

Parkinson's UK submission to the Commission on Funding of Care and Support

Summary

The social care system is chronically underfunded and this manifests itself in many ways, from the pay that the workforce receives, the quality of care delivered, to the needs that remain unmet. Additional funding from government is required to sustain care and support in the future in order to meet the needs of an ageing population. Without this it cannot be assumed that informal carers will be able to maintain their role, that the voluntary sector will be able to provide additional capacity and that the workforce will be willing to perform increasingly complex care work for little reward.

A major concern for people with Parkinson's are the inequalities that people face in accessing and receiving care and support. They have expressed general dissatisfaction with local authority funding decisions and strong support for decisions to be taken at a national level by an independent national body. When we put the tax funded option to people with Parkinson's as well as the three central options in the Big Care Debate in 2009, 57% supported the tax funded option.

We believe a national tax or national insurance funded model of care and support, delivering national entitlements to social care, is the fairest and most appropriate way to address the current postcode lottery in the system. It is a true partnership between individuals and the state and ensures that younger people with long term conditions and disabilities are not penalised because they may not have had the opportunity to set aside money for their care needs. We believe it can meet the principles outlined by the Commission, as well as principles we outline in our response.

For people with long term conditions, such as Parkinson's, integrated care planning, provision and review is essential. Placing health, public health and social care on a tax funded footing could also lead to greater system integration and therefore savings through reduced duplication of separate structures and systems. This could be the opportunity to build a service that operates around the person rather than in silos. It is vital that the value for money that could be generated by a more integrated, tax funded national long term care system is modelled by the Commission.

There is strong evidence that the NHS has gradually drawn back from responsibilities to provide healthcare in the community, leaving many being told theirs is a social care need, rather than healthcare need particularly when applying for NHS Continuing Care. It is vital that the Commission considers whether the social care funding system is to some extent "subsidising" what should be free healthcare. This is important so that funding models are not recommended to pay for care which in fact should be healthcare provided free at the point of delivery.

We do not support the incorporation of disability benefits into the social care funding system. These are much valued by people with Parkinson's and their carers. We also believe the devolved administrations should be free to identify and design their own country based solutions to the funding of long-term care, and not be limited by whatever funding model is proposed in England.

What is sustainable and resilient is subject to political judgements about the relative priorities any government should give to competing claims on limited public funding: what is certain is that service users who themselves pay taxes see this as a priority area for reform and support a tax funded option.

Full response

Parkinson's UK welcomes the opportunity to respond to this important consultation. We have contributed to previous consultations on care and support and this has enabled us to gather the views of people with Parkinson's on how they believe the care and support system should be funded.

About Parkinson's

It is estimated that 120,000 people in the UK have Parkinson's. Parkinson's is a progressive, neurological disorder, with no known cure. Parkinson's affects people from all social and ethnic backgrounds and age groups. The average age of onset of Parkinson's is between 50-60 years of age, though one in seven will be diagnosed before the age of 50 and one in twenty will be diagnosed before the age of 40

The three main physical symptoms associated with Parkinson's are tremor, muscle rigidity and slowness of movement. However not everyone will experience all three. There is also a long list of commonly occurring non-motor symptoms, which may or may not occur at different points throughout the course of Parkinson's, such as pain, sleep problems, depression and dementia. The severity of symptoms can fluctuate, both from day to day and during the course of the day, including rapid changes in functionality such as sudden 'freezing'.

Appropriate health and social care provision is crucial to enabling those affected to manage their symptoms, maintain quality of life and maximise their independence. As the condition progresses and there is a greater impact on daily living activities, this can result in an increased dependency for support and care, either informally or through private, voluntary or statutory care services.

Parkinson's UK position on long term care funding.

Parkinson's UK believes that everyone who needs long term care should get appropriate high quality support. This should be delivered through consistent, fairly funded national care systems that are easy to understand and ensure people with long term conditions and disabilities do not bear the financial burden for their condition. We do not support the incorporation of much valued disability benefits into the social care funding system.

