



Report:

Adult Social Care in Northern Ireland: Engagement with Older People

March 2015

Report commissioned by the Commissioner for Older People for
Northern Ireland

Table of Contents

| | |
|--|----|
| Background and Introduction | 3 |
| Methodology | 5 |
| Characteristics of Respondents | 8 |
| Summary of Responses | 8 |
| Recommendation 1 – Single legislative framework for Adult Social Care | 9 |
| Awareness of Legislation | 10 |
| Entitlement, Rights to Services, Personal and Public Involvement | 13 |
| Assessment of Need and Unmet Need | 18 |
| Advocacy and Support | 21 |
| Recommendation 2 – Support Visit for those aged 75 years | 24 |
| Recommendation 3 – Future funding arrangements | 27 |
| Mental incapacity and Adult Protection | 30 |
| Conclusion | 34 |
| Appendix 1: Recommendations from the Technical Report | 37 |
| Appendix 2: Case Study used in Briefing and Focus Group Sessions | 38 |
| Appendix 3: Focus Group Questions | 41 |
| Appendix 4: Recording Proforma – Current Users of Adult Social Care | 43 |
| Appendix 5: Recording Proforma – Current Users of Adult Social Care in Residential or Nursing Care | 70 |

Background and Introduction

This project was carried out by Age NI on behalf of the Commissioner for Older People in Northern Ireland (COPNI) in response to their request for a bespoke programme of peer facilitation with at least **50 individual older people across Northern Ireland**, to include family members, carers, service users and stakeholders.

COPNI has recently concluded a technical research project on the current legal framework and policy guidance underpinning adult social care legislation in Northern Ireland. The aim of that project was to consider if legislative change is required for adult social care legislation in Northern Ireland and to put forward proposals for the best options for reform.

As a follow on from this piece of work, COPNI wanted to obtain data relating directly to the experiences of older people in receipt of, or eligible to receive social care in Northern Ireland as well as potential future users of adult social care. In particular, COPNI wanted to ascertain whether older people, their families and their carers are aware of what their entitlements to social care are and whether they support the recommendations from the previous technical research project. The recommendations from this technical report can be found in Appendix 1.

In order to test the recommendations outlined in the technical report, Age NI has engaged with **58** older people, including current and potential future users of adult social care together with family members or carers, across a range of domiciliary, day care and group settings. The results of these engagements reflect 'real life' experiences, barriers and concerns of current users, carers or potential future users of adult social care. A range of case studies are also included, and these have been taken directly from the people engaged with as part of this exercise, along with a sample of cases which were referred by the Age NI Advice team.

The United Nations Principles for Older Persons, adopted by the UN General Assembly (Resolution 46/91) on 16 December 1991, encourage governments to incorporate a number of principles into their national programmes whenever possible. The Commissioner for Older People for Northern Ireland has a statutory

duty to have regard to these Principles. The Principles state that older persons should remain integrated in society, and participate actively in the formulation and implementation of policies that directly affect their well-being. The Commissioner has commissioned this piece of work in order to capture and record the voices of those older people and carers who would be at the heart of any proposed changes to social care legislation.

Age NI is a trusted brand among older people. As a result, we are uniquely positioned to provide this programme in light of our existing relationships and infrastructure that works with older people through our existing provision of products and services. Furthermore, the programme is a unique offering in Northern Ireland, offering as it does a 'peer led' engagement experience, where teams of trained older people are responsible for leading discussion and engagement with groups of their peers. The project was led and delivered by the Project Manager and team of Age NI peer facilitators.

Methodology

The project was carried out in the following stages:

1. Project Initiation Meeting

A meeting was attended by Age NI and COPNI representatives in order to discuss the project in detail, and to agree how engagements would take place. The aims of the initial meeting were to:

- Review and agree the project proposal
- Agree the proposed methodology for the delivery of the contract
- Agree the proposed outputs and timetable
- Discuss and agree the questions to be used at the engagement sessions
- Agree reporting and communication procedures for the duration of the contract
- Discuss and agree COPNI input into Age NI briefing papers, meetings with facilitators and delivery of engagement sessions if appropriate.

2. Peer Facilitator briefing

One full day session was organised and delivered to all participating facilitators (10 in total) on March 12, 2015. The day was an opportunity for facilitators to not only be briefed on the practical details and rationale behind the engagements they were about to undertake, but also to participate in the exercise themselves, as potential future users of the social care system. In this way it was recognised that the briefing sessions would not only provide a fulsome insight into the project, but would also allow facilitators to share their own personal experiences and expectations of social care.

The day was divided into two parts. For the first half of the day, facilitators were presented with a four part case study (see Appendix 2). After reading the case studies, facilitators were then asked a series of questions to check understanding. The aim of this part of the briefing was twofold. Firstly, we wanted to establish how much facilitators knew about social care legislation, as potential future users of the system. Secondly, through the discussions that followed, we wanted to ensure that facilitators understood the complexities of the legislation before they carried out interviews with existing users. The second part of the day focused on a series of

general questions relating to funding for social care, legislation, planning and prevention, and awareness (for questions, see Appendix 3). The aim of this part of the day was to gather the views of peer facilitators, as potential future users of social care services.

The desired outcomes of the briefing session were as follows:

- A shared understanding of the background to the provision of adult social care in NI, so that peer facilitators had adequate context and information prior to undertaking the engagement with current and potential future users
- An outline of the process, itinerary and practical details of engagement sessions, so that facilitators are clear about their role.
- A shared understanding of the use of questionnaires and prompt questions, to enable facilitators to keep the discussion flowing, and to maintain a focus on the requirements of the project.
- An opportunity to participate in the exercise themselves and have their voices heard as potential future users of the system, so that they can gain a fulsome insight into the project.

3. Engagement session with potential future users of adult social care

A second full day session was organised on March 27 2015 with a number of older people (8 in total) who could be considered as potential future users of social care. These older people were members of the Age NI Consultative Forum and Peer Facilitator team (including those facilitators who were unable to attend the previous briefing session, but still had an interest in the topic)

The same case study exercises and questions that were used for the Peer Facilitator briefing session were used again for this engagement session. For the first part of the day, participants were divided into small groups to discuss case studies and to give feedback to the wider group. The aim of the case study approach was to establish how much participants already knew about the social care system and social care legislation. For the second half of the day, participants were again asked a series of questions on funding, legislation, planning, prevention and awareness. As before, the aim of this part of the session was to understand the opinions of the group as potential future users of social care. All opinions were discussed and recorded.

4. Interviews with current users of care services- domiciliary care and day care

A series of individual interviews (19 in total) took place with older service users in the community. Service users were in receipt of day care, domiciliary care, or both. Interviews took place in the individual's own home or in a day care setting. For 3 of these interviews, a carer was also present or was spoken to by telephone. The Age NI Project Manager managed the placement of facilitators in each of these sessions. The Project Manager liaised with care managers, and the relevant groups of older people targeted as part of this project, to ensure the engagement happened at the most suitable time and venue for the older people involved. As an additional quality assurance measure, the Project Manager arranged that a member of staff would be present at a sample of interviews, to observe facilitation practice, with a view to shaping and informing best practice for all facilitators in subsequent sessions.

The questionnaire used by facilitators for these engagements can be found in Appendix 4. Care was taken to word questions in a 'plain English' format, so that it was clear to service users what was being asked of them. Responses were recorded on the questionnaire proforma, and submitted to Age NI Project Manager following each engagement session.

5. Interviews with current users of care services- residential care

A series of individual interviews were also carried out with older people across a number of residential settings. Facilitators engaged with a total of **15** individuals in residential care.

Family members were encouraged to be present during the interviews, and to contribute to the discussion. Peer Facilitators engaged with residents and their family using a questionnaire which can be found in Appendix 5 . Care was taken to word questions in a 'plain English' format, so that it was clear to residents and their families what was being asked of them. For 3 of these interviews, a carer or family member was present.

Responses were recorded on the questionnaire proforma, and submitted to Age NI Project Manager following each engagement session.

