‘Would you have sandwiches for your tea every night?’

Older people’s views of social care in Northern Ireland

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Contents

- Executive Summary 3
- Background 7
- Key Findings 9
- Conclusions and Recommendations 21

Acknowledgement

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1. **Executive Summary**

1.1 **Introduction and Background**

Age NI appointed the Social Research Centre (SRC) in February 2011 to carry out a research project in relation to social care.

1.2 **Aim of the Project**

The aim of the project was to consult directly with older people to ascertain their views on all aspects of social care and report on the main findings.

1.3 **Summary of Methodology**

SRC worked in partnership with Age NI staff and Peer Facilitators to recruit for and run three focus groups across NI. The focus groups were held in Belfast, Cookstown and Irvinestown. In total, twenty four older people attended the focus groups – two thirds male and one third female. All participants were over the age of 65 with just over half in the 75 to 84 age group. More than half of the participants were in receipt of social care services. The focus groups took place in April and May 2011.

1.4 **Key Findings**

**General Points**

A number of general points emerged from the focus group discussions:

- Clients who do not need the service are unlikely to ask for it
- There is a significant psychological adjustment from ‘personhood’ to ‘patient’ when a client accepts social care services
- The issue of finance is not disconnected from dignity
- There is a perception that there are sufficient funds to provide social care within ‘the system’ overall
- The particular need to support the carer, especially a long term carer was identified
- There was an acute awareness of the demographic changes and the need to plan for the growing needs of an ageing population.
Positive Experiences

- There was appreciation for the existence of a social care service, and a number of the participants reported specific positive experiences of social care including help with laundry, ironing, cleaning, shopping, meals and personal care.

Concerns about the Current Arrangements

There was widespread concern about several aspects of the current arrangements. The specific points raised have been grouped under five themes:

- Entitlement, Eligibility and Limitations
- Quality of Care
- Workforce Issues
- Carers and Family Support; and
- Finances.

1.5 Conclusions and Recommendations

The older people who participated in these focus groups gave their direct and indirect experiences of social care – from the point of access to actual provision and everything else in between. These views and experiences are valid and point to a system of social care that does not necessarily meet the social care needs – either physically or emotionally of the people it is meant to.

This is not to deny that a number of participants reported positive experiences of social care, but the discussion was dominated by the frustrations and a sense that social care was simply a set of tasks done to older people and their carers. However, despite this the participants highlighted and recommended how the service could improve.

These recommendations, collectively called for a radical re-examination of how clients are assessed and, subsequently, how the service is delivered and monitored.

Finally, there was a belief that with better service design, taking account of the actual needs of older people, and a recognition of the realities for older people receiving care (or not as the case may be), social care could be transformative and promote independence, choice and dignity for older people now and in the future.
Entitlement, Services and Limitations

Entitlements
- Provide clear and easily accessible information on what people are entitled to and the eligibility criteria surrounding care
- The service should be appropriately managed and all decisions about service provision should be made in an open, honest and transparent manner
- Make the decision in a way that ensures the person making the decision has actually seen the client for themselves
- Work in a collaborative fashion with others providing social care in local areas so that each party acts as an active sign post to other services
- Make it easy for people to find out what is available and who does what
- Provide copies of the care plan promptly and pro-actively.

Services
- Allow the client to select and decide which services are most meaningful for them
- Ensure that services are available at (and delivered at) the times that suit the client
- The quality of social care needs to be actively monitored to ensure that non-compliance is highlighted promptly.

Limitations
- Be realistic about the time that is actually required for social care, including travel time
- Ensure that the same process of assessment is used irrespective of the context i.e. in hospital or out
- Provide clients with more social care time
- Ensure that adequate numbers of qualified staff are available to interact with clients and their families at all times
- Ensure that clients have contact numbers and names for support.