We believe that a national tax or national insurance funded model delivering national entitlements to social care is the fairest and most appropriate way to address the current postcode lottery in the system and bridge the divide with health.

"My father suffers with Parkinson's and my mother is his carer. They have both worked all their lives, always paid tax and NHS contributions. They have never claimed benefits or gained anything from the state. It is only now in their later stages of life that they rely on support and services in the community."

Our preference for a national tax or national insurance funded system is because we believe this model is most likely to meet certain principles. Alternative models proposed may have merits, such as the potential to pay care costs through compulsory insurance or levies on an estate but are less satisfactory in terms of meeting these principles.

Our principles for funding care:

- Additional funding from governments is required to sustain care and support in the future in order to meet the needs of an ageing population.
- There should be national systems in place that guarantee everyone can get the support they need, wherever they live, regardless of ability to pay.
- The systems should share financial risk and ensure that people with long term conditions and disabilities are not penalised.
- The funding systems must be easy to understand – with clear information about how people are expected to contribute and how much.
- Disincentives for people to work and save when they are well should be minimised.
- Attendance Allowance and other disability benefits should remain available as a popular, effective and flexible means of meeting an individual's disability related costs.
- Accommodation costs should be covered by the funding systems in place.

Question 1: Do you agree with the Commission's description of the main challenges and opportunities facing the future funding of care and support?

This is a good summary of the main trends which affect care and support needs.

There is a research note under *changing care needs* which builds into projected demand an unchanged inclination to care amongst informal, unpaid carers. This could be an underestimate, as sociological changes and expectations about quality of life and levels of independence have risen amongst carers, and they may have less propensity to care in the future. Without reform of support systems, including the main benefit to support carers – Carers Allowance - there is additional pressure on the capacity of carers to care.

This also has implications for the workforce, who will need to step in to fill increasing demand or where informal care has broken down. There appears to be an implicit assumption that people will be motivated to fill these roles but the workforce is also a casualty of the underfunding of social care, with roles tending to be low paid and characterised by high turnover.¹

There also appear to be assumptions made on the role of the voluntary sector and its ability to increase the services it provides as part of the Big Society agenda. This is by no means certain in the current environment of cuts to budgets, as reported in a recent survey, which found two thirds of charities in the sector had seen their funding from councils cut.²

Scientific advances should also be listed under *changing social and technological trends* as research into conditions - particularly those associated with ageing - will have a major role to play. Our aim as a charity is to find a cure for Parkinson's and establish treatments that mean people can live their lives symptom free. Investment in research will therefore provide dividends in terms of the challenges listed and reducing care and support needs.

¹ Skills for Care. The State of the Adult Social Care Workforce (2010)

www.skillsforcare.org.uk/research/research_reports/state_of_the_adult_social_care_workforce_reports.aspx

² Community Care, Social care charities feel the pain (12 January 2011)

www.communitycare.co.uk/Articles/2011/01/13/116079/voluntary-sector-cuts-threaten-big-society-vision.htm

Additionally, there is a compelling argument that social care funding should not be seen as a cost to society but that it is a form of social and economic investment that has the potential to deliver better services, whilst also generating significant savings (for example, by freeing up people to contribute as active citizens, rather than relying on the welfare state).³ This could be listed as an opportunity.

Question 2: Do you agree with the Commission's description of the strengths of the current funding system, and its potential shortcomings? Do you think there are any gaps?

Strengths

We agree with building on principles of funding that provide a safety net, that deliver personalised, preventative services, achieved through a partnership approach and which are locally responsive to needs. However we wonder if any of these can be described as strengths of the current system.

For example, in spite of many policy pronouncements on the issue we do not believe prevention is embedded as policy at a national or local level, in practice. The scaling back of eligibility for services to those in critical or substantial need only has been the subject of a number of reports⁴ and runs counter to the preventative agenda.

