



Commissioner for **Older People**
for Northern Ireland

Expert Advisory Panel on Adult Care & Support

**Evidence from the
Commissioner for Older People
for Northern Ireland**

January 2017

Executive Summary

1. The Commissioner for Older People for Northern Ireland (COPNI) welcomes the opportunity to meet with the Expert Panel and to provide evidence which he hopes will positively contribute to the report which the Panel makes to the Minister.
2. The Terms of Reference of this Call for Evidence are clearly confined to seeking evidence of what works well to inform in other parts of the world and within the NI context, however the Commissioner believes that this approach to the collation of evidence offers no opportunity to learn from the particular examples of issues which are currently being experienced within the adult social care system in Northern Ireland.
3. Priority One: Would support in context of “total population” approach but will not address the pressure that greater levels of care and support are needed now (and for the next two generations). There is a rise in complex care needs for a population that is living longer in much greater numbers. Older people need information and certainty to allow them to plan for their future. Active Ageing Strategy is potential mechanism to promote healthy, active lifestyles for older people.
4. Priority Two: Self-directed support is appropriate as a priority for a small percentage of older people – post surgery, accident or illness. However, once older people are in in the “frail” category, their support needs will be greater. The lived experience of the older person is vital and HSC service must ensure that people are not made ‘prisoners’ in their own home. Recent policy development meant cuts to day centres, lunch clubs and transport schemes – which totally goes against helping older people to remain independent with only substantial domiciliary care needs being met. Offering self-directed support in the form of direct payments will very often not be suitable for older people.
5. Priority Three: The previous Commissioner published recommendations to the Minister on this which included older carers must receive the services, information and support to enable them to care for the people who rely on them, alongside having commitment from HSCTs that any needs identified through a carers assessment is met and implemented. Many carers are older themselves – and provide care for a relative and/or spouse. Whilst the levels of uptake of the carers assessment remain low, the barriers to uptake were identified but still have not been addressed. Whilst there is a duty on HSCTs to “offer” an assessment of a carers needs – there is no duty to meet those needs. Whether or not an

informal carer is available should not be a consideration when care needs are being assessed.

6. Priority Four: For “choice” to be real – social care and support requires the provision of services as well as budget / cash, however there is no “choice” in reality in the Northern Ireland context at present. Choice exists when a consumer can “shop around” for the best / preferred service. In parts of Northern Ireland there is no real choice due to limited service provision in certain rural areas. The reality is that “assessed needs” can sit on the brokerage system for a long time with no provider delivering care as they cannot provide the service for the tariff being offered. This results in SDS offered in the first instance. SDS is suitable for a certain level of care / support needs – not really for a frail older people in their end of years.
7. Priority Five: COPNI have previously made recommendations in this area in two previous reports ‘Changing the Culture of Care’ and the ‘Summit on Domiciliary Care Provision in Northern Ireland’. To date there has been very little movement in this area to improve working conditions for social care workers. Currently there are pressures on nurses and social care staff in relation to wages, feeling valued & respected and opportunities for training/development. COPNI also has concerns in the area of regulation, specifically in relation to domiciliary care provision. These standards need to be updated to reflect the reality of more older people living at home, for longer and often with comorbidities. There is also concern around the inspection process that focuses more on the records held by the care provider rather than the care that is actually provided.
8. Priority Six: Need for an in-depth economic analysis - required to underpin and inform an honest conversation with Government. It would seem that this is now the “tail that wags the dog” – will policy reform be dictated by what is affordable or what is good practice? The discussions around the adequate funding for adult care and support has been ongoing since 2012, when DoH launched the ‘Who Cares?’ consultation, and five years later there is deep disappointment and frustration that there is still no further movement.

The Commissioner for Older People for Northern Ireland

9. The Office of the Commissioner for Older People for Northern Ireland is an independent public body established under the Commissioner for Older People Act (Northern Ireland) 2011.

10. The Commissioner has an extensive range of general powers and duties which provide the statutory remit for the exercise of the functions of the office. In addition the Commissioner may provide advice or information on any matter concerning the interests of older people. The wide ranging legal powers and duties include amongst others:
 - To promote and safeguard the interests of older people (defined as being those aged over 60 years and in exceptional cases, those aged over 50 years);
 - To keep under review the adequacy and effectiveness of law and practice relating to the interests of older people;
 - To keep under review the adequacy and effectiveness of services provided for older persons by relevant authorities (defined as being local councils and organisations including HSCTs, education boards and private and public residential care homes);
 - To promote the provision of opportunities for and the elimination of discrimination against older persons;
 - To review and where appropriate, investigate advocacy, complaint, inspection and whistle-blowing arrangements of relevant authorities;
 - To assist with complaints to and against relevant authorities;
 - The power to bring, intervene in or assist in legal proceedings in respect of relevant authorities;
 - To issue guidance and make representations about any matter concerning the interests of older people.

11. The Commissioner's powers and duties are underpinned by the United Nations Principles for Older Persons (1991) which include Independence, Participation, Care, Self-fulfilment and Dignity.