Quality of Care
- Ensure that the values of compassion, empathy, dignity and respect feature prominently in the training of all social care staff and in the conduct of their duties
- Ensure that care staff are aware that the execution of duties alone is not enough - the duties need to be undertaken so that the core values are evident
- Do not permit social care staff to use their own discretion about when and when not to provide any aspects of a care package
- Use a variety of means to actively check the extent to which clients are satisfied or dissatisfied with the service
- Ensure that there are clear guidelines about the need to protect client confidentiality.
Workforce Issues
- Attract more people into social care
- Match social care staffing levels to level of need
- Provide continuity of relationships and ensure that the same social care worker provides the services required to specific clients.

Carers and Family Support
- Do not make assumptions about what level of support a client may or may not have
- If a client indicates that family support is not available, this should be respected and responded to accordingly
- A package should consider what support / respite care is needed for long term carers to sustain them in delivering care
- Sustaining the carers’ capacity to maintain social interaction is an important part of this.

Finances
- Centre first on the needs of the person and not on the finances
- Provide a service which is based on needs and not means-tested
- Unused funding from one Department should be moved to meet needs elsewhere (e.g. health and social care).
2. **Background**

2.1 **Introduction**

Age NI is the new, independent charity for older people in Northern Ireland. Its vision is to ‘create a world in which older people flourish’ and its mission is ‘to enhance and improve the lives of older people.’ It is against this backdrop that its strategic policy agenda has been set with a focus on a rights-based and citizenship focused model. Thus the policy direction of health and social care policy agenda is to ensure that rights are at the core of its work in this area.

This research project is part of a project within Age NI to fundamentally review social care to improve outcomes for older people to ensure that independence, dignity and choice are the cornerstones of our social care system.

Age NI has undertaken this project on a vision for social care to go back to basic principles – what is it that we want social care to deliver? An interim paper has been drawn up, *Independence, Dignity and Choice: The Provision of Social Care in Northern Ireland* (2010), and we have been holding listening events across Northern Ireland with older people on their vision for social care. Through our Peer Facilitator Listening Programme, we have also begun to capture older people’s views on the provision of social care. We plan to publish a paper on a Vision for Social Care in September 2011 in order to influence the direction of social care in Northern Ireland.

2.2 **Context**

Age NI believes that dignity, independence and choice should be at the heart of the social care system in Northern Ireland. For older people who need care this means being treated with respect and getting the care that meets their needs. It means having the same choice as anyone else about where and how they live. Trust is a major component of this as older people need to trust that they will be treated fairly and equally; trust that the care they receive is safe and of good quality; trust that they will get clear information and advice; and that those who care for relatives or friends are supported to do so.

Evidence from our advice and advocacy services, would suggest that for many older people and their carers in Northern Ireland this is not the case.

Government’s policy enabling older people to remain in their own homes is a positive step and what older people want for themselves. In *People First: Community Care in Northern Ireland for the 1990s*, there is no one standard definition of social care. It is a range of services and support including every day tasks such as cooking and shopping as well as personal care. Whatever the service, it must support the person with dignity and enable them to live their life independently and in the way that they choose. This equally applies

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1 DHSSPS (1993) *People First Community Care in Northern Ireland in the 1990s*
2 Help the Aged (2007) *The Challenge of Dignity in Care: upholding the rights of the individual*
to those who need and want care in a communal setting, either supported housing or a care home.

The Joseph Rowntree Foundation in its report, *Identifying a Fairer System for Funding Adult Social Care*, (2009) have argued that although previous reviews of adult social care have acknowledged the importance of fairness in assessing different models of care, funding has been given greater prominence in these reviews.

2.3 Future developments in Social Care in Great Britain

There have been numerous attempts in Great Britain to establish a framework for the funding and provision of social care services. The Royal Commission on Long Term Care 1999\(^3\); the Wanless Review in 2002\(^4\); and Shaping the Future of Care Together, (2009) have all suggested reforms in the area of social care.\(^5\) Parallel to these initiatives in GB, Appleby\(^6\) in 2005 carried out a review of health and social care services in Northern Ireland. More recently we have seen the Coalition Government establish the Commission on the Funding of Long Term Care and Support (Dilnot Review), as well as consulting on a vision for social care. In addition, the Law Commission is undertaking work on the reform of the law surrounding adult social care in England and Wales with a view to developing an effective legal framework that can accommodate current and future policies on adult social care. They are proposing a unified modern adult social care statute to ensure that practitioners and individuals understand their obligations and entitlements. These current initiatives will form the framework for the direction of social care in England and Wales with a White Paper expected in the second session of Parliament.