Characteristics of Respondents

A total of **58 individuals** were engaged as part of this project. The characteristics can be broken down as follows:

| Category | Male/Female | Age Range | Trust Area |
|------------------------|------------------|-----------|----------------------------------|
| Potential future users | 8 Male 10 Female | 58 - 75 | All Trust Areas |
| Day Care | 4 Male 8 Female | 74 - 92 | Belfast, Southern, South Eastern |
| Domiciliary Care | 3 Male 4 Female | 72 - 91 | Belfast, Western, South Eastern |
| Residential Care | 6 Male 9 Female | 76 - 90 | Western, Belfast, Southern |
| Carers/Family Members | 1 Male 5 Female | 45 - 75 | Belfast, Southern, South Eastern |

Summary of responses to recommendations

Older people and carers participating in engagements were not asked to comment specifically on the Technical Report from COPNI or the three key recommendations contained within that report. However, as the aim of these engagements was to test the validity of the issues underpinning these recommendations, questions were developed that would test the themes behind the recommendations in plain English terms. All questionnaires that were used in this exercise have been referred to previously, and can be found in appendices 4 and 5. For the sake of clarity however, responses have been organised below according to the three key recommendations.

Recommendation 1:

There should be a single legislative framework underpinning adult social care in Northern Ireland with accompanying guidance for implementation. This could either be new or consolidated legislation, based on human rights principles, bringing existing social care law together into one coherent framework.

In terms of potential future users of social care, focus groups revealed that while some were aware that social care legislation existed, they were not aware of the details of this legislation. One participant said that given her active role in the Age Sector, she was *'embarrassed and ashamed'* about her lack of knowledge in this area.

Potential future users all felt that a greater effort should be made to ensure that older people and their families are made aware of existing legislation, how this affects them, and any changes to this legislation. There was a difference however in terms of the level of detail potential future users felt it was appropriate to communicate. Some participants stated that they would want to know the details of any proposed new legislation and to be consulted in terms of what this legislation might look like. These participants felt very strongly that older people should be consulted on any new legislation in a meaningful way. *'People don't know about it (the law) now. If I need to use it in my later years, I would need to know about it. I would like to monitor how the law is implemented. If the law is amended in the future, people need to know about it'*.

Other potential future users did not want to be involved at this level of detail, but still felt it was important that they were made aware of existing legislation, any changes to this legislation, and what this might mean for them in the future. These individuals felt that while it was important that people should be made aware of legislation, it was **imperative that this is communicated in plain English.**

One participant stated that a leaflet outlining the law should also include contact details for advocates who are trained in this area, for example, Age NI. This individual said that while he considered himself to be fairly intelligent, legislation can

be interpreted differently depending on who is reading it. He stated that a telephone number for an advocate service would be necessary so people can check that their understanding is correct and get support if needed. An individual in another focus group also stated; *'You might need the support of experts, people need help getting interpretation of the law – this is where Age NI and others are important. Everyone interprets the law in a different way'*.

Typically most people seemed to think that while the legislation should be communicated to older people and their carers, this should be done in a straightforward way. It was seen to be important that advocacy services were communicated in conjunction with the legislation. A smaller percentage of potential future users wanted to understand the current legislation in more detail and any potential changes to this legislation.

In terms of the existing legislation, all potential future users agreed that it wasn't particularly 'user friendly' in its current form, mainly because of the number of pieces of legislation that exist. There were questions raised about whether legislation is ever really user friendly. While it was thought that one single piece of legislation might address accessibility to some extent, some participants felt that they weren't really qualified enough to comment here. There was some concern about how a single piece of legislation would link to mental capacity legislation and the Human Rights Act. Any new legislation must not result in less legal protection for older people; *'It's a difficult question to answer – one piece may not fit all? – for example how would this link to other legislation like the Human Rights Act and mental capacity legislation'*. *'New legislation should build on previous legislation, it shouldn't result in less protection'* Again, some people wanted to be actively involved in any review of the legislation, *'if we were involved in the creation of it we could see how it could be improved'*.

AWARENESS OF LEGISLATION

In contrast to the level of interest in legislation and 'rights' witnessed with potential future users of social care for the vast majority of people living in residential care, there was much less interest in the details of the legislation. There was also a particular reluctance amongst some of those living in a residential setting to even engage in conversation about legislation. *'had not heard of the legislation and would make no comment on the matter'*. Legislation was not something that many of the

respondents in these settings had a desire to understand in a great level of detail and was viewed as complex;

- *'I don't know anything about that'*
- *'She may have heard of it (legislation) but wasn't interested'*
- *'Never heard of them- I wouldn't be brainy like that'*

Some respondents in residential care did however show some interest in the legislation. However they wanted information in a broader sense (in terms of recognising that it might be helpful to know that the legislation existed and a broad sense of what it meant). They did not show the same level of interest as potential future users and had less interest in the complexities of the law and whether a single consolidated piece of legislation would be beneficial. Respondents were more interested in knowing what their rights were than in the details of legislation. Some thought that while they would not understand the legislation, it was important that their families were made aware of the fact that the legislation existed;-

- *'I'm sure some information on the law would be helpful'*
- *'Yes I do (think it is important for older people and their families to understand the law) so long as they are simplified enough and easy to understand'*
- *'I suppose it would be better for my family and I to be more familiar with these laws...I'm not familiar with details and need to know more.. it is always better to have information condensed if possible'*
- *'It is not so much important to understand the law as it is to know what facilities are available'*
- *'It is something I wouldn't understand, but it would be important for my nephew to know (the law)'*
- A carer stated that it was *'important, but it is more important that there is an understanding of family needs and the use of common sense when organising care'*.
- *'It would be helpful if we could have copies of the law and be told about them'*

In terms of respondents in day care and domiciliary care settings, findings were broadly similar. While some respondents had heard of the Human Rights Act, they were not aware of the other relevant pieces of legislation. Some were vaguely aware that legislation existed, but they were not aware of any details. Generally, people

were more concerned with having their rights explained to them in a simple way. They wanted to know less about the details of the legislation, and more about how the legislation could support them.

- *‘People should have their rights explained to them in simple language’ (75 year old female receiving day care and domiciliary care)*
- *‘I have never heard of these laws and I think I would be unable to understand them anyway...I suppose one clear law would be better though as it would be easier to find and understand’ (92 year old day care attendee)*
- *‘It probably makes sense to combine them but only if no provisions are lost; There is a risk that some things might not make it into the new law and people would be entitled to less – or worse, completely excluded. Most people don’t know how to ‘use the law’ (Carer for mother, 79)*

Case study 1

The following individual is a carer for her mother (89 years) who has dementia. It is of significance that this particular respondent has a background in social care policy, previously having worked in the Age Sector for a number of years. This case demonstrates just how complex the existing legislation is. This individual is very aware of the legislation and policy relating to social care – yet she still feels powerless in dealing with the system, and does not see evidence of legislation and rights being applied to her mother’s case; *‘I fail to see how they (the existing legislation) can change the type of care my mum gets’*

Given her policy background and current experiences of dealing with social services, this individual thought that the current legislation was overly complex and communicated a need for one consolidated piece of legislation, both for those arranging care and for those receiving care. She believed that this would promote a simpler, fairer system.

“How am I supposed to navigate these different statutes – social workers do not even know the extent of these regulations. For example cooking, cleaning shopping etc is allowed for but not provided. I am not sure how the HRA has actually impacted on care provision? The 1972 and Chronically Sick etc are discriminatory and the language used is old fashioned and out of date. It’s time for a modern single statute that is based on clear rights and entitlements. Similar to the work in GB on this by the

Law Commission. It is easier for me to understand, easier for social workers and carers to understand. Makes it simpler, fairer, clearer and when things go wrong you are clear why and where the responsibility lies. Also makes it easier to complain about bad care if there was one law'.

THE NEW, CONSOLIDATED FRAMEWORK SHOULD PROVIDE CLARITY ON ENTITLEMENT, RIGHTS TO SERVICES, PERSONAL AND PUBLIC INVOLVEMENT (PPI) AND HOW THESE LINK IN WITH THE DUTIES OF THE HEALTH AND SOCIAL CARE TRUSTS

There was a serious lack of knowledge amongst potential future users about what sort of help was available in terms of adult social care. Whilst participants were unsure about what was available they were of the opinion that there was variation in terms of *'what you can get'* depending on where you live. For instance, the recent decision by the South Eastern Trust to stop supplying daily meals and to deliver frozen meals once a fortnight was discussed. It was thought that this was an example of the *'postcode lottery'*, that if you lived in one area you could be entitled to a good meals service while if you lived in another you would not be able to avail of this. **It was thought that geography should not be the basis for deciding what services a person should get and that there should be a minimum standard and more consistency across Trusts.** It was felt that certain older people were being disadvantaged based on where they lived. A frozen meals service was not felt to be appropriate by most participants. Most potential future users had a very limited idea of what might be available for them if they ever needed it or what might have been available to the client in the case study example given (see Appendix 2) *'What help would I get? I would need someone to explain'. 'I don't know! The needs assessment would vary between trusts.'*

In terms of domiciliary care and day care, there also appeared to be a lot of confusion about services amongst older people and their carers across the Trusts. The vast majority of service users and carers are unaware of legislation, or that they had a care plan and could ask for a copy of this, and that carers had the right to a

carer's assessment. There was also a lack of knowledge about what Adult Social Care included and what services might be available if needed. This was apparent across the Trust areas covered in this exercise. All respondents wanted more information and better communication about what else they might be entitled to and what their rights were. It was very common for older service users to either say that they needed more help than what their care package provided for, but that they relied on their adult children for this care. There was often a reluctance to ask for extra help through a care package, usually because people assumed they could not get this. In some instances extra help had been requested, often by carers, but had been refused.