Introduction

12. First and foremost, COPNI needs to reiterate that the need for long term planning is of the utmost importance. Short termism in the context of Health & Social Care planning does not work and leads to confusion for both service users and HSC employees.
13. COPNI also believes that Priority Areas 1 – 5 cannot really be meaningfully progressed without having a very clear, fully evidenced understanding and an open and transparent conversation of what the ‘real’ cost of adult care and support will be, both now and in the future. COPNI has directly addressed the current Minister for Health on this gap and continues to reiterate the need for this part of the reform work to be prioritised in order to inform each of the other priority areas.
14. This conversation would need to take place alongside some level of explanation of affordability – i.e. ascertaining what the ‘real’ cost of care is and following on from this, what the state can / will be able to provide and what it will not.
15. The Commissioner believes that responsibility for funding and providing social care is a collective welfare state responsibility rather than an individual, private responsibility.
16. The principle of ‘universality’ must underpin any proposed reforms – i.e. those who have means as well as those who have not are eligible.
17. Equity - care and support must be available in the same way to all people with similar levels of need and regardless of where they live – this is a key feature of arrangements for funding and providing social care in other countries.
18. Ensuring choice for older people in need of social care and support will require the provision of services as well as funding / cash.
19. Support for carers is an integral part of HSC policy BUT eligibility for social care and support should not depend on whether or not a carer is available.
20. Reforming adult care and support requires a significant change in the relationships and responsibilities of the HSCTs, the individual and government.¹

¹ JRF – Rethinking social care and support: What can England learn for other countries? (2008)

21. Whilst the Commissioner welcomes this review and sees it as being very timely, it needs to be underpinned with updated and modernised Adult Social Care legislation which would bring together current outdated, disparate and piecemeal legislation to better reflect the reality of modern care.
22. Adult social care law dates back over forty years. During this time, service development, technological advancements and changing lifestyles within society have continued to evolve. In contrast however, the law and policy surrounding adult social care has not moved at the same pace.
23. Terminology and definitions contained within some of the oldest legislation are outdated, and there is unhelpful and confusing duplication as well as a lack of a coherent overarching rationale.
24. Many older people and their carers are unclear or unaware about their entitlements to social care and how to access these services. In addition, the ways in which adult social care can be accessed, delivered and funded are also confusing meaning that many people in need of support may be missing out on services which could have a real impact on their quality of life. This can include a lack of availability of suitable high quality beds in residential or nursing homes, adequate rehabilitation support as well as timely access to aids and adaptations. The provision and availability of these services can vary from HSC to HSC, leading to a sense of “postcode lottery” at play in Northern Ireland.
25. For many older people and their families, the first interaction with adult social care is at the point of a crisis where, for example, an older person becomes ill and requires more support or care, often at short notice. COPNI research² highlights that many people said that they felt pressurised into making significant decisions around discharge from hospital to a care home. In such cases, older people and their carers often do not know what social care support they are entitled to, when, where and from whom they should make a request.
26. Of particular concern to the Commissioner is those older people who do not have family or carers who can advocate on their behalf or to help them navigate the HSC system.
27. The Commissioner considers that the current legislation and policy for adult social care is in need of modernisation and reform, which should better reflect the changing needs of an ageing population and ultimately provide older people with the necessary information to make informed choices about their future.

² QUB - Review of Legislation and Policy Guidance Relating to Adult Social Care in Northern Ireland – Research conducted by QUB on behalf of COPNI (2015)

28. In 2014, COPNI commissioned Queen's University Belfast to review the current position in terms of law and policy in Northern Ireland and to compare its findings with international good practice with a view to developing a set of recommendations on how best to reform Adult Social Care for the future.

The review found that;

- Legislative reform is needed in Northern Ireland to benefit all adult users of social care.
- Such legislative and policy reform should be person centred and based on human rights principles.
- Northern Ireland has an integrated health and social care system. This carries both advantages and challenges in terms of service planning and provision.
- There is a lack of direct and reliable data available relating to current service provision and unmet need.
- There is an impression of regional and geographic disparities in service provision and development.
- Current legislation and policy guidance surrounding Adult Social Care is outdated, confusing and fragmented in Northern Ireland. Definitions and terminology used in the legislation need updated to fully reflect and meet the needs of modern society.
- The effect of the out of date legislation and policy position is to disadvantage older people in both understanding what social care services are available to them and in terms of how to access these services.
- Early intervention to assess need is key together with the provision of necessary support to enable older people to be fully involved in decisions about their future care needs. A preventative type of "Support Visit", similar to that currently offered in Scandinavia, to all over 75 year olds, would enable information and support to be shared and assessments conducted in a more controlled, proactive and consistent way.³

29. In 2016, the King's Fund and the Nuffield Trust produced a report entitled 'Social Care for older people: Home truths'⁴ which detailed key issues the social care system is currently dealing with in England. Many of these issues also very relevant to Northern Ireland, regardless of the integrated nature of our HSC system.

30. The report clarifies how home care services face particularly acute workforce shortages and are now in a critical condition everywhere, threatening to undermine policies to support people at home. The possibility of large-scale

³ QUB - Review of Legislation and Policy Guidance Relating to Adult Social Care in Northern Ireland – Research conducted by QUB on behalf of COPNI (2015)

⁴ Social care for older people: Home truths – The King's Fund & Nuffield Trust (2016)

provider failures is no longer of question of 'if' but 'when' and such a failure would jeopardise continuity of the care on which older people depend.