2.4 The position in Northern Ireland

Age NI is concerned by the lack of coherent policy direction for social care in Northern Ireland, demonstrated by the fact that we are still relying on *People First* from 1993 to determine the provision of social care. ‘People First’ was not designed to cope with the increasing numbers with dementia, to meet the current trends and there is no focus on social care as a preventative tool. The Dilnot Review is likely to impact on the provision of social care in Northern Ireland through the incorporation of tax and benefits in the funding allocation. Funding is an issue, but it is not the only determinant of social care. Age NI is calling for a fundamental review of social care as it is important that we actively shape the future of the social care system in Northern Ireland, rather than defaulting to the position in GB.

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3 *Long Term Care – Rights and Responsibilities*, Royal Commission on Long Term Care (1999) HMSO
3. Key Findings

3.1 Key Themes

The discussion schedule focused on two fundamental aspects:

- **Views and experiences of the present arrangements for Social Care in NI**
  - The positive experiences participants have had of social care
  - Their concerns about the current provision of social care in NI including their views on the issues that affect the provision of social care.

- **Their vision for a future Social Care system for NI**
  - Their views on what would good care ‘look like’?
  - Their proposals for improving the provision of social care.

3.2 Analysis of the focus groups

In reality, the above themes are closely inter-related. Therefore, understandably, participants often commented on more than one theme at a time i.e. a comment which started by highlighting a concern led, in many cases, to suggestions about what would improve social care, which in turn, implicitly articulated the vision that the participant had of future social care. In the same way, a comment which started by describing what ‘good’ social care looks like (the ‘vision’), was often accompanied by a contrasting description of the existing arrangements which implicitly highlighted participants’ concerns. Consequently, in the section below we have summarised the feedback as a collective which leads with:

- The positive experiences participants reported of social care, followed by,
- Their areas of concern, and allied to these
- Their views what makes ‘good’ social care and the specific changes that they consider are needed to improve social care provision going forward.
3.3 Findings from the focus groups

General points

A number of general points emerged from the focus group discussions:

Clients who do not need the service are unlikely to ask for it. The scarcity of social care was well recognised across the groups. For some, the way in which clients were required to justify their need for the service led some to perceive that Social Services seem to assume that some people are simply trying to maximise what they can get from ‘the system’ - as if, in some way, having social care services provided was a luxury, something to be attained irrespective of need. The feedback from those consulted appears to refute this unequivocally. Indeed, linked in with issues such as dignity and independence, it seemed that participants who could manage things for themselves would actively prefer not to have social care services provision. As one person put it, ‘If you were able [to do things for yourself], would you want it [social care services]?’ The answer was a resolute ‘no’!

There is a significant psychological adjustment from ‘personhood’ to ‘patient’ when a client accepts social care services. This adjustment may be one that, in favourable conditions, returns personhood. However, for some, there is a distinct possibility that it will not. This risk to personhood is a further reason why those who do not need it are unlikely to ask for it. However, there appears to be a lack of understanding and empathy on the part of those delivering the service of the considerable psychological energy required on the part of someone, who was previously fully independent, to make this ‘internal’ adjustment, ‘I worked away and tried to help myself… you have to open yourself out to allow somebody into the house to do something for you… I was never used to anybody showering me.’

The issue of finance is not disconnected from dignity – There was a general sense in the feedback from those consulted that reducing their needs to a discussion that focused heavily on ‘pounds and pence’ in some way ‘converted’ their ‘worth’ (albeit perhaps unintentionally) into a wholly inappropriate and demeaning currency, ‘We’re made to feel like beggars.’