As the discussion paper notes, the system is responsive to local needs, but there are concerns about the postcode lottery of care. This is a major concern for people with Parkinson's and has been highlighted in our members' survey and the recent All Party Parliamentary Group (APPG) for Parkinson's Disease Inquiry Report.⁵ We are running a national campaign – Fair Care – to address the inequalities that people with Parkinson's face: www.parkinsons.org.uk/faircare.

There has been criticism of local authorities' role in commissioning and whether this creates a flexible and locally responsive market. In our view, the dominant purchasing role that councils exercise can actually constrain consumer choice and limit the ability of suppliers to respond to local needs, for example by failing to stimulate alternatives to residential care.⁶ Certainly commissioning behaviour has been identified over a number of years as leading to a poorly paid, low skilled social care workforce.⁷

The concern is that this is beginning to manifest itself in the personalisation agenda with direct payments and personal budgets seen as a route to cut costs of care.⁸ Not all people with Parkinson's wish to utilise direct payments and personal budgets, and it is important that people are given genuine choice, including the ability to retain traditional services if they wish. This is illustrated by this comment from a carer of a person with Parkinson's:

³ University of Birmingham Health Services Management Centre. The case for social care reform – the wider economic and social benefits (2010) www.hsmc.bham.ac.uk/news/news/2010/2/social-care-reform.shtml

⁴ For example, Care Quality Commission. The State of Health Care and Adult Social Care in England. Key themes and quality of services 2009 (2010) Figure 8, page 35. www.cqc.org.uk/stateofcare.cfm

⁵ All Party Parliamentary Group for Parkinson's Disease. Please mind the gap: Parkinson's disease services today. (2009). www.parkinsons.org.uk/about_us/policy_and_campaigns/1/parliaments_and_assemblies/appg/appg_report.aspx

⁶ Deloitte and Touche, for the Resolution Foundation. Mapping care of older people, analysis of long term care markets. (2009). www.deloitte.com/view/en_GB/uk/industries/government-public-sector/885dd1800c0fb110VgnVCM100000ba42f00aRCRD.htm

⁷ Low Pay Commission, National Minimum Wage. Successive reports refer to the need for government to address commissioning behaviour and its impact on workforce pay and conditions. For example 2009 report, paragraph 3.65. www.lowpay.gov.uk/lowpay/rep_a_p_index.shtml

⁸ See, for example, Radio 4 You and Yours, Charities in social care personal budgets warning (3 December 2010) www.bbc.co.uk/news/uk11909505

"I was told that when my elderly mother came home from hospital that they could not provide two careworkers to assist in getting her up and putting her to bed....one carer could not manage her on their own, therefore she had to go into a home. We had not other choices offered to us (she had advanced Parkinson's disease). There should be a wider range of choice, not ultimatums."

Finally, the discussion paper should add in the strength of partnership between the voluntary sector, as well as the state, private sector and individuals. Whilst unable to quantify the entirety of funding provided by the voluntary sector, within Parkinson's UK alone we offer support through our Mali Jenkins Help Fund, which distributed £90,000 in 2010, enabling people with Parkinson's to purchase home adaptations, aids, and respite breaks for themselves and/or their carer. We also provide comprehensive information, advice and support through our helpline and network of Information and Support Workers who provide crucial support for people with Parkinson's within their local areas. Our work is replicated by small and large charities across the country.

The voluntary sector will continue to be a crucial partner in care funding delivery, often meeting shortcomings in state delivery, and should not be omitted, although as previously noted it will also face challenges in how to secure the funding it needs.

Shortcomings

An overarching issue is the current chronic underfunding of social care. It is this that is at the root of all the shortcomings listed, and manifests itself in many ways, from the pay that the workforce receives, the quality of care delivered, to the needs that remain unmet.

We believe that for people with Parkinson's fairness means having appropriate access to the good quality care wherever you live. As already noted such postcode inequalities are a major concern for people with Parkinson's and a focus of our campaigns work.