31. It also highlights how local authorities in England, as with the HSCTs in Northern Ireland, have sought to protect the most vulnerable older people with the highest needs, while at the same time encouraging others to be independent, drawing on the resources of their families and communities, and to reduce dependence on support from the state. For many people the experience of needing to find and pay for care comes as an unpleasant surprise for which, in general, they are unprepared. Unpaid carers will also be expected to do even more.
32. Across the UK, the situation for older people has been compounded by pressures elsewhere in the NHS. Cuts to social care cannot be viewed in isolation from overstretched general practice and community nursing and the uneven distribution of intermediate care beds. Under-investment in primary and community care threatens to undermine the policy objective of keeping people independent and out of residential care.
33. The most visible manifestation of pressures on health and social care budgets is the rapid growth in delayed discharges from hospital. While this is undoubtedly driven by funding pressures on both services and exacerbated by workforce shortages in social care, local authorities, NHS providers and commissioners must work more effectively together to address a problem that imposes a significant cost on the NHS and is taking an unacceptable toll on older people, their carers and families.

Priority Area One: Empowering people to make positive choices and plan for the future

The Panel is looking for:

- a. *Evidence of initiatives which can encourage people to make positive lifestyle choices and plan for their later years;*
- b. *Evidence of the most effective approach of providing information on the care and support system.*

34. People are still going to age regardless of how much information is provided to assist them with making healthy decisions. Whilst the Commissioner would support this as a necessary “theme” for this work (in the context of a total population approach), it will not solve the issue of older people needing care as they age and of the rise in complex care needs for a population which is living longer in much larger numbers.

Active Aging Strategy

35. In December 2015, the Office of the First Minister and Deputy First Minister (now the Executive Office) launched the Active Ageing Strategy (AAS). The purpose of the AAS is to transform attitudes to and services for older people.

36. As this is a strategy of the Northern Ireland Executive, all Ministers have made a commitment to its delivery with the aim of providing direction for departments’ policies, making connections between strategies and ultimately leading to the improvement of services for older people. The strategy also aims to increase the understanding of the issues affecting older people and promote an emphasis on rights, value and contribution as opposed to needs, costs and burden.

37. The main themes within the strategy are;

- Independence;
- Participation;
- Care;
- Self-Fulfilment, and;
- Dignity.

38. The AAS strategy, if delivered as intended, will provide government with the opportunity to promote healthy, active lifestyles for older people whilst ensuring their well-being remains on the agenda of each government department.

39. However, the need to plan for the future is an issue that comes to the fore time and again and this will also include the need to plan for how social care will be funded in the future. This is a discussion COPNI believed to be of primary importance and needs to be addressed urgently. This is to allow both government and individuals to make provisions as to how social care needs will be provided for now and in the future.
40. Whilst it falls under the remit of the Public Health Agency/Health and Social Care Trusts to provide information on the care and support system, COPNI is very clear that this must not become a 'digital by default' process. Older people must still be able to access information on the care and support system in 'traditional' methods to ensure equal access is maintained.
41. TYC and other HSC related strategies have described developing a 'community hub' structure that would provide a wrap-around service for services users incorporating primary and community care in one place. COPNI believes this structure would greatly improve the life of older people by providing care in a community setting, thus possibly reducing the need for hospital visits. This type of wrap-around service would also allow for the provision of information on the care and support system in a way that would allow older people to ask HSC professionals about their needs and how they would be best addressed.

Priority Area Two: Supporting people to regain, retain and maintain their independence

What the Panel are looking for:

Examples of local initiatives which have had a positive impact;

- a. Ideas on how government can improve awareness of supports which exist in local communities which can help maintain independence;*
- b. Ideas/evidence on how services can be redesigned to promote independence rather than fostering dependence;*
- c. Ideas on how the care and support system can work more effectively with Housing and Transport to support people in the community;*
- d. Views on how best to integrate the role of technology to support people to remain independent.*

42. The issue here is not necessarily about raising awareness of what supports exist in local communities to maintain independence – the issue is about having resources to support people who need assistance to remain in their own home and community (if that is the most suitable arrangement for them).
43. Recently, the DoH began a process of closing day centres that provided access to activities that would promote and maintain the social inclusion and confidence of the service users. These closures would ultimately mean that those older people who relied on this service would be forced to either receive care solely in their own homes (potentially leading to social isolation) or eventually need to use acute care services. This could also push these older people into using nursing/residential care as their needs could not be met elsewhere. If there is a desire to promote independence whilst ensuring people remain in their own communities, closing or reducing these services will only make the issue worse.
44. Many of the legal cases COPNI has in its caseload are in relation to domiciliary care and how older people are refused domiciliary care due to their needs being too great to be met at home or the inability of the HSCT to provide overnight care. This creates a huge amount of confusion, with many older people now aware of the drive for 'home to be the hub' of care, yet being told their needs cannot be met at home and being pushed towards nursing home care.
45. The numbers of people requiring domiciliary care services in Northern Ireland are increasing and will continue to do so. And this means that people with increasing complex needs like dementia and other long term needs will be treated through

primary and community care provision. Yet the Department of Health in England has projected that there will be a funding gap in social care alone of £6 billion in England by 2027. As Northern Ireland is faced with the same pressures as England and the rest of the UK, it too can expect a proportionately similar shortfall in funding.