- *'She knew what a care plan was but has never seen it' (Carer for 74 year old mother.)*
- *'She had no idea what other help she might be able to ask for...no one has ever explained this to her...she depends on her daughter for care...her daughter deals with everything' (Female, 74).*
- *'I go to a day centre and have a 'tablet lady' My son does a lot for me, he does all my cooking for me..I rely on him. I'm not aware of what I am entitled to' (Male, 74.)*
- *'I would maybe like extra help to get more cleaning. That would give my daughter some relief, I feel like I'm taking up her time. I haven't asked for help as I haven't seen my social worker in some time.'* (Female, 77.)
- *'I have a morning call, a lunch call and an evening call and I'm at the day centre 3 days a week. I never knew you might get help with cleaning and shopping or transport. My family do all my cleaning. I didn't know I could ask about other services'.* (Male, 84.)
- *'I pay my friend to do my cleaning' (Female,79)*

It was common for carers to state that they were under an immense amount of pressure to provide care for their parents. Carers often engaged with social services on behalf of their parents and reported that they felt frustrated about the lack of clarity in terms of what was available, what rights they had as carers and what rights their parents had as service users. As one carer stated 'What happens to those who can't pay? The burden will fall on families, many of whom already struggle themselves financially and NEED to work' The following case study reveals the level of confusion that exists, and the need to ensure that assessments and services are provided in a clear and transparent way. There is a general perception that families

are being expected to provide the bulk of care based on budgets and that decisions to provide care are not based on the consistent application of guidance.

CASE STUDY 2

The respondent is a carer for her 91 year old mother who lives in her own home. The respondent's mother receives domiciliary care and attends a day centre 2 days a week. As a carer, this respondent did not feel that there was enough support available in the Belfast Trust and she was consistently told that the support she requested was not available. She believed that decisions about care were based solely on monies available and that social workers determined what care you got based on how much money was available at the time in their area; *'When mum went downhill and we realized that we needed a care package in place. We contacted her GP and he put things in motion for us. We sort of knew what we would have liked for mum but we knew had no real say in anything. In essence the power lies with the social worker who determines what you get.'*

The respondent felt that engagement with social workers was futile as it was purely a lack of funds that prevented her mother getting the services she needed. *'These assessed services are restricted so much that any belief that you have a right to services is nonsense. Social workers are also aware of the cuts and lack of services on the ground. The care plan is determined by what money is available at a particular point in time, not by a right to be clean and fed. I asked for shopping and cleaning but was told that this was not available and not provided. We have basically given up asking as we know that we will get nowhere. Every time you ask you are told it's the cuts etc....they don't provide this...your mum is not entitled to this'. 'We also do not have the time to be constantly asking for stuff – its time consuming and it's easier not to!'*

A common theme to emerge from the engagement with service users and carers was that carers needed more support, though it was not clear how much the level of support offered to carers varied by Trust. A 77 year old female who received domiciliary care also depended on her daughter for care. She reported that she felt like she was a burden to her daughter; *'My daughter is very good to me. I feel that I am taking up her time. (I would like) extra time for cleaning to give my daughter*

some relief.’ One carer reflected on the lack of support she herself gets as a carer for her mother ‘I would like to take mum out, but I am not able to move her. She has not left the bed in 3 years. I have never been approached or offered any help. Its difficult at times – I have my own family and my own problems and would like some support’

Difficulties were also highlighted in accessing social services for a range of issues. The following case study highlights how failures in communication with social services and service planning have resulted in poor care and one service user being placed at risk, living in a rural and isolated location.

Case Study 3

The respondent, a female aged 75 and living alone in rural Fermanagh, attended a Belfast hospital in order to have a total knee replacement, in February 2015.

Before going into hospital, she decided to ring social services in Enniskillen in order to make arrangements for a care package upon her release from hospital. When she called the local social services in Enniskillen, she was told she would have to call the Western Health Trust, based in Derry. She did this, and spoke to someone who gave her a reference number and informed her that the staff at the hospital needed to call Social Services in Enniskillen when she was due to be discharged, quote the reference number and the care package would be put in place.

So the respondent attended the hospital with the reassurance that her discharge would be straightforward, and that she would be cared for in the immediate aftermath at home. Following her operation, the staff at the hospital started to call Social Services in Enniskillen, to make the arrangements for her discharge. They continued to call each afternoon for the remainder of that week, with no success in achieving any satisfactory outcome. They were told that a special committee met on Fridays only, to consider cases from that week. Upon quoting the reference number which had been given the previous week, staff were told by the Enniskillen Social Services, “That means nothing”.

By the end of the week, no communication was received from Social Services in Enniskillen about arrangements for a care package. This meant that the staff were faced

with discharging her with nothing in place. The respondent herself suggested they call her GP to see if he could help, and perhaps put in place a few days respite care in a nursing home, until such times that social services could organise a care package. Staff at the hospital did this, and spoke to the GP, who said he could do nothing.

Staff again called social services to report the seriousness of the situation, and were asked by the team in Enniskillen “Has she no family?” The staff explained that most of this respondent’s family lived in South Africa, and that she herself lived alone in a very rural location. They then asked “Has she not got any friends that could help?”.

The hospital kept her for an additional night, reluctant to discharge her without any support in place. However she was discharged on the Saturday as it was not physically possible for them to keep her any longer. The respondent understood their position, and she was grateful for all the support they had given her.

Her son took her home to Fermanagh in his car, and stayed with her that night. He had to return to his international job the following day.

He made sure she had water and other essentials, and that she had the phone near her in bed. However the door could only be locked from the inside, and she had to spend the next few nights alone in her home, which was unsecured. She felt very vulnerable. She said,

“When my son left, I thought..... I am just not worth the effort of anyone bothering to help me”. This was the first time in her life she felt like this, and felt extremely let down and helpless.

Two days later, a personal friend called to see her and was horrified at what she witnessed. The respondent had not eaten anything since her son left on the Sunday, and only with great difficulty could make her way to the kitchen to get a cup of tea. Her friend immediately started calling social services, and making a fuss. However it was only when she happened by chance to get speaking to someone she knew personally that something started to happen. As the respondent stated, “Only my friend knew this social worker personally, I feel nothing would have been done, it was just sheer luck”.

Carers were arranged to come twice per day, once in the morning and once at lunchtime, starting on the following Thursday. A district nurse also came to dress the wound, but as the respondent stated, “All of this came a little too late – why, when I had taken the trouble to call them before my admission to hospital, was I left in such conditions?”

She went on to develop an infection in her wound, and her recovery was comprised for a period of time.

A full 3 weeks after her operation, an assistant social worker visited her at home, to check on her, and to see if she was ok. She appeared shocked when told about the events of the previous weeks.

Reflecting on her experiences of accessing care through social services she said, “I am making a fuss about this on behalf of all those people who don’t have a voice, or who can’t speak up. I would like a system that can be accessed at any time, not just Monday to Friday. I need people who have the authority to make decisions in the short term and in the ‘here and now’, in response to my individual needs”.

THE PROPOSED NEW FRAMEWORK SHOULD PROVIDE CLARITY ON THE ASSESSMENT OF NEED AND UNMET NEED.