A belief that there is sufficient funds to provide social care within ‘the system’ overall - Participants considered that with better service design, greater efficiencies and sharing of funding across departments, there could be considerably more funding available for social care than there is currently.
The need to support the carer, especially a long term carer was identified – The risk of exhaustion and burn-out were noted and need to be prioritised in future arrangements.

There was an acute awareness of the demographic changes and the need to plan for the growing needs of an ageing population – As one participant put it, ‘If we don’t speak out now, in five, ten years time, it’s going to be worse’.

3.4 Views and experiences of the present arrangements

Positive experiences

There was appreciation for the existence of a social care service, and a number of the participants reported specific positive experiences of social care. These included help with:

- **Ironing** – This was especially helpful to a participant with a ‘bad back’ so much so that the participant paid for this service.

- **Laundry and cleaning around the home** – Again, this was helpful to a participant who because of their particular medical problems was unable to do this for themselves.

- **Shopping** – ‘Helping me with the shopping… carrying things… I have this ‘walker’ [rollater]… [because I need to hold on to the walker] a basket is no good to me… they [social care worker] can carry shopping… they can reach and carry.’

- **Provision of aids and appliances** – ‘[Person needing social care] got a gate made for the stairs… got an alarm [in case of a fall]… it was unbelievable… couldn’t have done more… got names of people in Age NI… really was excellent.’

- **Showering / meals** – One participant, who found it difficult to bend, explained that help with showering had been especially beneficial in their case. Another reported having received support with showering, breakfasts and getting back into bed during a 14 day period following eye surgery. This was enormously helpful at a time when the participant was physically unable to perform these tasks independently.

- **Meals after coming home from hospital** – One participant received meals and help four times a day for a year after surgery. This has been indispensable when they were unable to prepare meals etc for themselves during that period.
3.5 Concerns about current arrangements

There was widespread concern about several aspects of the current arrangements. These are listed below alongside participants’ perception of what ‘good’ social care looks like i.e. what they would like to see provided in future. The specific points raised have been grouped under five themes:

- Entitlement, Services and Limitations
- Quality of Care
- Workforce Issues
- Carers and Family Support
- Finances

Entitlement, services and limitations

Participants in the focus groups outlined a number of issues in relation to entitlements, services and limitations of social care. These themes, as will be seen, elicited many comments and highlights the sense of frustration that older people experience when they or their family members access and receive social care.

Entitlements

‘People don’t know what they are entitled to.’ This is a particular difficulty in terms of clients being able to ask for services that they may need or to challenge the ‘package’, if services they are entitled to are left out. This is linked to the notion that offers of social care provision are governed by ‘rules’ best known to Social Services. This becomes an issue when a client unwittingly omits to mention something (or perhaps they had not been specifically asked) that results in a material reduction in the type and/or level of care they are offered. One person described how they missed out for months on services, because their lack of family support was not picked up. This participant reported that the social services representative later said, i.e. long after the original assessment, ‘If I’d known you had no family help, then we could have done something’.
How decisions are made on who needs what

As indicated above, there was a general concern about the lack of clarity regarding the eligibility criteria for social care.

Compounding this was frustration where a social worker had indicated to a client that the latter needed, and would receive, certain aspects of social care (which the client needed and valued). However, this ‘promise’ was later revoked when the social worker had to explain to the client that their assessment had been overturned by a more senior member of staff – who – it was said - had never met the client. As participants saw it, the person making the assessment, the one there in front of the client, seeing the level of need, their assessment should prevail. In their view, it should not be the case that an assessment decision can be overturned by someone who has not assessed the client in the same way.

A further concern was the length and perceived complexity of the forms that had to be completed in order to be considered for social care services. ‘When you see a 20 page form … off putting right away… too complicated… sometimes the way they [Social Services] ask the question… feel like ‘trick’ questions… like they are trying to catch you out [insinuating that the person completing the form was cheating].’

Lack of awareness regarding what is available and who provides it

There was a particular issue raised about the lack of awareness about the ‘out of hours’ arrangements and who clients were supposed to contact if they needed help at weekends. It seems the contact numbers and locations are different from the weekday service and the onus appeared to be on the client to find these for them. As one person put it, ‘You can only be ill Monday to Friday’.