46. The DoH in Northern Ireland have also stated how the existing system cannot cope with the combined pressures of increased expectations, an ageing population and limited resources. Over the coming years, the funding available for care and support in Northern Ireland is unlikely to increase to match the demand that will continue to grow.
47. There is also the issue of 'unmet need'- many individuals with mild or moderate care needs do not receive domiciliary care services for a number of reasons (funding, increasing demand for complex need, etc). Whilst there is a focus on assisting individuals with the most complex needs (due to the demand on resources, this unfortunately results in an unmet need for others, which in turns can put pressure on acute hospital, especially during winter months).
48. Through conducting stakeholder engagement into how domiciliary care is delivered in Northern Ireland, it has pointed towards an inconsistency across HSCTs in how eligibility criteria for receiving domiciliary care are applied coupled with different tariffs dependent on HSCT area.
49. In light of the recently revised minimum standards for nursing homes, COPNI believes that it is time to re-examine the minimum standards for domiciliary care. Quality care that meets the needs of older people should be in place whatever the setting and whenever it is needed.
50. It is also important to note that there are no dementia specific standards within the domiciliary care minimum standards - with numbers of people with dementia forecast to rise to 23,000 by 2017 and around 60,000 by 2051. If more older people are living at home for longer with dementia, appropriate standards, training and resources must be in place to support the specific requirements of this section of Northern Ireland's older people.
51. It is vital that the regulation of domiciliary care includes quality indicators that reflect the 'lived experience' of older people and that measure whether service users are being treated with dignity and respect, have a good quality of life and are receiving the level of care and support that they need. It is not acceptable that it would be possible to regulate domiciliary care without assessing this.
52. Many older people do want to stay at home, and COPNI is aware of the balance that needs to be maintained between managing older people's expectations of the

type of care that can be provided in the home with the level of care that can be delivered by the care providers given the current economic difficulties of today.

53. The importance of reduced hospital stays cannot be underestimated. Not only does it bring cost benefits to the HSC system, but COPNI is told by many older people that they are anxious about going into hospital, even for minor procedures due to fears of contracting hospital acquired infections and delays in getting home again.
54. There is a key role to be played by occupational therapists in supporting older people to regain independence and functionality especially after a period in hospital. Often, following a health issue or incident, an older person's confidence may have suffered – it is during this period they depend on the personal and professional support occupational therapists can provide. Someone taking the time with them to understand their needs.
55. Providing support to older people through reablement means occupational therapists help older people get back to doing the everyday things to help them regain independence, often without needing to introduce a domiciliary care package. This ensures older people do not end up isolated from the activities that keep them mobile and actively participating within their communities, and has a positive impact on quality of life. Many older people also rely on occupational therapy services from responding to falls; providing acute services at home, to reablement.
56. However, whilst reablement allows older people to regain and maintain their independence after a period of rehabilitation, this will not always be the most suitable course of action and will only be appropriate for a number of older people.
57. One example of good practice is programmes such as the Acute Care at Home for the frail elderly, which work to ensure older people are supported to remain at home. Evidence proves that when it is appropriate to be treated at home, older people will have better outcomes there than in a hospital setting.
58. This was a pilot scheme run by the Belfast HSCT, which made sure that each person involved got the care they need in the right place and at the right time.
59. The Acute Care at Home Service is a short-term service to support elderly patients mainly over the age of 75 to:
 - Avoid unnecessary admission to hospital
 - Provide acute medical care at home
 - Help them to be as safe and independent as possible at home
 - Enable them to leave hospital as soon as they are medically stable to do so

- Our specialist staff in the Acute Care at Home Team (ACHT) will provide care or support during the Patient's acute illness.

60. The programme provides a 'Comprehensive Geriatric Assessment' at home. The patient will have the same access to diagnostics and laboratories as if they were a hospital inpatient.⁵ This in turn relieves pressure on hospital outpatient services.

61. There is also a clearly evidenced need to ensure transport and housing are integrated to support people in the community. The DoH needs to develop a long term plan to integrate housing and transport into the care of older people to allow them to stay in their own homes and communities as long as is safe for them to do so.

62. Community transport is a lifeline for many older people, especially those living in rural areas to allow them to access HSC services, again reducing the need for unplanned hospital visits. Community transport provides links where it is not feasible for traditional transport providers to do so. Therefore it cannot be underestimated how detrimental the reduction or removal of a service such as this will be for those older people who rely so heavily on it.

63. Many older people also rely on the 60+ SmartPass for accessing transport links throughout Northern Ireland. The concessionary travel pass entitles the holder to free concessionary travel within Northern Ireland on scheduled services operated by Translink and other operators. Free public transport is a vital support for thousands of older people across Northern Ireland to ensure that they can continue to engage with their community and enjoy a social life, with many depending on the scheme as the only means of getting out of the house. Free public transport also enables older people to continue to play a positive role in the community in many different ways such as providing childcare, caring and volunteering, as well as to attend medical appointments – all of which impact on older people's ability to regain, retain and maintain their independence.

64. Developing more supported housing options is also vital to ensure older people are not forced into residential and nursing homes due to lack of choice and because there are no other feasible options to help them maintain their independence.