As stated previously, day and domiciliary care users have articulated needs, such as those outlined under the Chronically Sick and Disabled Persons Act 1978, which are not currently being met. Family members have also stated that the needs of those they care for are not being met and that they are having to step in to provide care. Unmet need existed for three reasons;

1. The service user/ family did not know the services needed could potentially be made available:
 - *‘I get home help for half an hour a day and to the day center but it is not enough, my brother and his wife have to help me...I don’t know what is available..I don’t know about any other services I could get...I would not know where to go to get more help...I do not know what I am entitled to, no*

one has ever explained to me...but it is important for older people to know their rights, if older people don't know they will never ask for them and won't get the help they need' (Female, 92)

- *'Extra time for cleaning would be good to give my daughter a break, I haven't asked for more help though.. I haven't seen a social worker in a long time' (Female, 77)*
- *'There are things that I have to do because no-one else does. For example washing mum's hair, cutting her nails. Someone came once to do her toenails but they said they wouldn't come again that it was "just this time" – I don't know why. I had to cut mum's hair and it was very difficult as she is in bed and can't sit up at all; I don't like doing her toenails either, they are quite hard to do and I have nipped her with the clippers before' (Carer of mother (79) receiving domiciliary care in her own home)*

2. The service user/ family were told the service was not available or was refused the service:

- a. *'I was refused by rural transport' (Male, 77)*
- b. *'I need more help with transport to appointments. You have to ring on a Thursday to book for the following week. There is never any room for me. I then have to pay a taxi which is £14. I have complained to my MLA but there has been no satisfactory outcome' (Male, 81)*
- c. *I was refused a stair lift in my home because I was deemed not eligible (Male, 92 - See case study 4)*

3. A breakdown of communication. There were instances of social workers not returning the calls of carers when they asked for more help (see case study 5)

Case study 4

This respondent, Male, 92 lives alone in his own home. He suffers from arthritis in his left knee which causes him a lot of pain when trying to climb the stairs; he often does not make it to the toilet in time because of his disability. He applied for a stair lift in his home to make things easier for him in this regard. However, following an assessment by the Occupational Therapist, they determined that he did not fit the criteria, and he was refused the stair lift. The respondent was deeply unhappy with this decision, and approached Age NI Advice Services, who took up the case on his behalf. A letter was sent to Occupational Services, asking for a written copy of their decision in this case, with a view to challenging it. The respondent was subsequently contacted by Occupational Services with a view to installing a floor to ceiling lift in his home.

He stated that as a result of the advocacy from Age NI, the Occupational Therapist was more sensitive to his needs, and this resulted in a successful and fair outcome for him.

Carers also appeared to be particularly vulnerable to unmet need. It appeared that some adult children are providing a high level of personal care for a parent as formal help is inadequate. This can cause a lot of distress for carers who feel they are not having their needs adequately assessed by Social Services. An example of this is outlined in the case study below.

Case study 5

One carer described herself to be at her *'wits end'*. The individual's 74 year old mother lives with her and her family and has considerable care needs. The daughter described how, following the assessment of her mother by an occupational therapist, she was instructed that she would need to stay with her mother when showering.

She has to wash her mother, and prepare all her meals as her mother is no longer able to do this. *'I have to care for mum from she gets up in the morning till she goes to bed at night. I wash her, cook all her meals, look after her medication and money'*.

The daughter has spoken with social services and has communicated that she is

under a considerable amount of stress and that her mother urgently needs more help as she is struggling to provide the level of care she needs. Social services have not offered any assistance apart from placement in a day care setting three days a week.

The daughter insists that her mother needs more help however and that social services have taken it for granted that she will continue to provide personal care for her mother, but she feels *'pushed into it'*. The daughter stated that the current situation has been confounded by her mother's insistence that she can carry out personal care tasks *'Mother tells people she can do things which she cannot do and this leads to difficulty in getting support'*. She feels *'disillusioned'* and unable to continue this way physically and emotionally and is *'struggling to provide the care mother needs'*. Her own health is starting to suffer and her marriage is under strain.

Social Services are not returning her calls. The daughter stated that while she has received a carer's assessment she has received next to no support. She has no idea what her 'rights' are as a carer and what support she might be entitled to- no one has ever explained this to her. She stated that a television advertisement would be the best way to communicate rights with carers. In terms of legislation, the daughter stated that while has heard of the Human Rights Act, she is not sure how this applies to her case. She is unaware of other legislation but thinks it is important that carers are made aware of this. She also stated that she does *not 'have the courage to complain'*. (This lady has since been referred to Age NI's Advice Service).

ADVOCACY, SUPPORT AND OTHER CONTACT POINTS

Interviews with older service users and their families have clearly revealed the need for greater advocacy and support. As detailed, most older people and their carers are not clear about their rights and what they might be entitled to. Older people and their families tell us that they want clearer information about what they are entitled to. Some mentioned that this could be achieved through a campaign of sorts, a few mentioned a television campaign, most wanted a *'face to face conversation'* backed

up with written information *'in plain English'*. They also want an advocacy system in place that supports them if necessary. The GP was seen as a key and trusted point of contact and could play a key role. Interviews with current users of social care and their carers have confirmed the respect and trust older people place in their GPs in supporting them to get the help they need. Interestingly some of the respondents even stated that they would go their GP if they had a concern about the social care they were receiving:

- *'How do you let my mum know what her rights are – how do social services and carers deal with someone like my mum who has dementia! Where is the provision of true independent advocacy for my mum and us as carers. We need a set of rights. How are rights communicated – ie equal pay, right to work, disability – the COPNI should, once a set of rights have been legislated for – similar to the work in GB on a single statute that the law commission undertook, undertake a campaign informing people of their rights'*. (Carer for mum with dementia)
- *'I would definitely go to my GP if I needed any further help....People should be made aware of what else they can get...I would definitely ask my GP....I haven't seen my social worker for some time'* (Female, 72, receives domiciliary care and day care)
- *'The doctor arranged all this though I do remember a woman coming in to ask a lot of questions'. 'The doctor should tell me what I could be entitled to'* (Male 74, receives day care and domiciliary care)
- *'The GP should let me know what my rights are. TV is limited because of understanding. In an ideal world every person should have an 'active' social worker who explains your rights'* (Female, 78 receives day care)
- *'Definitely my GP'* (Male, 77 receives domiciliary care)

Where individuals are aware of their rights, speaking up was often seen as futile (see case study 9). This case study demonstrates the feelings of powerlessness for those who are willing to stand up for their rights, and the need for independent advocacy for such individuals:

Potential future users of social care also largely stated that GPs are the single best form of contact for older people who need social care services and that GPs would be more effective at raising awareness than a television campaign or leaflets. It was felt (quite strongly) that GPs are a dependable source of information and advice. Potential future users stated that they respected the GPs opinion and advice, but more importantly, they trusted their GP.

Potential future users stated that if they or a family member required assistance in the future, or when a family member has required assistance in the past, the GP has always and will always be the key contact for them. Potential future users were fairly negative in their appraisals of social workers, reflected in comments like *'you can never get hold of them, they are always on sick leave with all the stress they have'*. Another gentleman's experience in the care of his mother-in-law was that social workers kept leaving the post and not informing the family. His experience has reinforced his opinion that social workers are not dependable. For future care he has stated that he would always prefer to deal with his GP. Some potential future users did think a general campaign might be useful to raise awareness amongst the public more generally. A TV and mail out campaign would maybe support more focused efforts by GPs. These could run every 2 years. *People don't start looking for information until times of crisis.*

Some of the potential future users were aware that social services could be approached directly for an assessment, and some would contact an independent advice agency for guidance. However the vast majority would prefer to deal with a GP, and for care to be coordinated through the GP. One gentleman thought that this should be legislated for as *'things don't tend to happen if they aren't in the legislation'*. The gentleman who stated this thought that a system should be put in place that required GPs to regularly 'check in' with certain older people based on 'triggers'. For example, if certain health problems are present, if someone is bereaved etc. The GP should coordinate all the care through social services and be the main point of contact. The gentleman thought that there was too much confusion at the moment and that people could *'slip through the net'*. The GP is the person older people trust the most. It was thought that while GPs could play a role, but independent advocacy should also be promoted more when people receive care.

It was thought that at the moment, organisations such as Age NI only tend to support people if they are approached by the family or service user. It was thought however that a more comprehensive and proactive approach to advocacy is required. One potential future user stated that a family member was sent home from hospital with no care package in place (he refused it) However he was not aware of the consequences, and no one explained it to him. He was too proud to say he actually needed the help, and when he got home and realised it, it took a further 6 weeks to organise local community care. The potential future user stated that it would be good to have had an advocate to explain all the options – eg if you refuse the package, here is what happens. If you change your mind, here are the options. The future user pointed out that people in crisis situations are often traumatised, and people cannot take in all the information at that time.

Another potential future user stated that when an individual receives a care assessment this should automatically trigger an assessment for an independent advocate to ‘*check in*’ with the person and their family. This same individual explained the case of a neighbour and his wife who were concerned about a move to residential care and a lack of information surrounding the choice of suitable home as well as the costs associated with this move- this is outlined in case study 8.