There were frequent references to the existence of a great variety of ‘agencies’ that offered social care services. However, trying to find out who offers what appeared to be problematic because there was no single, central, easily accessible source of such information.

There was also evidence that undue responsibility was being placed on clients to source information and services when it was already clear they were in the least able position to do so. For example, one participant rang on a Saturday for further support to be told that they had to ‘ring the out of hours service’. However, no contact details were provided and the participant had to find these out. Moreover, the questions were asked, ‘Why did the person who answered the call either not provide the contact details for the out of hours service or, better still, call the out of hours service on behalf of the client and get out of hours to get in touch with the client?’
It seemed too, that efforts to access information often started when a crisis point had been reached. Hence, the importance of raising awareness and promoting ease of access to relevant information and contacts becomes especially important.

Not being told what the ‘package’ actually is

One participant indicated that after two years of persistently requesting written details of their ‘package’ from Social Services, they had still not received details despite its being ‘promised’ these on a number of occasions, ‘You [the client] should have [be given] this list of what you are getting… they [Social Services] told us they would send it… it never arrived’.

Services

Limited ‘scope’ of services and mismatch of services offered relative to practical needs and the seeming inflexibility of the service package

There were repeated references to the limited range of social care services that were currently available (particularly in relation to what used to be provided), ‘I have heard different people say that the home helps, there are certain things they will not do’. Participants questioned why only certain social care services were being offered (e.g. personal care). They believe that for some, other services which it seemed to them be easy to provide (e.g. cleaning the home), would have been more beneficial. But these services were not being offered. There was a preference amongst those consulted for more ‘practical help’ cleaning floors, changing beds, ‘It’s nearly impossible to get the duvet changed’.

A number of participants referred to the unsuitability and inflexibility in terms of when the service was offered, ‘I was allowed 6 and a half hours in the week… anything over and above that I would have to pay [for] myself… [the rate is over £8/hr]… I opted for direct payment [social services send me a cheque for the monetary equivalent of 6.5 hours] because they [the carers that were on offer from social services] were not able to come when it suited me… in the mornings… I get in my own carers and I have to send them [social services] a timesheet at the end of the month… [to show what care has been delivered]’.

There was a concern about the seeming reductionist and somewhat mechanical approach now being taken to social care delivery, a sense that the service need only concern itself with the execution of ‘tasks’. The link between ‘tasks’ and ‘personhood’ seemed to have been ‘lost along the way’. There was a clear reminder from one of the participants that any social care service is much more than simply ‘tasks’ and the style of delivery - with compassion and empathy built in – needs to fully reflect this. They summed this up in these words, ‘[Social Care Services should…] do for the person what they [as people] would do [or like to have done for] their own mother… it’s more than just a job’.
Too much onus on the cared for person to alert social services if something is wrong

There was a sense throughout the discussions that whilst, technically, a client could complain to Social Services if the service delivered was not satisfactory, there was too much onus placed on the client (typically a vulnerable person with limited physical and emotional capacity) to draw this to the attention of Social Services. In other words, the onus appeared to be on the client to ‘whistle blow’ rather than on the service provider to ‘protect’. Moreover, there was evidence within each of the focus groups that certain clients had put up with poor service from Social Service for months and years and the effort of doing this had contributed to a material degradation in their own health and well-being.

Limitations

Lack of time available for each client

There was almost unanimous view that the actual amount of time that social care staff were permitted to undertake specific tasks was unrealistic and unworkable, ‘The girls [social care staff] are curtailed into certain hours… how could they do all these things?… [in the time allowed]… it can’t be done’. It was felt that this issue was likely to impact more so in rural communities where the physical distances between individual clients was greater, ‘It’s not sensible in country areas… travelling distances’. Participants questioned why and how those planning the work schedules seemed to consider that this way of working was physically possible - to participants, it seemed physically impossible for staff to perform the duties specified and travel from one client to another in the time allocated. There was a perception that if (a) each social care worker had fewer clients (smaller caseload) and (b) the logistics were planned more efficiently that time and money could be freed up e.g. from travelling to actually provide more time and service to each client.