When we surveyed people with Parkinson's for the "Big Care Debate" in 2009, the majority of respondents (93%) said they wanted to see a fairer system of funding. We also found that there was general dissatisfaction with local authority funding decisions and strong support for decisions to be taken at a national level. Just twelve per cent believed that decisions about how much money should be spent on care should be decided by local government, with twenty three per cent favouring national government and sixty five per cent favouring an independent national body.

In our view some of the shortcomings of social care funding described by the Commission are also a manifestation of what has been a gradual redrawing of the boundaries between health and social care. This:

- leaves many people with complex health needs bearing the financial consequences of a means tested system and being cared for in a social care system which lacks the resources or staffing to manage those needs;
- places added pressure on informal carers, many of whom are effectively providing nursing care at home for people with very complex healthcare needs. People with Parkinson's can have particularly complex and time dependent medication regimes that are essential in controlling symptoms and may rely on their carer to help them manage this.

- places added pressure on local authorities that can no longer afford to offer preventative services as they concentrate on those with the most "critical" needs only, leading to unmet need or cuts to packages of care. A recent example has been Birmingham City Council's proposals to provide services for those with "super critical" needs only⁹ and the McDonald case where a package of overnight care was cut to the supply of night-time incontinence pads, despite the assessed needs of the person.¹⁰
- is unfair to the public, as it is often stated that they "don't understand what social care is", even though the goalposts have in reality shifted.

We have evidence from people with Parkinson's that their complex health needs are being deemed to be social care needs, and then means tested accordingly, particularly in the area of NHS continuing care. To quote one carer for a person with Parkinson's:

"I was stunned when they withdrew her continuing care after over four years. Despite having a degenerative condition, being under seven specialists, and in need of special equipment and nursing, I was told as a parting shot at the Tribunal that the more ill you become it is sometimes harder to qualify for continuing healthcare because the risks may be less. The PCT will not let anyone get in the way of protecting their budget."

The problem of NHS Continuing Care was recently highlighted by Stephen Dorrell MP, the chair of the Health Select Committee in an interview with the BBC¹¹:

"People are being charged for care that they would have got free from the NHS 20 or 30 years ago.

In effect there has been a change in the definition of what constitutes NHS care and that has happened without proper debate.

Unfortunately, it has been ignored because both politically and financially it is tricky for politicians to face up to it. But because it has not been done in a planned way there is great unfairness in the system. We see examples of cost shunting and bureaucracy that cause individuals problems."

Other practitioners have attributed the problems with continuing care to the NHS effectively "rebranding" its legal obligations to acute care only. Professor Luke Clements¹² has said:

"Individuals have expected the NHS to respond on the basis of the person's need for healthcare, whereas institutionally the NHS has sought to limit its responsibility for providing NHS care, to care in a hospital setting and to argue that other forms of care (for example care provided in community and domiciliary settings) is the responsibility of the social services means tested system.

⁹ Community Care. Birmingham's super critical threshold slammed as "cruel". 2 December 2010. www.communitycare.co.uk/Articles/2010/12/02/115939/storm-of-protest-greets-birminghams-super-critical-threshold.htm

¹⁰ Disability Law Service report. Court's decision could open door to more council cuts. 8 November 2010. www.dls.org.uk/Rights/News/2010/november/9.html

¹¹ BBC news. Vulnerable elderly forced to pay for their medical care. 29 September 2010. www.bbc.co.uk/news/health-11429779

¹² Pre-publication draft, available on Luke Clements website. Clements, L. Journal of Social Care and Neurodisability Volume 1 Issue 1 pp39 - 47 (2010) www.lukeclements.co.uk/downloads/NHS_Funding_for_CC_revised_Guidance.pdf

Accordingly, as it has become acceptable and feasible to care for all but the most acutely ill, in non- hospital settings, the NHS has admitted responsibility for fewer and fewer patients, The NHS has therefore redefined its role. It's raison d'etre is not to care for ill people but rather to care for certain limited categories of ill people, particularly, acutely ill people.”

