Assembly Government is currently preparing legislation which will give greater support and recognition to carers, and we urge the Assembly Government to ensure that carers of all ages are enabled and supported by the reformed care system to:

- Continue to provide the care that they wish to provide; and
- Take on an appropriate level of caring, to a degree which they (or professionals responsible for safeguarding children) consider to be within their capacity.

Recommendation 8: We recommend that the Welsh Assembly Government should proceed with legislation to ensure that carers of all ages are enabled and supported by the reformed care system to:

- * Continue to provide the care that they wish to provide; and
- * Take on an appropriate level of caring, to a degree which is within their capacity

This will require a far greater level of support to be put in place than is currently the case, in particular through providing advocacy services more widely.

Furthermore, this legislation should place a duty on the professionals involved to ensure that children and young people are not put in a position where they take on an inappropriate level of caring.

Everyone in society

6.14 We firmly believe that everyone in society should be responsible for paying towards the cost of care, whether or not they need care themselves at any point in their life. Care costs should be a pooled risk, in the same way that health care is, and care funding should be supported by the population as a whole - just as, for example, school education is, regardless of whether a family has children of its own. The Advisory Group believes that this is a matter of principle and fairness: that a civilized society should take care of its members when they are in need.

Recommendation 9: We recommend that any new system for paying for care should be based on the principle that the provision of social care for all those who need it is a duty of society as a whole. Care costs should therefore be a pooled risk across the whole population.

6.15 Whatever system is adopted in the reform of paying for care, we consider that there is a central role for both the Assembly Government and the UK Government in ensuring that funds intended for the care system are protected; that contributions are made by, or collected from, individuals in accordance with the scheme; that funding is sufficient to provide a good level of care for all those who need it; and that the scheme is run efficiently and to the benefit of those receiving care.

Recommendation 10: We recommend that both the Welsh Assembly Government and the UK Government should play a central role in ensuring that funds for social care are collected efficiently and protected effectively; and that the scheme is well run to the benefit of those receiving care.

6.16 We also consider that both the UK and the Assembly Government, and all stakeholders, have a central role to play in educating the wider public about why a reformed system is needed, what it will mean for individuals, and how and when the changes will be brought in. We recognise that it will be crucial to win the support of the vast majority of the population in order for the reformed system to be successful, and that this will need skilful handling and clear explanations of the benefits of the new system.

Recommendation 11: We recommend that the Welsh Assembly Government should work with the UK Government and all stakeholders to educate the public about the reform process and to win their willingness to buy in to the changes.

- 6.17 We consider that, in order for any new system to win the participation of the wider public, people need to understand the “care contract” that will exist between themselves and the State in future: in particular, they will need to be given a clear understanding of what constitutes “care” – what kinds of services are included and what services might fall outside the “contract”.
- 6.18 We note that “care” in this context will primarily mean chargeable care; in essence, it covers residential, nursing and continuing care, and non-residential social services (i.e. statutory services provided as a result of a community care assessment, and which are chargeable).
- 6.19 We understand that a clear definition will be ultimately reached largely as a result of the outcome of the Law Commission review of adult social care law. As an Advisory Group, we would prefer to see a new definition of care used by the UK and Assembly Governments which moves away from a “medical model” of care and is based instead on a social model.

Recommendation 12: We recommend that the Welsh Assembly Government should include a working definition of “care” in its forthcoming consultation document, as part of the context for its proposals for reform of the paying for care system; and that it should move ultimately to a more positive definition of care, based on the social model of disability and care needs.

Individuals

- 6.20 In our opinion, levels of public understanding of how the care system works, and is funded, are low. This viewpoint would appear to be borne out by the responses that the Assembly Government has received to its consultation exercise and that were expressed at the consultation events in North and South Wales. We feel that individuals need to learn more about the system, to be more aware of their own responsibilities regarding their potential need for care, and to prepare in accordance with the prevailing system. As previously recommended, governments have an important role in stimulating public participation in the debate and in encouraging and supporting individuals to plan for their potential care needs.

Recommendation 13: We recommend that individuals should take responsibility for planning to meet their own potential care needs in the future, identifying what steps they might need to take to meet those needs effectively. In their planning, individuals should address in particular their need to keep healthy and to maintain their wellbeing.