⁵ BHSCT Website - <http://www.belfasttrust.hscni.net/services/AcuteCareatHomeServiceforOlderPeople.htm>

Priority Area Three: Supporting Carers

What the Panel are looking for:

- a. Evidence of effective interventions including respite care/short breaks which can support carers in their caring role, including increasing resilience;*
- b. Initiatives which can encourage people to act as carers in the context of changing society (e.g. often greater distances between family members, increasing numbers of people working).*

65. Effective interventions for carers including respite care and/or short breaks should be regular and established at the earliest point – not just at the point of crisis. This could be something that is ascertained through a carers assessment and updated on a rolling basis. Only instigating respite at the point of crisis will not ensure the best care for both the carer and the older person being cared for.
66. The Commissioner's office was approached by the son of an older person (Mrs B) aged 90 years who is frail and vulnerable and wishes to remain living in her own home. Mrs B's son has sought additional respite and support for himself and his mother and has highlighted an apparent lack of a joined up approach in the HSCT between Mrs A's social worker, GP, community mental health team, domiciliary support team and adult safeguarding teams. This case highlights a need for proactive support for carers and the need for one informed point of contact to assist in complex and crisis situations.
67. The previous Commissioner published research on the low level of uptake on carers assessments in June 2014. The research highlighted how the level of uptake of carers assessments by older carers remains unacceptably low, despite a statutory obligation by the HSCTs to inform carers of their right to an assessment.
68. The research highlighted how there are no targets set for the HSCTs to help to identify older carers and to deliver on their statutory requirement. It also emphasised how many older carers do not recognise themselves as carers however more information and support would be welcomed by those who do identify older carers.
69. The carers assessment process is viewed by many older carers as a "paper exercise" that does not result in the support and services needed by the older carer, therefore making it a pointless exercise that only serves the HSC Trust in

meeting its obligation.

70. Providing better assistance for carers should be a priority for HSCTs. COPNI research ⁶ highlights how the total economic value that older carers contributed to the Northern Ireland economy in 2012 was £1.02 billion with the total rising to £34 billion over the next fifty years and how the 2011 census indicated that 23.2% of unpaid care is provided by people aged 60 and over.⁷ One way of ensuring older carers receive the support they need to allow them to continue caring could be to introduce 'Carers Navigators'. This is a service currently used for primarily for people with dementia and their families/carers.
71. The purpose of the navigator is to provide an individualised information and signposting service to people with a diagnosis of dementia. The navigator also provides an extended information and signposting service to immediate carers, families and friends of the people who are referred to the service. This is an example of good practice and could be extended to all people as an initiative that encourages people to act as carers in the context of changing society.

⁶ COPNI – Appreciating Age: Valuing the positive contributions made by older people in Northern Ireland (2014)

⁷ COPNI – Supporting Older Carers: Examining the reasons of the low level of uptake of Carers Assessments by older carers in Northern Ireland (2014)

Priority Area Four: Choice and Control

What we are looking for:

- a. Views on what barriers exist which restrict choice and control;*
- b. Initiatives which can empower people to exercise choice and control when they may be reluctant to do so;*
- c. Views on balance between recognising a service user's preferences about how their needs are met and potential additional risk to that service user as a result of the choice.*

72. Whilst the issue of self-directed support has been lobbied for by the disability sector, COPNI believes there are serious issues with this type of social care support being solely offered for older people. There is a very clear difference in a person with a disability who has successfully used self-directed support for a large part of their life and (often) a frail elderly person who has been awarded a care package at or after a crisis situation in their life and having self-directed support (usually direct payments) offered as the first option for care.

73. Based on cases the legal team in COPNI are currently representing, direct payments have presented the following problems:

- a. Hard to get staff generally – lack of suitable prospective employees in the area.
- b. Financial incentives – pay is lower than care workers may receive in other employment.
- c. Tax implications – care workers lose their benefits when they cross a certain threshold of earnings/hours. They do not want to be ‘on the books’ as is required.
- d. Lack of reliable staff – there can be high employee turnover or the care worker does not fulfil their role with obvious consequences for the person in their care.
- e. Onerous responsibilities as an employer – payroll, insurance, holiday pay, maternity pay, grievances, HSCT reviews and tax returns all have to be dealt with directly by the older person and/or their family member/carer.

74. There are also reported cases in relation to HSCT providing inadequate levels of care in rural areas right across Northern Ireland, and when the HSCTs cannot meet these needs there is a trend of pushing the use of direct payments for older people to source their own care. Many older people and their families are also unaware of the fact that if they decide to use direct payments as part of self-directed support, there can be serious difficulties in returning this responsibility

back to the HSCT if direct payments no longer meet the needs of the older person.