Recommendation 2: All older people in Northern Ireland, once they reach the age of 75 years, should be offered a Support Visit by an appropriately trained HSC staff member. This will be based on principles of choice and self-determination and is aimed at helping older people to be aware of the support and preventative services that are available to them.

Potential future users all agreed that early intervention/ prevention was extremely important and that an effort should be made in this regard. They believed that care is most often arranged when an individual hits ‘crisis’ point, for example when discharged from hospital. They felt that more could and should be done to delay more advanced care needs. Paradoxically, most participants, despite being in the older age category themselves, admitted that they had given little, if any thought to their own care needs. One participant put it simply ‘*no one wants to dwell on losing their health and independence*’. The same participant stated that they lived in the

present and didn't dwell on what might or might not happen. When challenged on this, and asked what would help/ encourage them to prepare for the future, the group agreed that some sort of timely 'check in' would be appropriate. Again the GP was thought to be best placed to do this as GPs are perceived as trustworthy.

It was proposed that the 'check in' could be offered every 5 years through the GP. If it was the norm, they and other older people would be more willing to do this – much like screening checks. It is also important that the service is offered through the GP and not social services for reasons already outlined. The group discussed how this could operate and agreed that on turning 60 or 65, everyone should be 'screened'. Everyone should receive some sort of MOT from their GP that includes; a health check (such as a blood pressure, cholesterol check, mobility check etc), and a 'pack' from the GP that included information on how to stay well, what help might be available if needed at present or in the future in terms of services, key contacts such as Age NI, information on benefits, housing etc. The group stated that information should be kept succinct and in 'plain English'.

It is common for care needs to develop after a 'crisis' of some sort as in the case study below:

Case Study 6

The respondent, male, 76 who is now residing in a residential care home, described how he ended up living in residential care as a result of *'a heating issue over a lengthy period of 6 months'*.

The gentleman went on to describe how his health deteriorated as a result of an issue with his central heating system. While he had tried to get help, the issue was not resolved and he was unsure what to do next. The respondent ended up being admitted to residential care after a stay in hospital. He said this was *'entirely related to the heat factor'* and could have been avoided. The respondent did admit to suffering from confusion but insists that if he had received the right support, he would not have ended up in this position. The respondent would have preferred to have remained at home.

The following case study illustrates a case where it has been possible, through advocacy and the provision of entitled benefits, for an older person to remain at home, and in a safe and suitable environment. It highlights the complexities of the system, and the importance of the provision of independent advocacy for people in these situations.

Case Study 7

The respondent, male, 67 approached the Age NI Advice Service. He had been recently bereaved, and was struggling to repay the funeral charges. His initial query was based on seeking assistance to deal with this issue alone – a considerable step for the respondent who had never before sought any advice of this nature. During the course of the conversation, it transpired that he had been living in a private rented house for several years, in a rural location, and that the house was in a poor state, with no heating or hot water.

Over a seven month period, the respondent was assisted in applying for pension credit, housing benefit, and following that, the Warm Homes Plus Scheme for a new heating system. Before this was installed, he decided that he would like to be rehoused in more suitable accommodation. He was assisted in receiving a housing assessment, and the local Health Trust and Social worker were helpful in providing supporting information for this. Environmental Health also carried out a report on his current accommodation which was deemed unfit for him to live in. This provided substantial weight for his application for housing, and he was classed as a Full Duty Applicant with Priority Needs for housing. He secured a place in a Fold Housing Scheme within a short period of time.

The respondent's health had been poor owing to a fall, and he was advised that he may be eligible for Attendance Allowance, and given help with the form filling. He was awarded the higher rate AA, which subsequently meant that as he was living alone with no-one claiming Carer's Allowance, he was entitled to additional money through his Pension Credit, called a Severe Disability Premium.

He moved into his new accommodation, although very little of his furniture could be

salvaged owing to damp and wear and tear. He was assisted in making a claim for a Community Care Grant, and was awarded funding to purchase essential items for his new home. He was also supported by the First Connect Service, which helped him improve his confidence and his overall quality of life.

Recommendation 3: Increasing demands for health and social care reinforce the importance of considering how these services should be funded. All future funding arrangements must be equitable and must not discriminate against any group, including older people, who have higher levels of need.

The vast majority of respondents recognised that domiciliary care was free, however most were unaware that the Trusts had the power to charge for this. Regardless of this power, the majority did not think it was fair to charge for care and most stated that they could not afford to pay towards their care;

- *'I do not think that care should be charged for – it is part of the NHS and like all NHS services should be delivered free at the point of use. This is an argument that effectively discriminates my mother and all older people including younger (18+) disabled people in receipt of care services'. (Carer)*
- *'The debate in NI is somewhat behind what is happening in Scotland and England – Scotland has free personal care and the Barker Commission in England has recommended that all care which is high should be provided free. It will be a brave Minister who brings in paying for care'. (Carer)*
- *'If I had to pay I would be most unhappy. I couldn't afford it'*
- *'I could not afford to pay for care and why should I? It should be free'*
- *'Not fussed about paying, even if the house has to be sold'*
- *'I take the view that if that is the rule, then I accept it'*

On the issue of funding, the feelings of potential future users mirrored those of existing service users. The vast majority also thought it was unfair to charge. A few did however think that the current system was 'unsustainable' and that Trusts might have to examine the possibility of charging those who could afford it. In principle though, the general opinion was that personal care should be provided free of charge. Again the argument came down to principles, even if people could afford it, it was viewed as unfair to expect people to pay for care.

- *Having to pay could put some older people into poverty*
- *Yes, if I can afford it. But what about the people who cant afford it> In Scotland, all personal and nursing care is free. It should be free in any setting.*
- *'It is not free. You have paid national insurance your whole life and you are just taking back a proportion of what you pay in. We all have the perception that care is free, it's not. Saying that the current system is not sustainable and it might be necessary to introduce a charge. In principle that is not fair though as folk have already paid'.*

By contrast, all of the respondents we engaged with who were living in residential care were happy to pay towards their personal care. All the residents we spoke to were unaware of a breakdown of the costs and how much they were charged for the personal care element of their stay. Most were happy to leave the financial arrangements of their care to their families. A minority did see their bills however they could not recall ever seeing a breakdown of costs. Everyone that we spoke to stated that they were happy to pay towards their personal care. Only one individual commented that it was '*strange and hard to understand*' why people in care homes were expected to pay towards personal care costs when people in the community receive this free of charge.

- *'I don't mind paying – you can't take your money with you and it's better company here...there is always help at the end of the buzzer' (Female, 86)*
- *'I get a bill every month but I'm not sure what's on it. I don't mind paying...I was glad to get in here' (Male, 78)*

- *'I pay out of my pension. I don't remember seeing any bills I just know they take money out. I don't mind paying because the care is so good'* (Female, 90)
- *'It is paid out of my husband's income and estate. My daughter looks after my finances so she would get the bill'* (Female 87)
- *'Part of my pension is used but I don't know the details.. my niece deals with all that. I don't mind paying'* (Female, 90)
- *'My son pays from my estate which makes everything easy for me. It would never enter my head that I shouldn't pay'* (Female, 82)
- *'Where else would you go to get help like this? You would expect to pay for this sort of help'* (Female, 89)
- *'The respondent was more concerned with the fact that the care in the home was superior to what she had in the community and therefore didn't mind paying'* (Female, 90)
- *'The respondent stated that his health is the most important thing, not the cost, so that he does not mind paying'* (Male, 76)

The individuals we spoke to in residential care did not seem to be aware of a breakdown of what they were paying for. They all stated however that family were not paying anything towards their care. In Age NI's experience however (mostly through calls received to our advice line) we are aware that the issue of charging for residential care can still be problematic. Families are often told they will have to contribute towards the cost of a care place. This is demonstrated in the case study below, which also shows the need for independent advocacy.

Case study 8

A potential future user described the situation for his older neighbour over the past 2 years. The neighbour's husband, in his eighties, had a number of health problems and had been admitted to hospital after a fall. The gentleman's health

had declined to such a point that he needed to be admitted to residential care. The gentleman's wife had been told that the Trust would pay a maximum amount towards a place in a home and that if the home she and her husband picked was more expensive, that she would have to pay the difference. This was causing the lady some anxiety as the home she and her husband preferred was more than what the Trust were prepared to pay. It was the only home in the area that had spaces available and the Trust could not offer a viable alternative. The lady was concerned about how she could afford to pay the extra amount.

The potential future user was able to refer the lady to Age NI where an advocate was able to help make a case that the Trust should cover the full fee for the home. In the same case, when the husband passed away the lady could not recall speaking to a social worker. She was very concerned about making sure that private pensions and finances were sorted out. Again the potential future user referred the neighbour to an advocate at Age NI and these matters were taken care off.