Difficulty getting through to anyone in social services who can help

It was unclear to what extent this was linked to (a) participants’ not knowing their way around the social service ‘system’ and knowing who to ask for or (b) the relevant personnel not being available when needed and/or (c) the key people not getting back to a client after a request has been made. Whatever the reason(s), the reality for some participants was that they spent considerable amounts of time trying to phone Social Services but found, ‘You can’t get talking to anyone’. We also heard about experiences in which participants had tried on different occasions to get an issue resolved only to find that they ‘never get [got through to] the same person’ and their whole situation had to be explained again.

In one of the focus groups, participants described how, in their area, there had been a ‘backlog’ of people waiting to receive social care services but had been told there was ‘no money’ for such services. However, it transpired that
personnel from England were appointed to ‘sort out’ the backlog and suddenly funds were available. Participants wondered how it had come about that (a) a backlog of such a scale (requiring outside intervention) had arisen and (b) funds were suddenly available when previously they had been told there was no money and (c) why had it taken staff from England to ‘sort’ things out.

The complexity of trying to set up arrangements from home after a hospital admission

There was a view that it was ‘too difficult to setup [a social care package] once you’re outside hospital’. It seemed that somehow, once a person was outside of the hospital context, the more difficult it was to convince the authorities concerned of your need. Allied to this some participants indicated that whilst they had had social care packages set up when they were in hospital (to assist them on their return to home), such packages ‘get reduced… almost immediately’ (i.e. upon their return home). There was a perception that the basis upon which the original package had been compiled was inaccurate and a suspicion that, ‘They [social care providers] would promise you anything’ (as a way of getting people out of hospital) only to reduce it later despite the fact that the client still perceives themselves to be in need.

3.6 Quality of care services

Participants noted that the quality of care provided was not what they expected and quite poor in some instances. There was a perception that senior decision makers and managers in Social Services did not fully appreciate the daily realities and challenges facing some people needing social care. Participants suggested that, ‘The Head of the [Health and Social Care] Trusts need to come out and see what it’s like in these homes’, ‘We need to be listened to’.

Three issues emerge in relation to the poor standard of service provided. Firstly, there was concern about the actual nature of the service. It appeared that the methods of service delivery centred more on what was convenient and expedient for the service provider rather than the needs of the older person. The following quotes from participants reflect this issue:

One participant invited social care managers to reflect on this question, ‘Would you like sandwiches for your tea every night?’

Another commented, ‘I remember a neighbour and they [social care workers] were coming to put her to bed at half seven, quarter to eight… on a summer evening. I mean, nobody would want to be in bed on a summer evening at that time’.
Secondly, participants spoke about the material difference in the quality of service offered by individual social care workers. For example, ‘[Friend who had a bad stroke]… the carers came round ‘til him… he chased the whole lot of them … they’d sit there and do nothing for him… watched television… he chased the whole lot of them’. The friend subsequently paid for other carers, of his choosing, to come in. Another participant said, ‘Some of them [social care workers] are quite shoddy’.

Lastly, this issue related to concerns about the professional conduct of individual social care workers in relation to confidentiality and dignity. Participants expressed their concern about the extent to which confidentiality was being breached and/or the general affairs of the cared for person were being disclosed inappropriately, ‘There’s a lot of idle talk [reference to the conduct of some social care workers]’.

The issue of dignity and courtesy was highlighted and references were made to some care workers calling a client by their first name when they had not been invited to do so. ‘Other issues arose in relation to practical issues such as setting down tea/coffee/food ‘roughly’ without taking time and effort to ‘present’ it to the person in a dignified manner. Those training social care workers were asked to ‘look for little [but important] things that need attention… don’t just slap a mug down… degrading [for the client]’.