- 6.21 We would want to see individuals enabled to continue working into older age, past 65 if they wish, in accordance with their own

preferences and circumstances. We consider that this is an important way for individuals to remain independent and to continue to contribute through taxation to the funding of the care system.

Recommendation 14: We recommend that government should enable individuals to continue working to whatever age accords with their own preferences and circumstances. We consider that this is an important way for individuals to remain independent and to continue to contribute through taxation and National Insurance to the funding of the care system.

Consultation Question: A national or local system?

6.22 We would want to see a national (Welsh) system introduced for giving support for care, as opposed to a local (for example, local authority area based) system. We consider that this is the most effective way to tackle the current “post code lottery”; and this approach chimes with action that the Assembly Government has in hand to introduce legislation that will make the system for non-residential social care charging both fairer and more consistent. However, we recognise that plans to reform the system in Wales will need to take account of those elements of the system which are not devolved to the Assembly.

6.23 We believe that this would enable Social Services Departments to move further towards a role of working with families, and advocating for them, without having to act at the same time as “gate keeper” to the funding. We consider that this would encourage local flexibility and innovation in local level care plans.

Recommendation 15: We recommend that the Welsh Assembly Government should establish a national (all-Wales) system for giving support to those who need care, encompassing a clear eligibility framework and a consistent and considered assessment methodology to operate across Wales. It should be dovetailed with the Assembly Government’s forthcoming legislation to make the system for non-residential social care charging both fairer and more consistent.

Models

6.24 We would prefer to see a new system that can be easily understood by those contributing to it, those using it and those administering it. In our view, openness and transparency are essential to a fair system that operates equitably. This is why we have included these elements in our proposed list of underpinning principles (see recommendation 1 in chapter 2).

- 6.25 We believe that we have a unique opportunity before us to be ambitious and radical in changing the way that care services are organised and paid for. In our view, the starting point should be restoring and maintaining the well-being of the citizens of Wales; and rather than prolonging a system which expects to fund a series of care interventions at points of crisis, we should be looking to establish a system that supports a broad social care model that promotes independence and wellbeing (encompassing housing, the voluntary sector, and education and family services, as well as the more traditional social care and health services).
- 6.26 The Assembly Government is in a strong position to use its sizeable health budgets to bring such a system into being; and we would prefer to see a logical, national level system put in place rather than the current patchwork of grant schemes and separate funding schemes.

Recommendation 16: We recommend that health and social care should be much better integrated, along with other related services, so that services are delivered in a more straightforward and seamless way, cutting through the bureaucracy that many service users experience at the moment.

The Welsh Assembly Government should use its pivotal position to nurture and increase the position and funding of social care within the new arrangements, recognising the fundamental importance of social care in maintaining individuals' wellbeing and independence.

- 6.27 It will be difficult for any new system for paying for care to be devised independently of having a clear idea of how much resource is actually required for care, both now and in the future. We therefore believe that it is crucial for the Assembly Government's resource review for social care to be carried out as quickly as possible, in order that we have a clearer picture of the level of funding that is likely to be required in Wales for social care over the next 10 to 20 years. We call on the Assembly Government to accelerate the completion of this review.

Recommendation 17: We recommend that the Welsh Assembly Government should complete its review of social care resourcing as quickly as possible, in order to provide a sound basis of evidence for considering how much funding any reformed system for paying for care needs to yield.

- 6.28 Our strong preference for a new model for paying for care is for one which is funded by payments from everyone in society, according to their ability to pay, primarily over the course of their working life. We recognise that some of the options for achieving this would include increasing general taxation, or establishing a new social insurance fund or National Care Fund to which most people would expect to contribute.