The article goes on to discuss the inadequacies of the current Department of Health guidance on NHS Continuing Care and its failure to adequately reflect the law, particularly the definitive judgement in the Coughlan case, which set the boundary at which local authorities could provide nursing care.¹³

It is vital that the Commission considers whether the social care funding system is to some extent “subsidising” what should be free healthcare due to a gradual scaling back of boundaries. This is important so that funding models are not recommended to pay for care which in fact should be healthcare delivered free at the point of delivery.

Question 3: Given the problem we have articulated what are your suggestions for how the funding system should be reformed? How would these suggestions perform against our criteria that any system should be sustainable and resilient, fair, offer value for money, be easy to use and understand and offer choice? Please take into account the impact that your suggestions will have on different groups.

We believe that a national tax or national insurance funded model delivering national entitlements to social care is the fairest and most appropriate way to address the current shortcomings in the system. It lends itself to creating a much more integrated and comprehensive system for long term care that bridges the divide with health and helps deal with the shortcomings and the bureaucracy in the system. It is a true partnership between individuals and the state.

We are not in a position to provide economic analysis and modelling of the various options but we have put the case of funding reform to people with Parkinson's during consultations, for example during the Big Care Debate in 2009 in England. During that debate there was criticism that the tax-funded option was not open for debate, of the paucity of modelling of the three central options and that a more generous partnership option had not been considered.

When we put the tax funded option to people with Parkinson's as well as the three central options, 57% supported the tax funded option.

Of the three options on the "table" during the Big Care Debate, people with Parkinson's expressed the view that:

- The partnership option would still leave people facing huge accumulated costs. People with a long term condition such as Parkinson's can face many years of care costs, including possible residential care in the latter stages of the condition. It also did not include accommodation costs and lacked clarity as to which level of care related costs it would meet. Therefore only 9% of people favoured this option.

¹³ The Judgment of R v North & East Devon Health Authority ex Parte Coughlan, July 1999 can be read at www.bailii.org/ew/cases/EWCA/Civ/1999/1871.html

- People with pre-existing conditions such as Parkinson's stated that they would find it difficult to obtain insurance through a voluntary insurance model. One in four of the 13,000 respondents to our 2008 members' survey reported that they have had a problem obtaining or claiming insurance. Therefore only 13% of those surveyed favoured this model.
- The comprehensive model was by far the most popular of the three options proposed at the time, favoured by twenty two per cent of those surveyed. However several commented that it was confusing that the comprehensive model referred to all care costs being met by the National Care Service, whereas in reality people would still be faced by a high level of residential accommodation costs.

The majority of respondents were also opposed to accommodation costs in residential care not being covered by the National Care Service. 78% felt that accommodation costs must be included in the modelling.

Attendance Allowance and other disability benefits are seen as an effective, flexible and popular means of meeting an individual's disability related costs, such as laundry, transport and heating costs. For the purposes of the Big Care Debate, we asked people with Parkinson's how they felt about the prospect of Attendance Allowance being subsumed into social care funding. Of those surveyed:

- 62% stated that Attendance Allowance should not be abolished under any circumstances. Only five per cent would be happy for it to be abolished and incorporated into the funding of a National Care Service
- 7% would be happy to see a reduction in Attendance Allowance if the majority of their care needs were met by a National Care Service
- 26% would support the abolition of Attendance Allowance if all their care costs were met by a National Care Service.

Tax/national insurance funded option

Sustainable and resilient

Recent King's Fund modelling¹⁴ suggests a tax funded model that delivered a benchmark of free personal care (but not accommodation costs) would require an extra £3.5 billion a year from 2015 in annual expenditure, but concludes that all models of delivering better care to more people will essentially cost more. For example, a revised partnership model of 50% contribution by state and 50% contribution by the individual could still require an extra £2.5 billion a year from the state from 2015.