75. The Commissioner's office has been approached on many occasions by older people and their family members/cares in relation to this issue. One example is when the office was contacted by the family members of an older person (Mr A) aged 91 years who was living with dementia and who had been discharged home from hospital after suffering a heart attack. Prior to entering hospital, he had availed of a support package which included visits from carers twice a day and two overnight stays per week.
76. When he came home, the HSCT removed the night support on the basis that Mr A was bed bound and that his daily support needed to be increased from two visits to four visits. The family were able to support their father during the day and asked instead for additional night time support to enable them to have overnight respite. This would still fall within the same number of hours being offered by the HSCT, but in a different arrangement. The HSCT refused and stated that the family would have to procure the additional night stays privately or else consider moving Mr A into nursing care.
77. Mr A did not want to leave his own home and when the family attempted to arrange for private night time support they learned that there was a severe shortage in their area. The flexible support requested by the family was unavailable leaving both Mr A's needs and those of his carers feeling unsupported and frustrated.
78. Another example highlights the problems Mrs. C, who is a 75 year old lady who has a number of specific assessed health needs and requires regular domiciliary care, experienced. Mrs. C's domiciliary care package provided by the HSCT was withdrawn in January 2016.
79. Since then she has been informed that there are no other in-house care package options available due to a general shortage of domiciliary care staff in the HSCT area. This position is being reviewed on a monthly basis to check for availability. The only other option for at home care presented to Mrs. C was direct payments. This places a heavy responsibility on Mrs. C's daughter as she is fulfilling the duties as an employer.
80. These cases clearly highlight the barriers which exist in relation to older people fully utilising self-directed support (and primarily direct payments).

Priority Area Five: An effective, innovative and resilient care and support market underpinned by a valued social care workforce

What the Panel is looking for:

- a. Evidence outlining specific challenges to the care and support market and workforce in the North;*
- b. Initiatives which can improve the functioning of the care and support market, including improving public levels of trust in the independent sector;*
- c. Initiatives which can improve the experience of the care and support workforce and bolster recruitment and retention of the care and support workforce.*

81. In September 2015, COPNI held a summit to bring together individuals and organisations involved in the design, procurement, delivery and regulation of domiciliary care services to discuss what good quality, well-resourced and sufficiently supported domiciliary care should look like in Northern Ireland.

82. Prior to the summit, the Commissioner's team engaged with domiciliary care workers from both the statutory and independent sectors to hear directly from them about the experience of working in this sector. Domiciliary care workers are amongst the lowest paid workers in the Health and Social Care sector. The work they do is physically and emotionally demanding and many of those workers who spoke directly to us are committed, diligent and have great compassion for the older people they support and care for.

83. However, this issues discussed at the summit would also be relevant for all social care workers. There are specific challenges to the care and support market and workforce in Northern Ireland that need to be addresses as a priority to ensure the sustainability and continuity of care.

84. Recurring themes COPNI are aware of in this area include;

- Salary – poorly paid care staff are likely to take up offers of better paid work for less hours in other sectors
- Training and development opportunities – lack of training means social care workers are being asked to perform increasingly medicalised care without the proper training.
- Risks and pressures – Understaffing is leading to potentially unsafe practices.

Salary

85. Investment in domiciliary care at levels that do not meet the current demand lead to huge pressures on tariffs paid to providers. Almost the entire domiciliary care workforce is paid at the minimum wage level.
86. The introduction of increases to the minimum wage have raised concerns among contracted providers of care. The Commissioner has heard from the United Kingdom Homecare Association (UKHCA) that discussions of the HSC Board suggest that no further increases to the tariff will be possible to meet this increased salary cost.
87. It is clear that many of these workers are highly committed to their jobs and the role they undertake. However they experience pressure and distress when they are working in circumstances which do not enable them to provide good quality, compassionate care for older people. As previously referenced it is frequently the case that domiciliary care workers are also required to meet the costs associated with their work, including;
- Travel costs
 - Uniform
 - Training and development
 - Compulsory registration
88. It is essential that career progression is available for domiciliary care workers. At present a worker with fifteen years' experience can be on the same rate of pay as someone who has been in work for two days and conditions vary greatly for those working in the statutory sector compared to the independent sector.

Training and development

89. Domiciliary care workers who have contacted the Commissioner's office have highlighted how little training and supervision is actually mandatory before being able to undertake hands-on work with older people who need care in their own homes.
90. COPNI has learned about domiciliary care workers who are providing care and support for older people with complex medical needs or living with dementia as part of their everyday routine visits. Many domiciliary care workers have to provide care such as changing catheters and stoma bags or treating ulcers and pressure sores.
91. Evidence gathered from domiciliary care workers highlights that frequently, due to staff shortages, care workers are required to provide care to older people with varying levels of complex needs at short notice, without a proper handover and in some cases, without proper training. Despite policies and practices that restrict

domiciliary care workers to tasks involving hygiene, feeding and toileting, there is evidence that workers are being required to carry out tasks which are properly delivered by nurses or other health care professionals.

Risks and pressures

92. Understaffing poses serious risks and creates pressure in all social care settings. It can place social care workers in dangerous situations in relation to lone working and can also mean that those older people in receipt of social care are not receiving the care they rely on in a safe manner.
93. In addition, there appears to be a lack of re-assessment of need in relation to older people who are in receipt of domiciliary care packages. Domiciliary care packages begin with an assessment of the older person's needs (using the NISAT) and the development of a care plan which is then provided by a HSC Trust or contracted by the HSC Trust to an independent provider to deliver.
94. Domiciliary care workers have told the Commissioner that there are instances when an older person's needs are assessed but not in the context of their own home. This means that a full picture is not provided of the support required for an older person to remain in their own home. They also say that re-assessments to ensure that changing needs are being met for those in receipt of domiciliary care do not happen as scheduled.
95. Feedback to the Commissioner's office suggests that varying approaches to the use of the NISAT tool exist in practice at a local level. The delivery of good quality domiciliary care relies on an effective and up to date assessment of an individual's needs taking place.
96. Failures to accurately assess needs, or to note and adapt to changing needs of older people raise risk levels for both the older person and for the care worker. For the older person, their support needs may not be fully addressed, or important changes in their capacity to carry out tasks for themselves may be missed. For the worker, they may find themselves required to carry out unfamiliar tasks or unable to fully address needs that the older person may have. Good quality care planning and re-assessment will enable older people to live healthily and securely in their own homes for longer, reducing the cost of alternative care, e.g. in hospital settings, for the health service.
97. What measure could be introduced to mitigate these issue?
- A regional tariff (the value that providers are paid for providing domiciliary care) should be set. This regional tariff should allow for sustainable rates of pay and conditions for domiciliary care workers to be introduced.