- 6.29 In our view, there is not one obvious solution for a reformed system to pay for social care. If additional money were to be collected through taxation, for example, there would be no certainty that it would be used to fund social care – and even if it was used in this way initially, there could be no long-term guarantees.
- 6.30 If there was an attempt to broaden the remit of the current National Insurance arrangements to include social care, we recognise that flaws in the current NI system could be perpetuated – in particular, the siphoning off of “surplus” funds for purposes that do not immediately seem to be relevant to health (or social care). We would have concerns about the economic impact of raising National Insurance contributions, particularly for employers running small businesses.
- 6.31 The particular benefit of establishing a specific, new fund, such as a National Care Fund, would be that money for social care would be ring fenced, and people would know exactly what they were paying for and why; whilst the benefit of collecting the money via taxation (or National Insurance) would be that it would reinforce the message that social care was not a separate, “special interest” type of service, but was integral to the business of government and fully a part of the responsibilities of society in the same way as other major policy areas (like education or transport). In both cases, there would be the significant benefit that means testing would no longer be required, doing away with the stigma and indignity that many people feel about going through this process.

Recommendation 18: We recommend that any reformed system should be funded by payments from everyone in society, according to their ability to pay, primarily over the course of their working life. We consider that the framework for this system needs to operate at an all-Britain, or all-UK, level.

We urge the Welsh Assembly and UK Governments (with the other relevant administrations) to think radically about reform on these lines, drawing on the expertise and advice of a wide range of stakeholders.

Our initial thoughts are that, of all the possible models we have considered, a fundamentally reformed National Insurance Fund, covering both health and social care, might be the way forward. However, it would need to be more clearly focussed on promoting well-being and independence for individuals than the current NI scheme is, and it would need to be more effectively protected from being “raided” for resources by other areas of government.

- 6.32 If some kind of social insurance Fund is established, we consider that contributions should be compulsory for all people in paid work, to ensure that people are not tempted to skip or postpone their payments. If the National Insurance Fund scheme is to be broadened to collect contributions for social care, we ask that maximum levels of income (after which further contributions are not taken) should be looked at

again to ensure that the level is not set too low, penalising (proportionately) those on lower incomes.

Recommendation 19: We recommend that contributions should be compulsory, and that they should be proportionate to the individual's level of income.

6.33 We would welcome consideration by government of creative options which enable communities to some extent to support themselves – for instance through a “caring credits” scheme, which would give people undertaking caring tasks a form of “bankable” credit, which could be cashed in when they need care themselves; or alternatively through supporting a version of mutual societies that could help communities to plan and arrange care.

Recommendation 20: We recommend that governments should look into creative, community based responses such as “caring credits” and “mutual society” approaches.

6.34 In our view, it would be difficult to devise a model based on principles of co-payment or partnership which was compliant with human rights legislation, or with principles of equality and fairness. We would be concerned that an unacceptable “two-tier” service would develop under such a regime. We therefore recommend that such an approach be treated with great caution.

Recommendation 21: We are unable to support any model based on principles of co-payment or partnership. We consider that an unacceptable “two-tier” service would develop under such a regime and that it would be difficult to devise such a model that was compliant with human rights legislation, or with principles of equality and fairness.

6.35 We would also be concerned about any reformed system which relied on individuals (or the majority of individuals) taking the lead in organising their own arrangements for paying for care - for instance through personal insurance schemes or annuities. In our view, people with lower levels of personal wealth would be unlikely to receive as good a service as wealthier people, and people with pre-existing conditions or genetic propensities could find it very difficult to get insurance, or their premiums might be too high. Furthermore, we have some doubts that private insurance companies would be sufficiently well informed about disabled people's needs to be able to provide them with appropriate services.

Recommendation 22: We have serious concerns about the suitability of systems which would rely on individuals (or the majority of individuals) taking the lead in organising their own arrangements for paying for care - for instance through personal insurance schemes or annuities. We feel that some people may not get the coverage or services they need and that some would not be able to afford to make the necessary arrangements.

- 6.36 We do not consider that people should be encouraged to take up the equity release options that are currently on offer. Group members with knowledge of existing schemes have evidence of negative outcomes of various kinds; and in the current financial climate, notions of “equity” delivered by rising property prices are in any case being challenged.
- 6.37 There is a recognition within the Advisory Group that, where it does exist, equity might not necessarily be available to pay for care. In many families, it is being tapped for various purposes already, in particular to fund higher education or homes of their own for offspring; and we feel that families should retain their autonomy in determining how best to allocate their wealth among family members. There does not appear to us to be any particular logic to attempting to designate care funding alone (as opposed to any other area of spending) as the appropriate beneficiary of property wealth. Looking at the position of Wales’ current younger generations, for whom property purchase is often a challenge, we feel that patterns of property ownership and of inheritance may well change significantly over the next 20 years in any case.
- 6.38 We consider that equity release is potentially a complex, as well as an unfair, system if it were to be introduced on a compulsory basis. We note that there is a parallel in the way that some continuing care decisions (which have involved people giving up their homes) are being challenged, causing distress to families and significant bureaucratic burdens and costs to the reviewers.