Although some of these issues may appear insignificant, taken together they represent a number of concerns:

- The person receiving the care is dependent on the care and is already vulnerable
- The person receiving the care has very limited choice over who actually provides their care
- There is a reticence amongst some people receiving social care to complain, in case it results in:
  - their service being taken away (e.g. if there is no-one else to replace the social care worker)
  - their relationship with the social care worker being damaged and this in turn, potentially adversely affecting the nature and/ or quality of care they receive
  - the cumulative effect of all of the above on a client’s health and well-being is likely to be negative.
3.7 Workforce Issues

Too few social care staff

A number of participants commented on how few social care staff (in total) appeared to be available to service, what seemed to them to be, a high level of need.

The sheer number of different carers coming in

There was a sense that dealing with so many different social care personnel, at a vulnerable time in their lives combined with the fact that they had little or no control over who these personnel would be, was highly demanding and unsettling for some participants. ‘You need to know who is calling… you need the same person… not different people all the time.’

3.8 Carers and Family Support

Assumptions made about level of help available

There were frequent references to the optimistic, and often incorrect, assumptions made by social services in terms of the level of family support available to a client. However, for some participants, the reality was that while family members may be living nearby, they could not be assumed to be ‘available’ because of their own commitments, study, work, child care, own health status etc.

Concern about the needs of carers

There was an awareness that a family member, relative or friend, caring for someone long term could risk jeopardising their own health and well-being. We listened to views from a person who was in receipt of care (from a family member) and who themselves had cared for a spouse long term. They described the impact from both perspectives:

As the cared for person – ‘I live with my daughter and son-in-law… she’s getting a downstairs annex for me… it’s hard for her… she’s caring for me… her husband’s not well… the grandson’s not well.’

- As the carer – ‘...My husband, I cared for him for 25 years because he had a lot of problems… [For a while] I managed but then he took a stroke and they [the hospital] weren’t going to let him home and I pleaded with them, I worked with the OT [Occupational Therapist] … at the hospital and I brought him home… Now that evening I thought, ‘What have I done?’ but I persevered. Within a year, I had got him to walk with a walking aid. I needed help to shower him, to put him into bed, to get him out of bed… it took two [of them] to do that. I had said [had specified] 9 o’clock [as being the bed time]. Some evenings they [the social care workers] were coming at 7[pm] because they were
‘going out to a meeting’ and I was just at the end of my tether… It [social care workers persistently suiting themselves rather than the client] did affect me because I just broke down one evening and I just couldn’t take anymore… and then if you said anything [complained] you were the worst in the world…I thought if they were getting paid for a job and had taken on to do a job for a certain time that they should do it.’ While, this participant did eventually report the situation to Social Services and a new social care worker was appointed, they had, up to that point, tolerated carers repeatedly coming at times that had not been agreed with them.

- The participant went on to explain how socially isolating the long term caring experience had become, ‘For a lot of the time, I couldn’t even get out across the door, not even to do my shopping because he [her husband] couldn’t be left [alone]’. Eventually, the situation reached crisis point when, ‘My daughter was at university…. And, there was nobody else. So one day she came home and … I was just down to skin and bone. I was taken to the Doctors and I collapsed in the Doctor’s surgery [exhausted]… You [the social care service providers] need [to provide] help for the carer as well.’ In situations where social isolation sets in, the threat to mental health increases. It was evident from this participant’s description of the positive emotional impact of getting back to their choir (even on one occasion) that social interaction, especially social interaction that is meaningful for that person, contributes in a real way to a renewed sense of well-being, ‘It [getting back to the choir, for one evening] was wonderful!’

A different participant, who had also been a long-term carer, described the impact of providing long term care on them, ‘It was stressful… always looking out for someone.’

**Finances**

**Concern that finances alone are determining service delivery**

Participants at the focus groups acknowledged the current economic climate and were very much aware of the likely impact on the delivery of public services including health and social care services. However, their experiences to date suggested that financial considerations were determining the level of service available.