- It should be ensured that all costs incurred by the domiciliary care worker through work (including mileage costs, training and uniform) are reimbursed or paid for by the employer.
- A recognised qualification framework with a clear pathway for career progression for domiciliary care workers should be introduced.
- All domiciliary care staff should be trained to the level required to provide safe and effective care.

98. If these recommendations were introduced, it would begin to improve the experience of the care and support workforce and bolster recruitment and retention of the care and support workforce.

Regulation

99. The current regime of regulation and inspection for domiciliary care providers gives RQIA the authorisation to regulate and inspect domiciliary care standards in line with the DoH minimum standards. The Commissioner advises that standards must focus more on the user experience of care rather than inspecting the records held by the organisation providing this service.

100. As already stated, the population of Northern Ireland is ageing and therefore more older people will be living with dementia. The projected figures for older people living with dementia in Northern Ireland show numbers rising to 23,000 by 2017 and around 60,000 by 2051.⁸

101. There are currently no dementia-specific standards within the domiciliary care minimum standards. If older people are living at home for longer with dementia, appropriate standards, training and resources must be put in place to support the specific requirements of these older people.

102. The regional dementia strategy outlines Ministerial commitment to enabling people with dementia to remain in their own home environment and maintain their independence for as long as is possible. This means that domiciliary care provision will have a key role in supporting the implementation of this strategy. It is imperative that the standards ensure appropriate care and support for older people living with dementia.

103. Since the development of the current set of minimum standards, published 2008 and updated 2011, the Commissioner advises two specific changes to the standards framework. These are;

- Dementia specific standards
- Requirement that the user experience of older people in receipt of domiciliary care is included as an essential part of the inspection of the care provider.

⁸ DHSSPS - Regional Strategy on Improving Dementia Services in Northern Ireland (2011)

104. The current minimum standards for domiciliary care and in particular the current inspection policy and regime focuses most heavily on the inspection of the records held by the domiciliary providers' organisations. Although the standards do reflect the service users perspective (standards 1-7) these focus on ensuring the user is aware of the services to be provided and other elements of practice such as the referral arrangements and management of medicines.
105. The Commissioner advises that there is a need for a duty to be placed on the regulator to seek feedback on the user experience of older people when inspecting the effectiveness of the provider's service. Until recently domiciliary care provision was regulated without any contact with the older person in receipt of services.
106. Since 2013, RQIA has built in a small sampling of user feedback of domiciliary care users but this is insufficient to provide a sound overview of the real experience of domiciliary care in the home, and RQIA enabling legislation places no such requirement on them to do so.

Priority Area Six: Financial Sustainability

What the Panel is looking for:

- a. Evidence of efficiencies within the care and support system which could release funding for investment in additional services;*
- b. Factors unique to the population in the North which should be considered in the context of charging for care and support services;*
- c. Evidence of the impact of charging on people who use services and care provision;*
- d. Measures which could be adopted to address the perceived unfairness of charging for residential care.*

107. The current structure of adult social care stems from the system introduced in Great Britain in 1948. Unlike healthcare which is free in primary and secondary settings, in England adult social care is fully means tested and social care services are resourced separately from the NHS falling fully to the responsibility of local government.

108. The position in Northern Ireland is significantly different than that of the rest of the UK. Since 1973, an integrated structure of health and social care has been in place in Northern Ireland and currently five integrated Health and Social Care Trusts have responsibility for hospital, community and social services. According to the ARK Programme (a research programme run by the Ulster University and Queen's University Belfast), the funding of social care has not kept pace with health care funding, nor has it increased in line with demographic changes resulting in greater demand for services.

109. It is clear that there has been a shifting of responsibility (and cost) between health care, social security and social care with substantive aspects of long term care now categorised as social care rather than health care provision. This can be viewed as an attempt to limit the cost of health care ⁹ due to certain key elements of social care being means tested. There has also been a significant shift towards individuals contributing towards their own care on the basis of a means test with successive governments suggesting that people needed to be encouraged to make provision for the cost of their long term care.