Recommendation 23: Whilst we recognise that equity release remains an option for certain individuals at the moment, we recommend that it is not a suitable mechanism for addressing the social care funding gap in Wales in the long term. Equity release should not therefore form a major plank of any new system for paying for care.

Transition

6.39 We note that the earliest it would be feasible to have new legislation in place would be 2012. We would therefore want to see transitional arrangements in place, that will need to be consistent with the system we will be moving to ultimately, with clear information about how long the interim arrangements will last and when the new system will be introduced. It will be important for all this to be explained clearly and comprehensibly to the general public.

Recommendation 24: We recommend that transitional arrangements will be necessary, and will need to be both comprehensive and consistent with the new system to be introduced. Government(s) will need to explain them clearly and comprehensibly to the general public.

6.40 We recommend four potential transitional actions for the Welsh Assembly Government:

- To invest more funding into local authority social services, thereby demonstrating the benefits of better funded social care.
- To undertake an awareness-raising campaign – giving the public better information about the current system and about what might happen in the future, thereby encouraging people to take action themselves now, where they can.
- To reduce the impact of charging for non-residential care by putting additional resources into the implementation of the forthcoming Assembly Measure.
- To bring about closer working between health and social services within the current policy framework, moving away from the vicious cycle of having to consider whether meeting people’s care needs should fall to health or social care. A joint system for providing care is needed, and the legislative mechanism to enable this to happen is already in place through Health Act flexibilities.

Recommendation 25: We recommend four transitional measures to the Welsh Assembly Government:

- * Increased investment in social care services;
- * An awareness-raising campaign for the public about social care funding and how the current system and the planned reforms affect individuals;
- * Additional resources to implement the forthcoming Assembly Measure on non-residential care charging; and
- * Immediate action to bring about closer working between health and social services, perhaps through piloting more flexible models of integrated care.

6.41 We see a limited role for personal insurance schemes in the medium term, as a way for some groups of people to make better preparation for their potential care needs – with the incidental benefit that they would be saving the taxpayer some money. There might be some public reluctance to embrace private insurance arrangements, given the current financial climate and public perceptions of the financial products sector, and this would need to be tackled if such an approach were to be successful.

Recommendation 26: We see a limited potential role for private insurance schemes in the medium term, in enabling some groups of people to make better preparation for their potential care needs. We recommend that the Welsh Assembly Government, working with the UK Government, should take steps to encourage the development and marketing of high quality private insurance schemes.

6.42 We considered carefully the Joseph Rowntree Foundation’s proposal that the current process of means testing should be overhauled prior to the introduction of the reformed system. In particular, JRF suggested that the upper capital limit should be raised (from £22,250 to £42,500) so as to remove a perceived disincentive to saving. In our view, this could be done within the Assembly’s existing legislative competence, but we do not favour this option. We believe that it does little to move the agenda forward and would therefore deliver little gain for £14 million expenditure.

Recommendation 27: We recommend that raising the upper capital limit when assessing care home charges, at an estimated cost of £14 million, would not represent best value for expenditure of this order when compared with other options for transitional action. However, should the proposal be adopted by government, we advocate that the upper level should be set at £50,000, as recommended by the recent Assembly Measure Task and Finish Group in respect of non-residential care charging.

6.43 Finally, we call on the Assembly Government to double the personal expenses allowance (currently set at £21.90 per week, to allow people supported by local authorities who live in care homes to pay for personal items such as clothes and shoes). We do not see this as a “transition” issue, but as a matter which needs immediate remedy in its own right, as an issue of individual dignity and human rights.

Recommendation 28: We recommend that the personal expenses allowance for people in care homes should be doubled (from £21.90 per week to £43.80).

ANNEX A

List of Members and Attendees

Chair:

Steve Milsom Director (Acting), Older People and Long-term
Care Policy Directorate, Welsh Assembly
Government

Members:

Yvonne Apsitis	UKHCA
Wendy Bourton	Care and Repair Cymru
Jim Crowe	Learning Disability Wales
Jonathan Davies	NHS Confederation
Nancy Davies	Pensioners Forum Wales
Rhian Davies	Coalition on Charging Cymru (Disability Wales)
<i>Miranda Evans</i>	<i>Coalition on Charging Cymru (Disability Wales) *</i>
Amanda Edwards	Social Care Institute for Excellence
Giovanni Isingrini	Association of Directors of Social Services
Dr Pradeep Khanna	National Partnership Forum for Older People
Tom Moran	National Partnership Forum for Older People
Lowri Griffiths	Age Alliance Wales
Gordon Jones	Welsh Local Government Association
Mike Kemp	Care Forum Wales
<i>Brian West</i>	<i>Care Forum Wales *</i>
Ana Palazon	Help the Aged in Wales
Phyllis Preece	National Pensioners' Convention
Robert Taylor	Age Concern Cymru
Vin West	Coalition on Charging Cymru (service user)
Valerie Thomas	OPAN
<i>Jenny Hambridge</i>	<i>Coalition on Charging Cymru (service user) *</i>
Helen Williams	Ceredigion/ Pembrokeshire Local Health Board
Roz Williamson	Carers Wales

Observers:

Peter Hosking	Office of Children's Commissioner for Wales
<i>Gareth Jones</i>	<i>Office of the Children's Commissioner for Wales *</i>
Sarah Stone	Deputy Commissioner for Older People Wales

Adviser:

David Groves	Equality and Human Rights Commission
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Speakers at First Meeting

Gwenda Thomas AM	Deputy Minister for Social Services, Welsh Assembly Government
Alexandra Norrish	Head of Social Care Strategy, Department of Health

Assembly Government Officials:

Liz Lockwood	{ Older People and Long-term Care Policy
Penny Hall	{ Directorate, Welsh Assembly Government
Marilyn St Roas	{ (Secretariat)
Huw Gwyn Jones	{ (Secretariat)

** denotes those who deputised at a meeting.*

ANNEX B

Background papers considered by the Advisory Group

'A National Care Fund for Long-term Care: A Policy Brief' – by James Lloyd (ILC-UK, February 2008)

'Funding Long-term Care – The Building Blocks of Reform' – by James Lloyd (ILC-UK, December 2008)

'Funding Long-term Care for Older People: Lessons from other countries' – by Caroline Glendinning, Bleddyn Davies, Linda Pickard and Adeline Comas-Herrera (Joseph Rowntree Foundation, 2004)

'Independent Review of Free Personal and Nursing Care in Scotland: A report by Lord Sutherland' (The Scottish Office, April 2008)

'Lessons from the funding of long-term care in Scotland' (Joseph Rowntree Foundation, February 2004)

'Paying for long-term care' (Joseph Rowntree Foundation, April 2006)

'Securing Good Care for Older People: Taking a long-term view' – by Derek Wanless (Kings Fund, 2006)

'The Future of Care Funding: Time for a change' (Caring Choices, c/o Kings Fund, January 2008)

'Overview of Disability and Carer Benefit and Related Support' (Social Care Strategy Unit, Department of Health)

'Fulfilled Lives, Supportive Communities: Improving social services in Wales from 2008-1018 (Welsh Assembly Government, February 2007)

'Care and Social Services Inspectorate Wales: Annual Report 2007-2008' (CSSIW, November 2008)

'Options for care funding: what could be done now?' – by Sue Collins (Joseph Rowntree Foundation, March 2009)

ANNEX C

Relevant articles from human rights legislation and instruments

The work of the Advisory Group has been underpinned by the following human rights legislation and conventions/ principles:

- Human Rights Act 1998
- United Nations Convention on the Rights of the Child
- United Nations Principles for Older People
- United Nations Convention on Disability Rights

Listed below are the articles / principles deemed to be most relevant to the work of the Advisory Group.

HUMAN RIGHTS ACT 1998

Article 2: the right to have one's life protected by law

Article 3: the right to be free from torture or inhuman or degrading treatment

Article 5: the right not to be deprived of one's liberty except in certain specific circumstances and where there are clear legal procedures

Article 8: the right to respect for one's privacy and family life, one's home and correspondence

Article 14: the right not to be discriminated against in access to these rights because of one's sex, race, colour, language, religion, political views, national or social origin, property, birth or other status [age is not specifically mentioned but is included]

UN PRINCIPLES FOR OLDER PEOPLE

Independence

1. Older persons should have access to adequate food, water, shelter, clothing and health care through the provision of income, family and community support and self-help.

5. Older persons should be able to live in environments that are safe and adaptable to personal preferences and changing capacities.

6. Older persons should be able to reside at home for as long as possible.

Participation

7. Older persons should remain integrated in society, participate actively in the formulation and implementation of policies that directly affect their well-being and share their knowledge and skills with younger generations.

Care

10. Older persons should benefit from family and community care and protection in accordance with each society's system of cultural values.

11. Older persons should have access to health care to help them to maintain or regain the optimum level of physical, mental and emotional well-being and to prevent or delay the onset of illness.

12. Older persons should have access to social and legal services to enhance their autonomy, protection and care.

13. Older persons should be able to utilize appropriate levels of institutional care providing protection, rehabilitation and social and mental stimulation in a humane and secure environment.

14. Older persons should be able to enjoy human rights and fundamental freedoms when residing in any shelter, care or treatment facility, including full respect for their dignity, beliefs, needs and privacy and for the right to make decisions about their care and the quality of their lives.

Self-fulfilment

16. Older persons should have access to the educational, cultural, spiritual and recreational resources of society.

Dignity

17. Older persons should be able to live in dignity and security and be free of exploitation and physical or mental abuse.

18. Older persons should be treated fairly regardless of age, gender, racial or ethnic background, disability or other status, and be valued independently of their economic contribution.

UN CONVENTION ON THE RIGHTS OF THE CHILD

Article 6

You have the right to life. Governments should ensure that children survive and develop healthily.

Article 7

You have the right to a legally registered name and nationality. You also have the right to know and, as far as possible, to be cared for by your parents.

Article 8

Governments should respect children's right to a name, a nationality and family ties.

Article 9

You should not be separated from your parents unless it is for your own good – for example, if a parent is mistreating or neglecting you. If your parents have separated, you have the right to stay in contact with both parents, unless this might harm you.

Article 12

You have the right to say what you think should happen when adults are making decisions that affect you, and to have your opinions taken into account.

Article 16

You have the right to privacy. The law should protect you from attacks against your way of life, your good name, your family and your home.

Article 17

You have the right to reliable information from the mass media. Television, radio, and newspapers should provide information that you can understand, and should not promote materials that could harm you.

Article 18

Both parents share responsibility for bringing up their children, and should always consider what is best for each child. Governments should help parents by providing services to support them, especially if both parents work.

Article 19

Governments should ensure that children are properly cared for, and protect them from violence, abuse and neglect by their parents or anyone else who looks after them.

Article 20

If you cannot be looked after by your own family, you must be looked after properly, by people who respect your religion, culture and language.

Article 22

If you are a child who has come into a country as a refugee, you should have the same rights as children born in that country.

Article 23

If you have a disability, you should receive special care and support so that you can live a full and independent life.

Article 24

You have the right to good quality health care and to clean water, nutritious food and a clean environment so that you can stay healthy. Rich countries should help poorer countries achieve this.

Article 25

If you are looked after by your local authority rather than your parents, you should have your situation reviewed regularly.

Article 26

The government should provide extra money for the children of families in need.

Article 27

You have a right to a standard of living that is good enough to meet your physical and mental needs. The government should help families who cannot afford to provide this.

Article 39

If you have been neglected or abused, you should receive special help to restore your self-respect.

Article 41

If the laws of a particular country protect you better than the articles of the Convention, then those laws should stay.

UN CONVENTION ON DISABILITY RIGHTS

Article 28

Adequate standard of living and social protection.