The future user made the point that while the advocacy service at Age NI had been a great source of support for this lady, she would not have approached the service had it not been for him. He pointed out that the times older people need support are often times of upheaval and in this case grief. On these occasions people may need intensive support and even 'hand holding'.

THE PROPOSED NEW FRAMEWORK SHOULD PROVIDE CLARITY ON EXISTING FRAMEWORKS FOR MENTAL INCAPACITY AND ADULT PROTECTION.

Respondents in a residential setting were asked who they would contact if they felt unsafe. While respondents did not have concerns about their safety at present and felt safe, it is perhaps a worry that most were not sure who they would speak to if they did. Of further concern is that a significant minority did not feel that they would be able to raise a concern if they were unhappy with the care they were receiving.

- *'The respondent said that she had often wondered about this. She said that she didn't know what she would do. She said she might tell another resident, but not a member of staff as "you have to be very careful"'* (Female, 90)
- *'She would not complain, her generation do not do that. She would not complain in case she upset someone'* (Female, 92)
- *'I haven't a clue who I would contact. Nothing has ever happened so I don't worry about this'* (Male, 76)
- *'I would tell people higher up. I don't know who my social worker is'* (Female 86,)
- *'You would have to speak up. I don't know who to'* (Male, 78)
- *'I would either speak to the manager or I could contact my social worker'* (Male, 76)

In terms of individuals in receipt of domiciliary and/ or day care services, again there seemed to be some confusion about how a concern should be raised. Most people were not aware of who their social worker was or how to contact them. Of particular concern was one individual who stated that she *'would not complain as they (the carers) never listen'*. See case study below:

Case study 9

The respondent, female, 75 year is receiving domiciliary care and day care in Dunmurry Day Centre. She explained how she has been unsatisfied with her care and has spoken up about this to a supervisor, but *'nothing has changed'*. The respondent, who has carers calling 4 times a day needs help with her personal care.

Her main concern is that she has *'different carers every time, at least 7 or 8 when I (she) would prefer 1 or 2. It would give them a chance to get to know me, my likes and dislikes and for me to know them'*. Furthermore the respondent has had her meals on wheels cancelled but was told they would start again which they

haven't.

When asked if who she would contact if she had a worry about her safety, the respondent stated that she had '*spoken to too many carers without success...they never listen.. it is not worth complaining.*'

- '*I would report a problem to social workers...I don't know who mine is*' (Female 77)
- '*I've never had a problem but I suppose I would talk to the person concerned*' (Male, 80)
- '*I have spoken to many carers without success...it is not worth complaining...I don't know the name of my social worker*' (Female 75)
- '*This is not something I have to worry about*' (Female, 74)
- '*I would complain to my Doctor*' (Male, 74)
- '*Mum isn't happy a lot of the time. I've tried complaining but you don't get very far. The cooker ring has been left on by carers 2 times. I rang the second time and the person I spoke to said the carer would not have been using the cooker as they weren't allowed. I asked how they would be preparing a meal without heating it, and they had no answer – it was very frustrating*' (Carer for mother, 79)

The following is a case study which highlights the issues facing older people from an ethnic minority background on two levels; It describes the issue of raising a concern with social services relating to the safety of a terminally ill man, and also the broader need for increased support or advocacy for those from ethnic minorities so that they are in a position to understand the options facing them, and are empowered and equipped to make their own decisions.

Case study 10

The respondent is a lady (65) of ethnic minority background living in the Western Health Trust.

She was caring for her terminally ill husband (69) at home, until he was admitted to the local hospice. Towards the end of his life, he asked to return home. The respondent knew that her husband was too weak to walk around in the house; Her husband insisted that she continue working throughout his illness, and she knew the only way he would be safe from falling and injuring himself whilst she was at work was through the use of a wheelchair in the house.

Social Services did not carry out an assessment, but rather had a telephone conversation and informed her that as their house was quite small, her husband did not need a wheelchair, and that he could “surely walk around”. Due to his frailty, he was not in a position to walk.

The respondent stated “I needed empathy from the social worker. I was panicking and worried for my husband’s safety. Reassurance was all I needed” She eventually got a wheelchair from the Red Cross.

When talking about her experiences, the respondent wished to point out the broader issues facing older people from ethnic minority backgrounds. She stated that she had no close family living here, and only had some friends, and she did not want to place all the responsibility onto them. She said that she felt very alone and frightened.

She said, “I feel sorry for ethnic minorities – if someone says things like ‘palliative care’, many older people do not know what this means. They do not know what to ask the nurses to do when they come to the house. We have never had these services before; we don’t know what to ask. We need an advocate or someone to advise us what to ask for. I needed someone to talk to me like a normal person, to encourage and support me to make decisions which were right for me and my husband”.

Conclusion

In conclusion, this engagement exercise was carried out in order to test the recommendations contained within the COPNI technical research report which examined the current legal framework and policy guidance underpinning adult social care in Northern Ireland. Age NI, through its team of peer facilitators, engaged with a total of 58 older people, including current and potential future users of adult social care, together with family members and carers, across a range of domiciliary, day care and group settings. As detailed in this report, several important themes have emerged from the engagement with current and potential future users of adult social care in Northern Ireland, their families and carers, and are summarised as follows:

- **Legislation**

There was a considerable lack of awareness of the current legislation relating to adult social care across the range of respondents. There was also little awareness of how it could be accessed, or used by individuals. Many people receiving care either at home or in a residential setting were more concerned with having their rights explained to them in a straightforward way, and in knowing how the legislation could support them. Some potential future users also demonstrated a lack of knowledge about the legislation, however were interested in being consulted in the development of new legislation. The majority of respondents across all categories felt strongly that any changes to the legislation must be communicated in plain English, using straightforward and accessible methods.

The need for advocacy in relation to the legislation also emerged strongly with respondents stating the need for support to help them understand the legislation, and interpret it to make it relevant to their needs and requirements.

- **Service Provision and Funding**

The key point to emerge here was the perception that service provision was inconsistent and 'ad-hoc' across the health trusts, and that people can be disadvantaged as a result. There was a significant lack of awareness of what services were available to service users (and carers), also a lack of understanding of how to access any services that were available. Many thought that service provision

was not based on rights or entitlements, but rather on the resources that were available. The role of family members as carers is significant, with the burden of responsibility placed on many of them, often leading to increased levels of stress and frustration.

Most users of residential care however, were happy to pay for the care they received, particularly if the care was good, and they felt secure and happy in their residential setting.

- **Unmet need**

The report has highlighted the reasons relayed by respondents for unmet need, and the issues facing older people and carers in accessing services they need. There was a significant lack of awareness of what services could be obtained, and who to contact to request a particular service. It is important to note that many respondents said they did not know what they needed. If they found themselves in a situation where they were coping with a new illness or change of circumstances, and someone came to ask them what they needed, often they did not know. Some lost out on services because of this. Again, it highlights the need for advocacy, and a greater level of support for people to understand their rights and entitlements, and how to access them.

- **Preventative support**

Engagement with potential future users on this issue has highlighted a definite need for prevention visits or 'checks' to be in place for older people, possibly at crisis points in their lives, as opposed to at a certain age. It was felt strongly that the GP is the most trusted source for most people, and that any prevention check should be administered in the first instance by the GP. It was felt that any campaign or promotion of this should be communicated in a clear and straightforward way, and in plain English. Advocacy was again mentioned, especially for those faced with difficulties in understanding or accessing what is available.

- **Paying for Care**

A significant majority of potential future users, and those receiving day or domiciliary care felt it was unfair to charge for care. This was based mostly on the principle of having already contributed over the course of their life, and the expectation that care should be provided free of charge as a result.

Almost all respondents in receipt of residential care on the other hand were happy to pay for or contribute towards their personal care. Most left it up to family members to arrange, and many were unaware of what they were actually paying for, however the overall sense was that they expected to contribute and were happy to do so.

- **Adult Protection**

What has emerged is a sense of reluctance to complain in cases where problems arise, or there are risks to the health and safety of individuals. Also, alarmingly, most respondents did not appear to know who they would contact should any concern arise. Further to this, the broader issue of accessing the right person in social services, to get a response to a complaint or problem was raised, as well as the need for empathy and respect.

Finally, Age NI, through its team of peer facilitators, was privileged to facilitate the engagement and participation of current and future users of adult social care and their families and carers, so that their views could be captured and recorded in this report for the Commissioner for Older People in Northern Ireland.