⁹ ARK – Attitudes to Social Care for Older People in Northern Ireland (2012)

110. Inadequate research has been conducted in Northern Ireland to adequately guide and support essential future planning of both healthcare needs of older people together with adult social care and support in Northern Ireland. Too often reviews consider one area in the absence of the other. There is a lack of transparency around decisions taken by Government and a confusing plethora of tariffs and rates charged for different services within trust boundaries and an inconsistent application of these services on a regional basis.
111. There has been no up to date assessment of the cost and resourcing of adult social care. In 2004, Professor John Appleby's reviews in 2004 ('Health and Social Care Services in Northern Ireland'¹⁰) and 2011 ('Rapid review of Northern Ireland Health and Social Care funding needs and the productivity challenge: 2011/12 – 2014/15') identified the funding gap that had developed and the productivity challenge now facing the health service in Northern Ireland. Specific guidance on modelling for tariffs for various care settings was not considered.¹¹
112. Both the Donaldson Review and the expert panel on the configuration of health and social care services in Northern Ireland, chaired by Professor Bengoa, focus mainly on health care. COPNI has identified a need for robustly evidenced analysis setting out the real cost of adult social care in each of the settings currently under pressure i.e. residential care, nursing home, domiciliary care, Day Centres, Aids and Adaptations, Personal care, Community meals, Social housing and safeguarding and crossover areas including NHS Continuing Healthcare.
113. Previous discussions between COPNI and DoH had already identified an absence of prioritisation of the necessary resources required to be able to commission an independent economic review of the provision of adult social care and support services. A commitment from the DoH to establish clarity on the cost of adult social care was not fulfilled under the last Programme for Government period nor is such a commitment contained within the current Programme for Government period.
114. In 2012, the then Department for Health, Social Services and Public Safety (now DoH) launched a consultation that looked at the future of adult care and support in Northern Ireland. The 'Who Cares?' document stated how "it is widely accepted that the adult care and support system in Northern Ireland is coming under increasing pressure for a number of reasons, including increased expectations, an ageing population and limited resources".¹²

¹⁰ Appleby, J. – Independent Review of Health and Social Care in Northern Ireland (2005)

¹¹ Appleby, J. - Rapid review of Northern Ireland Health and Social Care funding needs and the productivity challenge: 2011/12 – 2014/15 (2011)

¹² DHSSPS – Who Cares? The future of adult care and support in Northern Ireland (2012)

115. The consultation document also explained that if the DoH is to be in a position to respond to that challenge, it needs to find a fair, sustainable and efficient way to fund and provide care and support in the future, sharing responsibility with the individual, to ensure that those who need it have access to high quality, value for money care, at the right time and in the right place.¹³ Due to these pressures over the coming years, the funding available for care and support in Northern Ireland is unlikely to increase to match the demand that will continue to grow.

116. In 2011, London School of Economics (LSE) produced a report¹⁴ that detailed the fundamental elements of successful long-term care funding systems. The report highlighted three main objectives;

- a. Equity - ensuring that care funding systems are equitable is an important policy goal. At a fundamental level there is an aspiration that care and support systems should achieve equal access to support for people with equal need, where 'need' takes into account the physical and mental dependency of the individual and their carer.
- b. Efficient use of resources – another objective for any long-term care system is that it should get the best value from resources. This principle requires that resources are used where they give the greatest benefit, and that services and support are produced at the lowest cost for the required quantity and quality.
- c. Sustainability of the social care support system - self-evidently, social care funding systems need to remain financially solvent and also to continue to command public and political support. The sustainability of a system in this sense will be affected by:
 - i. People's perceptions of its fairness and value, set against the cost (affecting political sustainability).
 - ii. The affordability of the system to the public purse. Affordability is a relative concept but the system needs to ensure that the costs of the system stay generally in line with societal willingness to pay for its benefits.
 - iii. The system's capacity to adapt to changes in circumstances to remain solvent. For example, both the willingness and capacity for the country to cover the costs of the system may change with economic prosperity; a sustainable system will be one that adapts quickly to the fiscal position of the economy and to perceptions about the value of care and support for older people.

¹³ DHSSPS – Who Cares? The future of adult care and support in Northern Ireland (2012)

¹⁴ LSE - What Works Abroad? Evaluating the funding of long-term care: International perspectives (2011)

117. Ultimately what is needed now is an in-depth economic analysis – required to underpin and inform an honest conversation with Government about the ‘real’ cost of care. Without this analysis, it seems that any reform of Adult Care and Support will be the “tail that wags the dog” – policy reform dictated by what is affordable rather than what is good practice.

118. In addition, there appears to be little empirical evidence that illustrates how cash payments are effective in stimulating care provider markets or in regulating or improving the quality of care – primarily due to how the HSCTs set the agreed tariffs paid to care providers within each Trust area.

Conclusion

119. The Commissioner is deeply disappointed that the ‘Who Cares?’ consultation, launched in 2012, which examined what reform of the adult care and support system in Northern Ireland, is still not further advanced in 2017. The Commissioner remains hopeful that this call for evidence will be the start of difficult conversations that will ultimately lead to the provision of sustainable and compassionate care for older people, when they need it and in the place where their needs can be most appropriately met.
120. The Commissioner has also expressed disappointment that there is no specific commitment to older people within the draft Programme for Government and no reference to the reform of adult care and support. Without this visible commitment, there is no guarantee from government that this reform agenda is a priority.
121. Given the current political instability, there is also concern that this reform agenda will not be of the utmost priority with a potential new Minister of Health and a potential different appetite for change. Better care for older people must not be lost in an unstable political landscape.
122. If you would like to discuss any of these points in further detail, please do not hesitate to contact the Policy Team via:

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