They were alive to this reality having ‘always [been] told that money is scarce’. What concerned participants was the use of the financial position as ‘the starting point’, or ‘the only point’ that determined what could be offered, rather than a person’s specific need. One participant repeated what had been said to them by a social services representative when they were being ‘assessed’ for social care, ‘Before we start, there’s no money… but to keep you on the files…we need to fill out the forms.’
Concern about possibly having to pay for a service

As noted above participants were aware of the current squeeze on public spending, there was a sense in which some participants considered it was unfair to be asked to pay for a service when, as they perceived it, they had already contributed to the payment of such a service during their working lives, ‘We’re of a generation who worked and paid taxes… told we would get [receive, not pay for] certain things when we retire’. Consequently, there was a view amongst some that the provision of the service should be based on the needs of the person and should not be means tested.

Lack of ‘pooled’ funding streams

There was a sense of the need to see the delivery of health and social care in its widest sense. In two of the focus groups, there were references to the high level of unclaimed social security benefits, ‘There’s millions in unclaimed benefits’. There was also a reference to the high cost of residential care and a preference expressed for the re-allocation of such funding to help maintain people in their own homes. It was suggested that Government should allow and promote flexibility between different funding streams across departments.
4. Conclusions and Recommendations

4.1 Conclusions

The older people who participated in these focus groups gave their direct and indirect experiences of social care – from the point of access to actual provision and everything else in between. These views and experiences are valid and point to a system of social care that does not necessarily meet the social care needs – either physically or emotionally of the people it is meant to.

This is not to deny that a number of participants reported positive experiences of social care, but the discussion was dominated by the frustrations and a sense that social care was simply a set of tasks done to older people and their carers. However, despite this the participants highlighted and recommended how the service could improve.

These recommendations, collectively called for a radical re-examination of how clients’ needs are meet, needs that promote independence, dignity and choice, including assessment and, subsequently, how the service is delivered and monitored.

Finally, there was a belief that with better service design, taking account of the actual needs of older people and recognition of the realities for older people receiving care or not as the case may be, social care could be transformative and promote independence, choice and dignity for older people now and in the future.

4.2 Recommendations

Entitlement, services and limitations

Entitlements
- Provide clear and easily accessible information on what people are entitled to and the eligibility criteria surrounding care
- The service should be appropriately managed and all decisions about service provision should be made in an open, honest and transparent manner
- Assess needs in a way that ensures the person making the decision has actually seen the client for themselves
- Work in a collaborative fashion with others providing social care in local areas so that each party acts as an active signpost to other services
- Make it easy for people to find out what is available and who does what
- Provide copies of the care plan promptly and proactively.
Services
- Allow the client to select and decide which services are most meaningful for them
- Ensure that services are available at – and delivered at- the times that suit the client
- The quality of social care needs to be actively monitored to ensure that non-compliance is highlighted promptly.

Limitations
- Be realistic about the time that is actually required for social care, including travel time
- Ensure that the same process of assessment is used irrespective of the context i.e. in hospital or out
- Provide clients with more social care time
- Ensure that adequate numbers of qualified staff are available to interact with clients and their families at all times
- Ensure that clients have contact numbers and names for support.

Quality of Care
- Ensure that the values of compassion, empathy, dignity and respect feature prominently in the training of all social care staff and in the conduct of their duties
- Ensure that care staff are aware that the execution of duties alone is not enough. The duties need to be undertaken such that the core values are evident
- Do not permit social care staff to use their own discretion about when and when not to provide any aspects of a care package
- Use a variety of means to actively check the extent to which clients are satisfied or dissatisfied with the service
- Ensure that there are clear guidelines about the need to protect client confidentiality.

Workforce Issues
- Attract more people into social care
- Match social care staffing levels to level of need
- Provide continuity of relationships. Ensure that the same social care worker provides the services required to specific clients

Carers and Family Support
- Do not make assumptions about what level of support a client may or may not have
- If a client indicates that family support is not available, this should be respected and responded to accordingly
- A package should consider what support or respite care is needed for long term carers to sustain them in delivering care
- Sustaining the carers capacity to sustain social interaction is an important part of this
Finances

- Centre first on the needs of the person and not on the finances
- Provide a service which is based on needs and not means-tested
- Unused funding from one Department should be moved to meet needs elsewhere (e.g. health and social care)