What is sustainable and resilient is subject to political judgements about the relative priorities any government should give to competing claims on limited public funding: what is certain is that service users who themselves pay taxes, see this as a priority area for reform and support a tax funded option. This is evidenced from our own work with people with Parkinson's, from independent research with service users¹⁵ and from evidence to previous inquiries, such as the Health Committee inquiry in 2010.¹⁶

¹⁴ King's Fund. Securing good care for more people (2010).
www.kingsfund.org.uk/publications/securing_good_care.html

¹⁵ Joseph Rowntree Foundation. Funding social care, what service users say. (2010)
www.jrf.org.uk/publications/funding-social-care

¹⁶ Health Select Committee. Third Report Social Care. Paragraph (2010). Paragraph 237.
www.publications.parliament.uk/pa/cm200910/cmselect/cmhealth/22/2209.htm#a60

Placing health, public health and social care on a tax funded footing could also lead to greater system integration and therefore savings through reduced duplication of separate structures and systems. This would be the opportunity to build a service that operates around the person rather than in silos. As far as we are aware, the value for money that could be generated by a more integrated, tax funded national long term care system has not been modelled into the estimated costings for free personal care.

“There are ongoing battles between services as to who pay for what and who is responsible for what! The needs of the person become lost to bureaucracy.”

Fairness

This option shares financial risk and ensures that younger people with long term conditions and disabilities are not penalised because they may not have had the opportunity to set aside money for their care needs. Those without any means to fund or provide their own care are enabled to access appropriate support. Options such as partnership, insurance and comprehensive models all have elements of means testing and distinguish between working age and older age contributors: these approaches are often seen as unfair.

“The big problem facing younger people with Parkinson’s and their carers is that most are living in relative poverty through having to give up work at a young age and aren’t able to save for their pension, let alone their care needs.”

Choice

In terms of delivering an affordable choice of services, and helping people plan for their future, we believe this option is preferable to other options, such as insurance, which risk a two-tier system in which some people can afford contributions and some cannot.

We note that in submissions to the Big Care Debate, some representative associations of providers of services supported the tax funded option as a way of ensuring security of demand for the services they supply, and would allow them to plan coherently for delivery. Other options make it harder for providers to forecast how the public will respond in terms of insurance or contributions they are willing to make. This may reduce choice.

Value for money

In one local study, the Nuffield Trust estimated that 90% of people who received social care also received secondary health care over a three year period¹⁷ which indicates significant overlap and duplication occurs. The last decade has seen a move towards integrated approaches in both structures and budgets, which are proving there can be savings in money and better outcomes for people.¹⁸

¹⁷ Local study cited in Care Quality Commission. State of Health and Social Care (2010). Page 47.
www.cqc.org.uk/db/documents/CQC_Complete_2009_18.pdf

¹⁸ For example see the Total Place pilot in Bournemouth, Dorset and Poole which concluded a £10 million saving could be made across the subregion by investment in community services and using place based budgets
www.dorsetforyou.com/media.jsp?mediaid=143386&filetype=pdf

As previously noted, we believe a tax funded option could best lead to a more integrated national system of health and social care and potentially save costs through the reduction of duplication, through reduced likelihood of appeals or disputes between which "system" may be responsible for the person and through overall better outcomes that could be delivered for the person.¹⁹ For people with long-term conditions, such as Parkinson's, integrated care planning and review is essential. This is one of the goals of the National Service Framework for Long Term Neurological Conditions.

Ease of use and understanding

The tax funded model for social care provides parity with health and public health - both tax funded systems that this government has "protected" and in the case of public health, provided ringfenced funding for nationally. Both are also free at the point of delivery.

By removing means testing, there is also less of a disincentive for people to work and save when they are well. There is also the issue of trust and certainty about future needs being met: requests or expectations for contributions are more likely to be acceptable for the public if there is some form of guarantee from the state. Again we believe the tax funded system is of all the options, the most understood and acceptable way of providing that guarantee.