Appendix 1

Recommendations from the Technical Report

1. There should be a single legislative framework underpinning adult social care in Northern Ireland with accompanying guidance for implementation. This could either be new or consolidated legislation, based on human rights principles, bringing existing social care law together into one coherent framework providing clarity on:
 - Eligibility
 - Entitlement, Rights to Services, Personal and Public Involvement (PPI)
 - Assessment of Need and Unmet Need
 - Health and Social Care Trust Duties
 - Existing frameworks for mental incapacity and adult protection
 - Other support services including housing and benefits entitlements.
2. All older people in Northern Ireland, once they reach the age of 75 years, should be offered a Support Visit by an appropriately trained HSC staff member. This will be based on principles of choice and self-determination and is aimed at helping older people to be aware of the support and preventative services that are available to them.
3. Increasing demands for health and social care reinforce the importance of considering how these services should be funded. All future funding arrangements must be equitable and must not discriminate against any group, including older people, who may have higher levels of need.

Appendix 2 Case Study used in Briefing and Focus Group Sessions

Part 1

Florence, aged 74 lives alone in a rented property in Island Magee. She has lived there since her late husband retired over twenty years ago. Florence has always been active and involved in the community, however her health and confidence have declined significantly since she had a stroke six months ago. When Florence was discharged from Hospital after the stroke she was offered some assistance, however at the time she refused this and has relied on her daughter Susan for help.

Florence's mobility has been affected due to some weakness in her left side. She finds practical tasks such as cooking a meal, cleaning the house and even climbing the stairs a challenge now. She is also starting to show some signs of memory loss Florence's daughter Susan lives in Whitehead. She is concerned that her mum hasn't been taking care of herself and is struggling to cope. Susan has been rushing to her mums every lunch time and evening after work to check in on her, clean and tidy the house, and prepare her lunch and dinner. Susan is finding this process exhausting and a colleague has suggested that her mum might be able to get some help from social services

Questions:

If you were in Susan's position what would you do?

- How would you go about getting help/ who would you ask?
- What would you ask for?
- What sort of things do you think social services might be duty bound to provide?
- Who is responsible for paying for the care provided?

Part 2

Susan ends up ringing social services and explains the situation. She is told that someone will be out to see her mum to carry out a care needs assessment. Susan takes the morning off work to be with her mum while the assessment is being carried out. Susan explains to the social worker that, while she wants to help, the process of caring for her mum on top of work and other family commitments is causing her a lot of stress. Ideally, Susan says she would prefer to call to her mum every other day. Susan will also be going on holiday for two weeks in August.

Florence tells the social worker that she misses getting out and about in the community and chatting with people. As it is a fairly rural area she used to drive everywhere, but since the stroke she is not able to do this. This is getting her down and agitated. Florence wants to know if there is anything in the area for older people in her position.

Following the care assessment, the social worker phones Susan and explains that the Trust will provide a meals on wheels service for her mum. Meals will be delivered every Monday and will be frozen. The social worker explains that the Trust has had a reduction in funding, so that a care worker will not be available to call to the house to prepare meals. Florence will have to prepare the meals herself. The social worker also explains that there is a day centre in Whitehead that Florence can have a place at on Wednesdays, though the bus does not travel to Island Magee so the social worker has suggested that Florence takes a taxi. This would be at her own expense. An occupational therapist will call out to assess Florence's house for adaptations. The social worker explains that due to budget cutbacks, they will not be able to provide any other assistance at this time.

Susan is quite upset about this. She explains that she is concerned for her mum's safety. Florence is getting more forgetful and Susan thinks she isn't able to prepare meals herself. Susan will have to continue calling every day to help her mum. Susan is concerned about her own health and wellbeing. The social worker agrees that this will put a lot of pressure on Susan, but says that due to the cutbacks there is nothing else she can do. Susan will have to cancel her holiday in August.

(At this point provide focus groups with the legislation – ie the Health and Personal Social Services Order 1972, the Chronically Sick and Disabled Person's Act 1978, the Human Rights Act 1998, etc)

After reading the legislation;-

Questions:

- Has the Social Worker followed her duties? Do Florence and Susan have any come back here or not?
- What action would you take next if you were Florence or Susan?

Part 3

Susan decides to go to Age NI for help. Age NI advises Susan to request a copy of her mother's care assessment. Upon reading the care assessment it is clear that Florence has what would be considered 'substantial' needs. The risks to Florence's health, safety and well-being, if services are not offered, are clearly documented. Susan speaks to Age NI again.

Age NI tells Susan that the Trust is not following their duty to provide services where a high level need has been identified. Age NI also tells Susan that she should have received a carer's assessment and that she is under no legal obligation to provide care for her mother. The Trust however do have a duty to provide care if Florence's needs are assessed as being above a certain threshold. Susan contacts the Trust to outline her rights. On this basis, the Trust agrees to provide more support to both Susan and Florence.

Questions:

- Do Susan and Florence have a case for Florence moving to the home in Whitehead?
- Should Susan be expected to pay towards this?

Appendix 3 – Focus Group Questions

Awareness

1. Has anyone had a recent experience of social services/ community care/ residential care?
2. Was this a positive experience? In what way?
3. Did you encounter any of the problems outlined in the case study? Being refused services, paying for care etc
4. Did you know all the services that were available before today and who was responsible for providing these services?
5. Would you have known where to turn to for an assessment?

Funding

6. Domiciliary care is currently funded by the Trusts in Northern Ireland. In the future, do you think older people should be charged for care in their homes?
7. The Trusts do not currently charge for personal care if it is provided in a service user's own home. This is not the case in a residential or nursing home setting, where service users are charged for personal care. As a future user how do you feel about this? Would you be prepared to pay or not?

Legislation

1. Were you aware of the legislation before today, and your 'rights' according to the legislation?
2. As a potential future user of social care, do you have an interest in this law for your own care?
3. Is it important that older people and their carers are made aware of this law? Why is it important or not important?
4. After reading the legislation- if you now faced a problem regarding a decision about your care, would you be confident that you could use the law to challenge that decision?

5. Looking back at the legislation- could this be improved in any way? Are there any problems with the legislation? Would one single piece of legislation be more straightforward to use?
6. Should the legislation include a duty for someone to have a right to have an 'advocate' or someone who is trained on these issues to act on their behalf?
7. Should the legislation be extended to include duties to assess benefit entitlement?
8. What could government do to make the process of navigating the community care system easier? What could government do to make sure people know what their 'rights' are, know what is available and where to go for help. (For example, a one to one visit? A letter from their GP? Media advertisement? Would a paper leaflet be preferable to a website?)

Planning and prevention

1. As a potential future user of social care, have you given much thought to what your own needs might be in the future and how you could prepare for these needs? Are you preparing for this in any way? How? (prompt only if needed, for example, have you considered if your home would be suitable?)
2. Do you think people in your peer group should be encouraged to think more about their future care needs? Why is this important? How could it be done?
3. There has been a lot of interest in the value of preventative services to delay the onset of more complex health and social care needs. It is thought that a preventative approach to social care might help older people to remain as independent as possible. One approach to this would be to have a 'preventative visit', where an older person is paid a visit to establish how they can be supported to remain independent in a way that will delay the development or progression of health and social care needs.
 - a. Under what circumstances or when should preventative visits start in order to be most effective? (prompt only if needed- certain ages, or circumstances such as bereavement)
 - b. What should be the scope of preventative services/ what should they focus on? (prompt if needed, benefits, housing, social inclusion, practical tasks)
 - c. Should legislation include a focus on prevention? Why?

Appendix 4 - Recording Proforma

Current Users of Adult Social Care

All information will be treated as confidential

| | |
|-----------------------------------|--|
| Location (daycentre or own home): | |
| Age: | |
| Name of Peer Facilitator: | |

Note to Facilitator - Please note there is a separate space for each question to note responses given by the carer (if present). It is important to note down service user and carers answers separately for each question.

Introduction

I am here today to talk to you (and your carer) about the help and care and support you receive in your home or in the community. We will be talking to about 30 older people and their families about the care and support they receive, and we are very interested in hearing your views.

I have quite a few questions to ask you (and carer), about twenty in total, although some only require short answers.

Don't worry if you don't have an answer for all of the questions – this is fine. I will do my best to explain anything that you are not sure about.

Let's get started.

Show the printed sign with the words
'ADULT SOCIAL CARE' and
'Community CARE' written on it

What do you think these terms mean?
What sort of services might they refer to?