Evidence of unmet need

The Commission has also asked for evidence to supplement limited data in a number of areas, including measurement of unmet need. Through a Care and Support Alliance survey in 2010 there has been some initial analysis of cutbacks and the impact this has on unmet need. Parkinson's UK is part of the Alliance and we understand that this evidence will be submitted by the Care and Alliance to the Commission shortly.

Unmet need was also a feature of our own comprehensive survey of members in 2008.²⁰ This found, for example, that of the 26% of people with Parkinson's who needed personal care services, such as help with dressing or bathing, nearly one in five of these (19%) were not receiving this support. 11% of carers were receiving support from social services, a fall from 16% in the 1997 survey. And seven out of ten carers were not aware of their right to a carer's assessment.

In addition, one in ten respondents said that their home was unsuitable to live in, because it needed adaptations or because of steps or stairs. Of those who purchased the equipment they needed to live at home, many did so without professional advice, for example 49% of those purchasing bathroom aids and 43% of those installing ramps or rails outside their house.

It does not help that assessment criteria often do not currently include sufficient requirement to take account of the long-term impact of a condition. We have heard of instances of people with Parkinson's who found that their file had been marked as closed after the provision of an initial service, such as a one-off respite break or installation of a piece of equipment.

¹⁹ Audit Commission. Under Pressure: tackling the financial challenge for councils of an ageing population (2010) www.audit-commission.gov.uk/nationalstudies/localgov/underpressure/Pages/default.aspx

²⁰ Parkinson's UK. Life with Parkinson's today - room for improvement (2008) www.parkinsons.org.uk/about_us/results_of_the_members_survey.aspx

We are also aware of modelling undertaken on behalf of Age UK²¹, and the report by CSCI on the state of social care in 2007 which attempted to estimate levels of unmet need and found there were at least 450,000 older people, who self-fund or fail to meet tightening eligibility criteria.²²

Implications for the Devolved Administrations

The Commission has also asked for submissions to consider the impact of suggestions on the Devolved Administrations.

We also gained the views of members in Wales in a 2010 consultation on paying for care in Wales, run by the Welsh Assembly Government. Here it was clear that members shared the views of people in England in terms of favouring the tax funded option. In Wales, there are moves towards reform of the social care charging system, to make it more equitable and limit the variations in charges, although further reform is needed.²³

In Scotland, the free personal care option has already been adopted. The conclusion of the Independent Review²⁴ of the policy by Lord Sutherland found that despite some practical difficulties *“the Free Personal & Nursing Care policy remains popular and has worked well in the largest part, delivering better outcomes for Scotland's older people.”* In Northern Ireland, the structures for delivery of health and social care are integrated, although not the funding system.

We urge the Commission to ensure that its recommendations leave the devolved administrations free to identify and design their own country based solutions to the funding of long-term care. For example, we note the complications that arose following the decision by the UK Government to cease making payments of Attendance Allowance for residents in care homes in receipt of Free Personal and Nursing Care in Scotland.

We hope that our submission is of interest and value to the Commission, and look forward to seeing the recommendations for reform.

Yours sincerely,



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²¹ PSSRU Discussion paper 2723. The impact of a tightening fiscal situation on social care for older people (2010). www.pssru.ac.uk/pdf/dp2723.pdf

²² CSCI. State of Social Care 2006-7 (2008). Not available on web since CSCI was disbanded.

²³ National Assembly for Wales. Social care charges (Wales) measure (2010) <http://wales.gov.uk/legislation/programme/assemblymeasures/socialcarecharges/?jsessionid=JNnDMNssqydrTkjtrzGKGKKTCT1PB0QT8vPhZbXcL5Mct6Xch20!82924164?lang=en>

²⁴ Independent Review of Free Personal and Free Nursing Care in Scotland (2008). www.scotland.gov.uk/Publications/2008/04/25105036/0