RESPONDENT:

CARER:

If the older person does not know what the terms mean, reassure them that this is fine and move on - you could say "that is fine, we will find out a bit later"

Simple explanation:

Adult Social Care is the umbrella term which covers care provided in your own home, in a nursing home or a residential home.

Community Care is care provided specifically in your home (eg care workers coming in to your home), or care provided in a day centre.

Can we talk about you and the help and support you get, either in your own home or in the community? Can you tell me about any support you currently getting?

RESPONDENT:

CARER:

If the person struggles to answer you may prompt, 'for example meals on wheels, a carer coming in to help you get washed, dressed etc

Do you have a 'care plan' - have you seen this care plan?

RESPONDENT:

CARER:

A written document outlining the care you receive and why you are receiving it

Do you pay for any of the help you get?

(This is to establish which services are provided by social services)

RESPONDENT:

CARER:

Do you ever worry about having to pay for care?

RESPONDENT:

CARER:

At the minute, care that is organised through a social worker is free of charge if provided in your own home. However, if you move into a residential home, you have to pay towards the care you receive with your own money. What do you think about this?

RESPONDENT:

CARER:

Do you know what other services might be available if you ever needed these in future? Do you know how to go about arranging these?

RESPONDENT:

CARER:

Ask this **unprompted** in the first instance, and let the person answer.

Then Prompted - Which of the following do you think are things that social services can provide if you need them? (read one at a time and tick the services they think are provided through social services)

- help in your home with things like cleaning and shopping
- disability equipment and adaptations to your home
- day centres to give you or the person who cares for you a break
- care homes/nursing homes
- support for carers
- benefits checks
- Transport to appointments and activities
- Help to take a holiday
- Meals on wheels

Is there anything you struggle with that you would like more help with?

RESPONDENT:

For example, help with cooking, cleaning, or more of what you already get eg longer hours?

Encourage the person to discuss why or how they would benefit

CARER:

Have you asked for help?

RESPONDENT:

Please note that the person may not know what's available, where to go to ask for help. Or the person may have asked for help but been turned down – encourage the person to discuss their experience

CARER:

Are there any problems with the services you currently get?

RESPONDENT:

CARER:

Is there anything you would change?

If you are not/were not happy with the help you are getting, would you be inclined to say something, or would you 'just leave it'?

RESPONDENT:

CARER:

If the person says they wouldn't be comfortable complaining, try to establish why

NB: this question should assess how older people view themselves ie as 'right holders' or not

If you were very worried about the care you were receiving, for example, if you ever felt unsafe with a particular carer, what would you do?

RESPONDENT:

CARER:

E.g – would they know the name of their social worker, and go to them?

Let's go back a bit, to when you first started to get help in your home. Can you tell me how you came to get it?

RESPONDENT:

CARER:

For example, did your GP tell you about it, did a family member arrange it?

Did you deal with a social worker, or was it a family member?

Would you have known where to go if you didn't have any help?

Did you know what was available, or what you could get?

Thinking back, did you/ your family/ carer face any difficulties getting you the support you needed?

Prompt if needed: for example, did it take a long time to get the services

RESPONDENT:

CARER:

As an older person you have certain rights according to the law to get support. Has anyone ever explained your rights to you, and what you are entitled to?

RESPONDENT:

CARER:

Find out what the person knows about their rights. Are they aware they have rights? (Tick)

- The right to be assessed for care if you ask to be.
- The right to receive certain services if you are assessed as needing them.
- The right to receive a written copy of your care plan
- The right for your carer to be assessed for support if they are a family member or friend

Do you think it is important for older people in your situation to know what their rights are, and what they are entitled to?

RESPONDENT:

CARER:

Why?

Why not?

What do you think is the best way to let people know what their rights are?

RESPONDENT:

- Their GP should tell them
- A leaflet
- A tv campaign
- A local newspaper The internet
- Anything else?
-

CARER:

Have you ever had any services stopped or reduced?

RESPONDENT:

CARER:

Which ones?

Why?

What happened?

Did you challenge the decision at all?

There are actually a number of laws in Northern Ireland that health and social care professionals have to consider when organising your care. For example, the Health and Personal Social Services Order 1972, the Chronically Sick and Disabled Person's Act, and the Human Rights Act. Before today, had you heard about these laws?

RESPONDENT:

CARER:

Do you think one clear law would help you, and other older people like you?

Why/Why not?

Would older people and their families be more likely to use the law if it was in one place, rather than all these different laws?

Do you get any help at the minute with benefits such as attendance allowance, DLA or carer's allowance?

RESPONDENT:

CARER:

QUESTIONS TO BE DIRECTED ONLY TO THE CARER (IF PRESENT)

Did you know that as a carer you are entitled to have what's known as a carer's assessment?

CARER:

Have you had one?

Can you tell me a bit about the support you give to.....NAME OF PERSON THEY ARE CARING FOR (your mum, dad, spouse etc)

CARER:

Ideally would you like more help from the social services to care for (NAME)

CARER:

What would help you out?

Is there anything you don't get at the minute but you think might help you?

Have you asked for any more help or support?

CARER:

Have you heard of Carer's Allowance, a benefit you may be able to claim if you are caring for somebody?

CARER:

Appendix 5 - Recording Proforma

Current Users of Adult Social Care in Residential or Nursing Care

All information will be treated as confidential

| | |
|---------------------------|--|
| Name of Home: | |
| Age: | |
| Trust Area: | |
| Name of Peer Facilitator: | |

Note to Facilitator - Please note there is a separate space for each question to note responses given by the carer (if present). It is important to note down service user and carers answers separately for each question.

Introduction

I am here today to talk to you (and your carer) about the help and care and support you receive in your care home. We will be talking to about 30 older people and their families about the care and support they receive, and we are very interested in hearing your views. I have quite a few questions to ask you (and carer), about twenty in total, although some only require short answers.

Don't worry if you don't have an answer for all of the questions – this is fine. I will do my best to explain anything that you are not sure about.

Let's get started.

How did you come to be living here?
What were your reasons for moving to this home?

RESPONDENT:

Try to find out what led to the person being there – eg, a fall, illness, came straight from hospital, felt unsafe, bereavement of spouse etc

CARER:

Thinking back to when you lived at home, did your health and mobility decline gradually or suddenly?

RESPONDENT:

CARER:

Can you tell me about this? If it was gradual, when did you first notice problems, and what did you struggle with?

If you had received more help in your home earlier, do you think you would be here now? Or would it not have made a difference? Why?

RESPONDENT:

This is to see if prevention measures would have made a difference – eg someone to talk to them about falls, befriending, help with the housework, home adaptations etc

CARER:

Do you wish you had thought about your care needs earlier in life? Would this have made a difference? If yes, how would you have prepared differently, what sort of things would you have thought about

RESPONDENT:

CARER:

Prompt if needed: for example they might have thought about their housing and whether or not it would be suitable for their needs in older age.

Might have saved more

Might have got legal advice etc

How did you arrange a place in this care home?

RESPONDENT:

CARER:

Was it yourself, or your family who arranged it? Or was it through a social worker?

Was it left up to you or your loved ones to arrange it?

Was it easy to find somewhere you liked?

Was this home your first choice?

RESPONDENT:

If not, why were you not given a place in the home you wanted?

CARER:

How is the care you get paid for?

RESPONDENT:

Do social services pay for the care? Do you pay anything towards the home? Or your family members?

CARER:

Were you ever given a breakdown of costs for the home ie what you pay for? In other words do you know what you are being charged for?

RESPONDENT:

CARER:

Would you get a bill telling you what you pay for?

Older people in a care home are charged a fee for personal care. Older people living in their own are not currently charged for the same care when they get it at home. What do you think about this?

Note: personal care is help with bathing, washing, getting up or getting to bed, going to the toilet, help with eating meals etc

RESPONDENT:

CARER:

Each resident should have an individual and up to date care plan which they can see if they want to. Were you aware of this written plan of your care and have you seen it?

RESPONDENT:

CARER:

A care plan is a document which outlines what exactly how the home is providing care for the person.

If you had concerns about your safety or about how a care worker was acting towards you, what would you do?

RESPONDENT:

CARER:

Do you have a named social worker you can contact if you have concerns?

There are actually a number of laws in Northern Ireland that social workers have to consider when organising your care. For example, the Health and Personal Social Services Order 1972, the Chronically Sick and Disabled Person's Act, and the Human Rights Act. Before today, had you heard about these laws?

RESPONDENT:

CARER:

Do you think one clear law would help you, and other older people like you?

Why/Why not?

Do you think it's important for older people and their families to understand these laws when organising care?

RESPONDENT:

CARER: