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An Roinn Sláinte
Männystrie O Poustie
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RAPID LEARNING REVIEW OF DOMICILIARY CARE IN NORTHERN IRELAND

October 2020

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FOREWORD

Domiciliary care is an essential frontline community service which has remained in place throughout the pandemic. It remains a vital service as the pandemic continues and this review is a very welcome initiative that will support the delivery of domiciliary care as we move forward.

I am very grateful to NI's 18,000 plus domiciliary care staff for demonstrating their huge commitment to those they support in what have been very challenging and frightening times. Service user feedback has talked about the kindness, care and continuity that their domiciliary care staff have provided.

However, it is also important to note that we didn't get everything right and there are many lessons to be learned in this review. We've had feedback about many practical things that staff struggled with such as PPE, training and testing. The review also tells us that we need to improve on the support we provide for domiciliary care staff. Staff also told us that they sometimes felt overlooked and that domiciliary care didn't get the recognition it deserved. The review has also highlighted the wider systemic issues that affect domiciliary care. I am very conscious that the value of the service provided in domiciliary care is not always reflected in the pay, terms and conditions of the workforce. The lessons from this review on these issues will be included in the Reform of Adult Social Care process which continues alongside the pandemic response.

Domiciliary care service users and their family carers also told us that they sometimes felt forgotten about. Many felt afraid to use domiciliary care because of fear of infection during the earlier stages of the pandemic and for many others, domiciliary care was the only service that continued for them. Both situations placed service users and carers under very significant pressure.

This review seeks to learn the lessons of the pandemic to date and to use that learning to inform the ongoing response. I am very grateful to those who contributed their time, experience and expertise to the work of the review. I'm particularly grateful to those service users and family carers who contributed their lived experience to the learning. I hope we can continue to work in partnership with each other to deliver on the recommendations.

SEAN HOLLAND
Chief Social Worker Officer/Deputy Secretary

"The individual kindness of care workers makes a big difference"

Service user comment

"I would go as far to say those caring at home were forgot about. The suspension in my eyes should have been reviewed after 1 month"

Family carer comment

"I am feeling drained and nervous about the 2nd wave. We are getting equipped to work from home - a lot of community staff now are. It is strange going to be with so many isolating and during Winter with viruses we usually get into our system. I'm face to face in homes, so who knows what they will recommend. Its strange times!"

Staff comment

"Thanks for your interest - it makes us feel less alone and respected when asked how it has been".

Staff comment

"I felt the unit I work in was left abandoned, with staff on sick leave and staff shielding, our work load trebled and no extra staff or support was given".

Staff comment.

AIMS OF THE REVIEW

This Rapid Learning Review has collated and considered any learning about domiciliary care issues during the Covid 19 pandemic in NI in order to inform current and future planning as the pandemic continues. It is acknowledged that there are many aspects of the current systems of domiciliary care that need reformed but this review has concentrated on immediate Covid related learning and actions. Learning from this review about systemic issues and the longer term issues for domiciliary care has been passed to the DoH's Reform of Adult Social Care team.

The review focused on four themes:

- Service user and carer experience
- Service provision
- Workforce experience
- Infection prevention and control

Four key questions were asked:

- What worked well?
- What didn't work well?
- What lessons have been learned?
- What next/suggestions for action?

PROJECT TEAM

Name	Role	Organisation
Aine Morrison	Chair	OSS Professional Officer, DOH
Patricia Higgins	Lead for Workforce	CEO, NISCC
Laura Collins	Lead for Service User/Carer	Lived Experience Expert
Joyce McKee	Lead for Service Provision/Business Continuity	Programme Manager, HSCB
Pauline McMullan	Lead for Infection control	Allied Health Professions Consultant, PHA
Lorraine Conlon	Project Co-Ordinator	Office of Social Services, DOH
Rosemary Smyth	Secretariat	Office of Social Services, DOH
Ann Gamble	Steering Group Member	Service User
Geoff Hayter	Steering Group Member	Service User
Brendan Whittle	Steering Group Member	Deputy Director of Children and Social Care, HSCB
Colin Dunlop	Steering Group Member	Head of Elderly and Community Care, DOH
Linda Kelly	Steering Group Member	Deputy Chief Nursing Officer, DOH
Kathy Kearney	Steering Group Member	Operations Manager, Regulated Services, SEHSCT
Joanne Armstrong	Steering Group Member	Contracts, Social Care Procurement and Commissioning Manager ,SEHSCT
Clodagh O'Brien	Steering Group Member	Home Care Service Manager, BHSCT
Dory Kidd	Steering Group Member	Director, Rosecare Lodge
Ryan Williams	Steering Group Member	Director, IHCP
Leslie-Anne Newton	Steering Group Member	Director, ARC NI
Lesley Megarity	Steering Group Member	CEO, Domestic Care NI
Pauline Shepherd	Steering Group Member	CEO, IHCP
Julie-Ann Walkden	Steering Group Member	Deputy Director for Assurance, RQIA
Rodney Morton	Steering Group Member	Executive Director of Nursing, Midwifery & AHP, PHA
Johny Turnbull	Steering Group Member	Involvement Manager, Patient and Client Council
Jillian Martin	Steering Group Member	Professional Officer, Office of Social Services, DOH

Thank you to both UNISON and NIPSA who contributed to this review. The Department recognises the value of engagement and although we unfortunately did not effect this from the outset, we are grateful for the consideration and comments from both Unions on the draft report and recommendations.

Literature Review

The DoH is also grateful to Mary McColgan, Emerita Professor of Social Work, Ulster University who provided a literature review for the project. This focused on a review of a selected body of literature specifically covering the post March COVID 19-time scale. The preliminary work was undertaken by Laura Collins, Lived Experience Expert whose search identified 37 reports, articles, and regional and government guidance. Further internet searches led to consideration of an additional 14 reports and articles. Mary Maguire, HSC Librarian also undertook a literature search which was included in the review.

Contact was also made with Professor Gavin Davidson and Claire McCartan, QUB who are undertaking a broader rapid review of Adult Social Care. In sharing their initial COVID and Social Care search results, they offered access to articles in their review and a further 15 articles were examined.

The review was undertaken over a two week period and has focused on key messages reflected in the literature. It is not an exhaustive examination of the literature but it draws on a broader national and international context to supplement the regional findings from the lead representatives exploring the four themes.

The literature review also included evidence from across the UK and further afield so references to legislation, policy and organisational systems may not apply in NI and may not directly transfer but are included to allow for potential learning across systems.

Literature review references are attached at Annex A.

Review Methodology

Each theme lead was asked to engage with relevant stakeholders to seek their views about the domiciliary care pandemic experience to date.

In addition, a workforce and management survey was completed which asked for feedback on three of the four themes. These were workforce, service provision and infection prevention and control.

An overarching steering group was also formed, which met twice. The steering group provided additional feedback under the four themes and also provided commentary on the draft report.

This report is divided into six core sections. These are:

1. Workforce and management survey outcomes;
2. Workforce theme;
3. Service provision & business continuity theme;
4. Service user and carer experience theme;
5. Infection prevention and control theme;
6. Recommendations.

The sections on the four themes are organised under the four questions the review asked: What worked well? What did not work well? What lessons were learned? What were the suggestions for action?

Each theme firstly considers the literature review findings for that theme and then reports on the stakeholder feedback. Literature review findings are shown in blue. Stakeholder feedback has been reported largely as given. It has not been subject to any further analysis and should be read as representing the sometimes diverse opinions of a wide variety of people involved in domiciliary care.

1. WHAT IS DOMICILIARY CARE?

1.1. Domiciliary care is an essential frontline community care service which has been sustained throughout the pandemic and needs to continue throughout the pandemic and beyond.

1.2. The current DoH definition is:

> **"It is *the range of services put in place to support an individual in their own home. Services may involve routine household tasks within or outside the home, personal care of the client and other associated domestic services necessary to maintain an individual in an acceptable level of health, hygiene, dignity, safety and ease in their home*."**

However over time, understanding of what is included within the definition of domiciliary care services has expanded to include increasingly complex tasks such as the administration of medication; support to people with advanced dementia; stoma and catheter care; support to people with dysphagia and end of life care.

Domiciliary care also plays a key role in underpinning a more efficient healthcare system through supporting timely discharges from secondary care.

1.3. Supported Living - Some forms of domiciliary care are provided in what are known as supported living services. Supported living provides extra housing support and/or an element of care to meet the support needs of individuals and help them lead as independent a life as possible. Settings may be shared between several people and have communal space or consist of separate units of self-contained accommodation – with or without communal space. Supported living services are delivered in people's homes, involving tenure rights for renting or ownership with associated occupancy rights. In general, people move into specific housing in order to be able to access the support from a supported living scheme. This differs from a more traditional model of domiciliary care where the person receives the support in their existing home.

1.4. Domiciliary Care Statistics

- 16,206 registered domiciliary care workers;
- 531 registered domiciliary care managers;
- 2,073 registered supported living workers; and
- 120 domiciliary care providers in Northern Ireland.

Source NISCC Register September 2020

The DoH annual domiciliary care survey in 2019 details the following figures for a sample week.

Contact Number of Hours Per Week: 276,188 contact hours of domiciliary care provided (**29%** by statutory sector, **71%** by independent sector).

Clients Receiving Domiciliary Care
HSC Trusts directly provided/commissioned domiciliary care services for **23,425 clients.**

Duration of visits - 31% - 15 mins or less

54% - 15-30 mins

15% - over 30mins

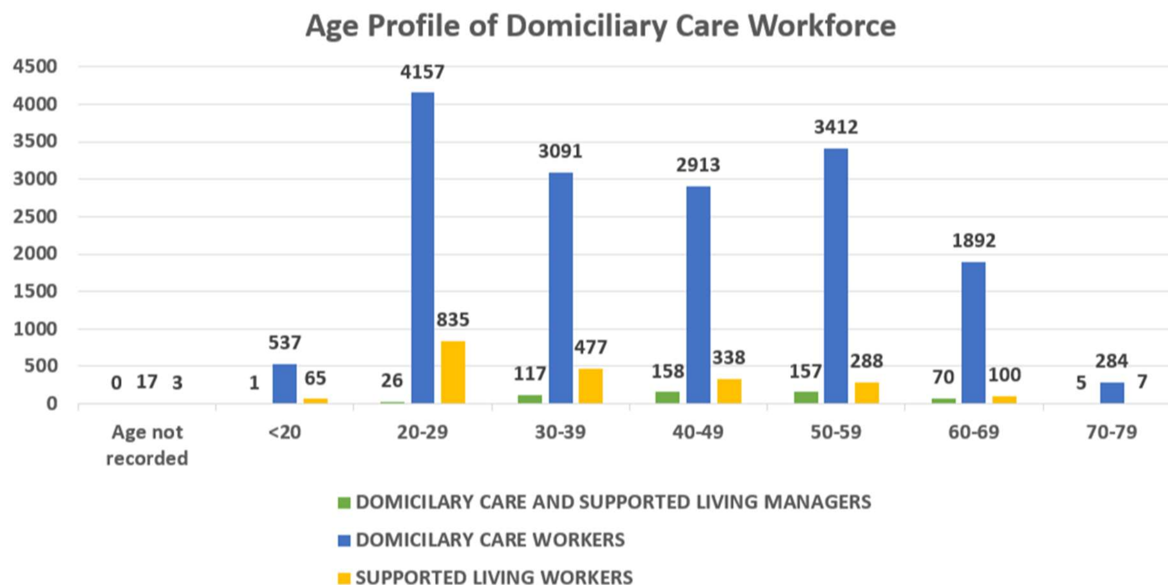
Clients Receiving Intensive Domiciliary Care

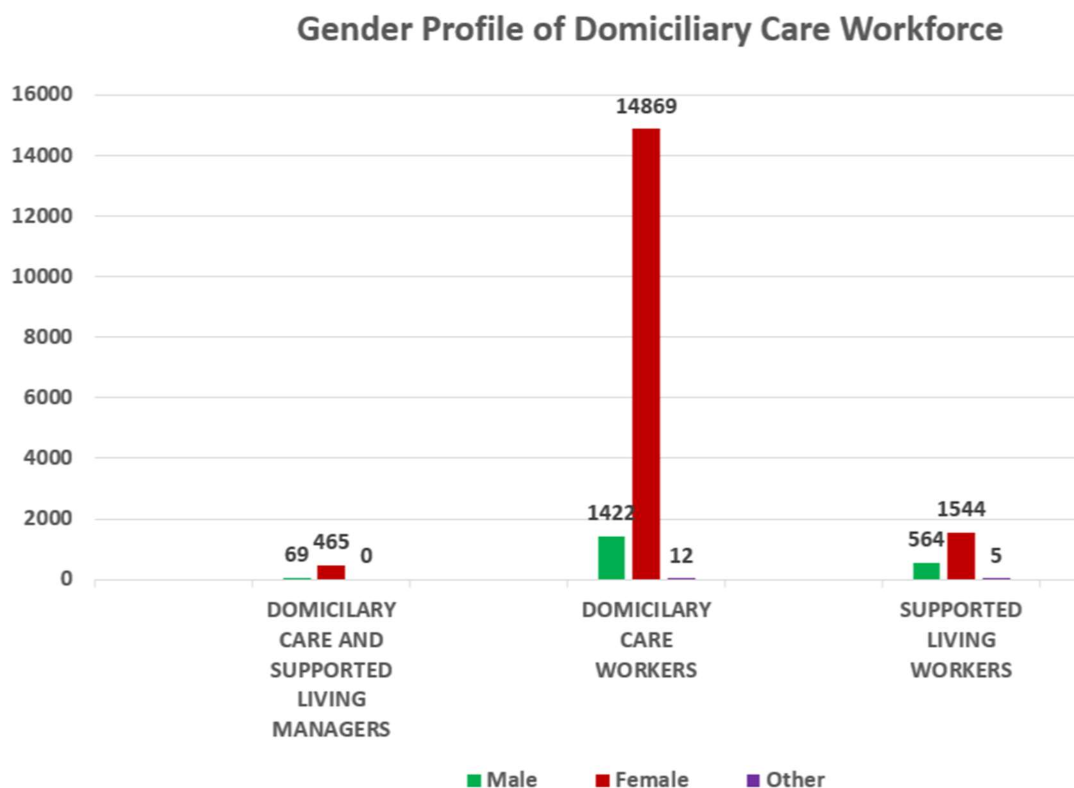
- 8,904 clients received intensive domiciliary care services (this is defined as 6 or more visits and more than 10 contact hours during the survey week. Of these;
- 80% were older people;
- 11% had a physical disability;
- 5% had a learning disability; and
- 4% had mental health difficulties.

Age Group of Service Users: 84% - aged 65 + years old
16% - aged 18-64 years old

1.5 Workforce Profile

Source – NISCC register





2. SURVEY OF DOMICILIARY CARE WORKFORCE AND MANAGERS CARRIED OUT BY NISCC, COVERING WORKFORCE EXPERIENCE, SERVICE PROVISION AND INFECTION PREVENTION AND CONTROL

While there were variations on individual questions, an initial analysis did not find any substantial differences between the responses of HSCT staff and Independent Sector staff. A planned repeat survey will include a more detailed analysis of any differences.

Quotations from the survey can be found at Appendix C.

2.1. NISCC Survey

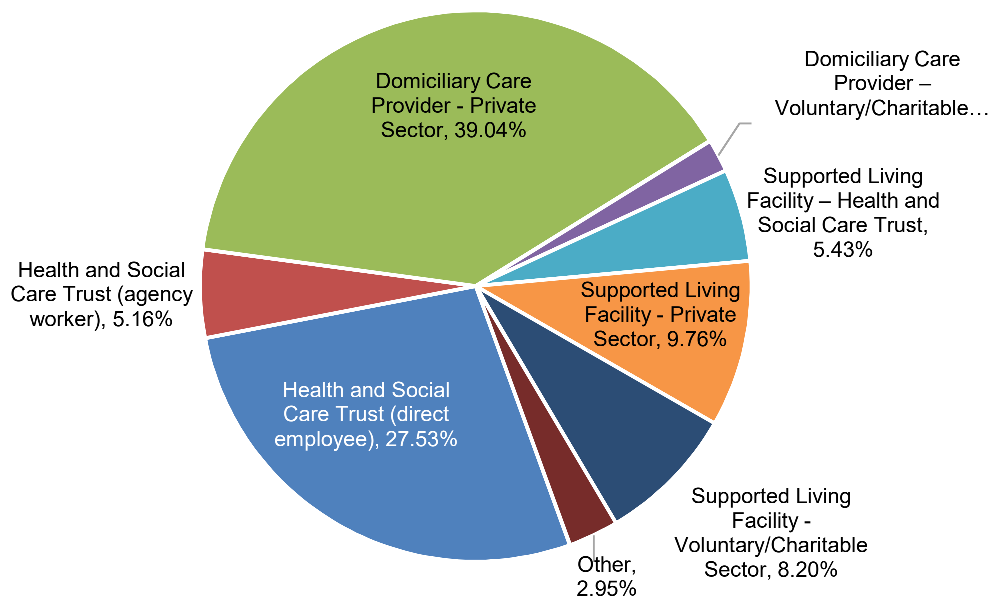
- Separate online surveys were created for managers and front-line workers.
- Direct emails were sent to those with a valid email address and a single reminder email was sent after 3 days to those who had not completed the survey.
- The surveys were open for one week - from 15-21 September 2020.
- Respondents welcomed the opportunity to share their experiences (55% of manager responses and 46% of front-line worker responses were returned within the first 24 hours).
- 1925 frontline workers and 73 managers submitted responses.
- Respondents commented that they appreciated that the opinions of ordinary staff like domiciliary care workers were being included in the Departmental Review.

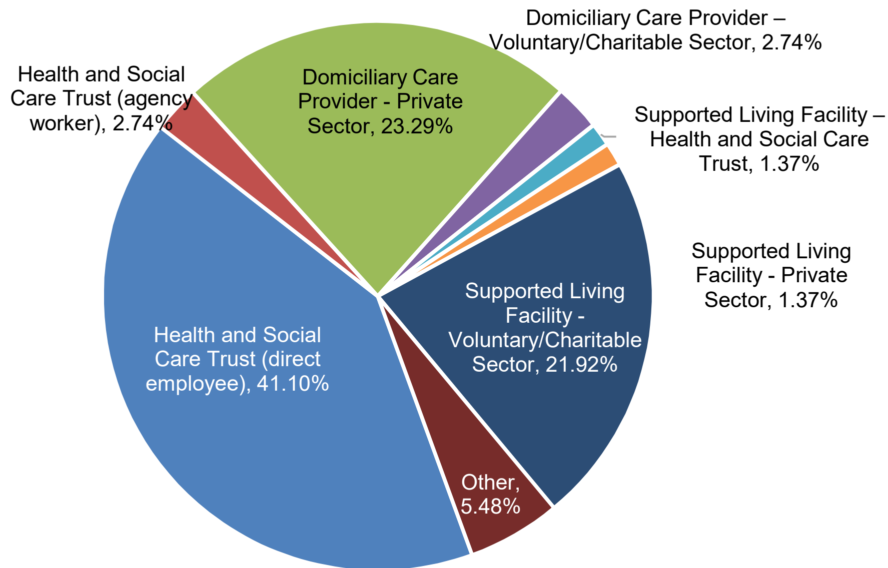
2.2. **42,451** social care workers are registered to practise in Northern Ireland (making up 85.5% of the Social Care Register).

- **38%** (16,228) are employed as Domiciliary Care Workers.
- **5%** (2093) are employed as Supported Living Workers.
- **1.3%** (539) are employed as Managers for these services.

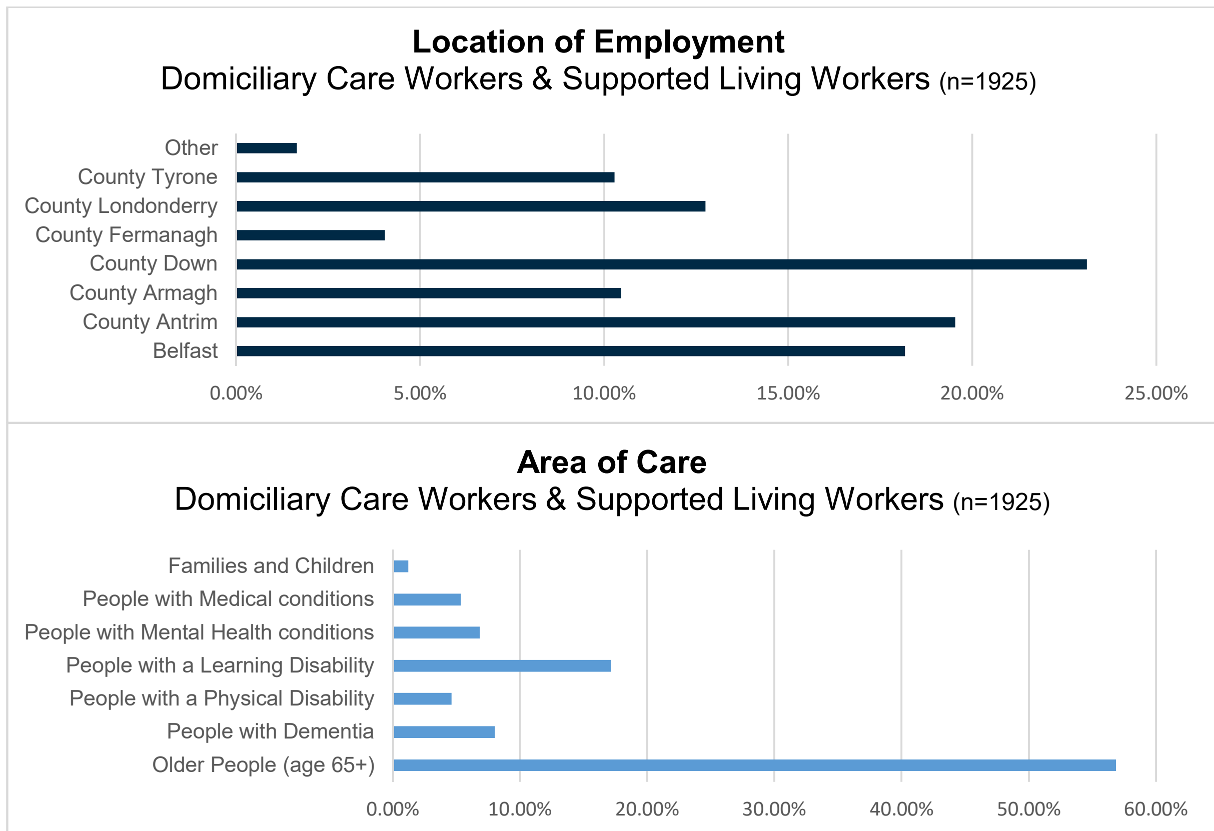
Target Group	Survey Invites Issued	Surveys Completed	Survey Response Rate
Domiciliary Care Workers	**15228**	**1573** 9.7% of the total number of registered domiciliary care workers	**10.3%**
Supported Living Workers	**2019**	**352** 16.8% of the total number of registered supported living workers	**17.4%**
Domiciliary Care and Supported Living Managers	**516**	**73** 13.5% of the total number of registered managers for these services	**14.15%**

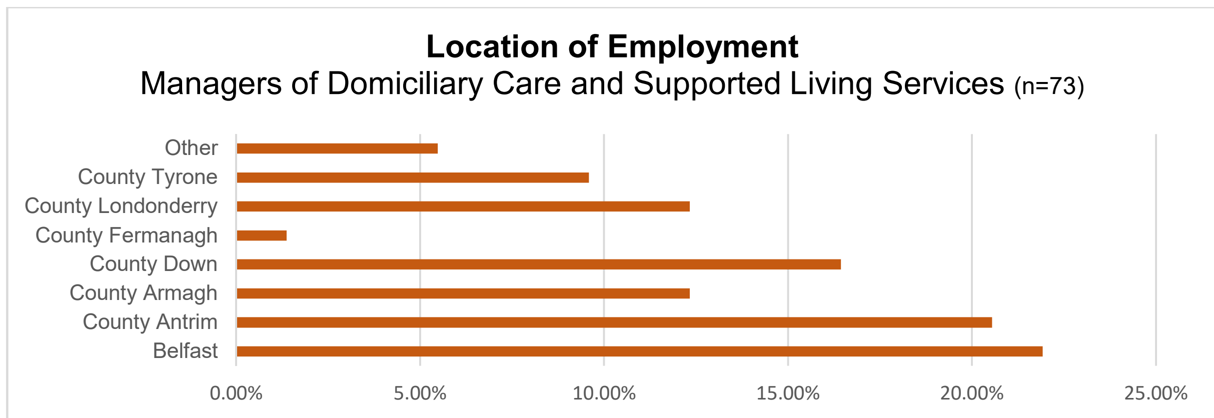
NISCC Survey Respondents – Employment Sector

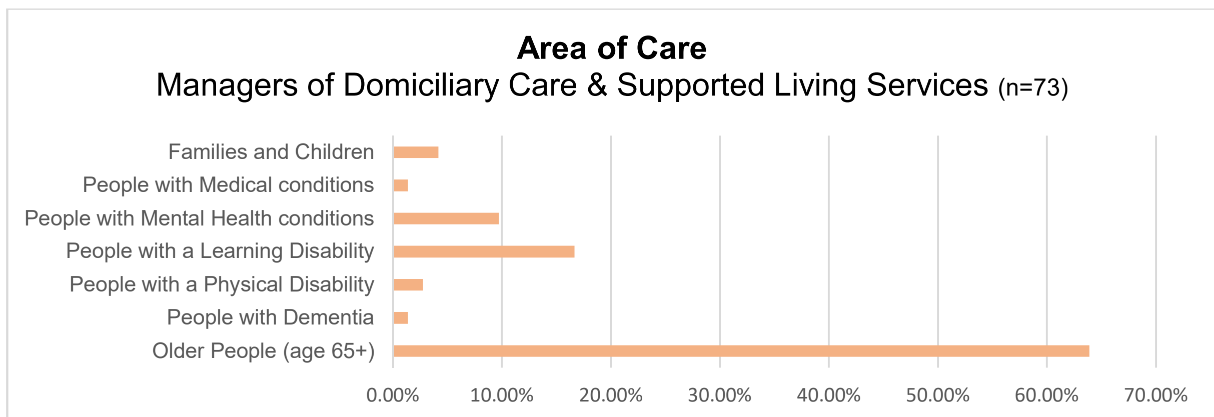




2.4. Survey Respondents – Employment Location & Area of Care NI







2.5. NISCC Survey: Changes to Job Role Due to the Pandemic

Managers and workers were asked to comment on how their job role has changed:

- Across the workforce, an average of **65%** of workers continued with their usual job role throughout the pandemic and **30%** continued their role with some adaptations
- Supported living workers were most affected by redeployment, with **8.61%** reallocated to alternative services or service users as a result of the pandemic

Changes to job role as a result of changes to services during the COVID-19 pandemic	Managers	Domiciliary Care Workers	Supported Living Workers
Yes, I was reallocated to a new area/group of service users	2.78%	3.50%	8.61%
Yes, I volunteered to go to a new area/group of service users	1.39%	1.42%	1.99%
No, but parts of my role have changed	36.11%	25.52%	36.09%
No, nothing was different in my role	59.72%	69.56%	53.31%

- **59%** of workers stated they received enough information ‘all of the time’ from their manager about any changes to their job role
- **72%** of managers stated they had enough support from their manager/organisation regarding changes required for staff and service delivery to adapt to working during the pandemic.

2.6. NISCC Survey: Supports Available to Support Service Delivery

Managers and workers were asked to comment on the availability of supports such as: PPE, technology for communication, practical assistance from HSC colleagues and their manager. They were asked to consider these both in the early weeks of the pandemic (March – May 2020) and in recent experience (June – September 2020). Questions, and responses* for managers and workers have been grouped in to three key areas, with a summary of lessons learned and recommendations:

- Health and Personal Wellbeing;
- Learning and Development; and
- Ability to Practise Safely and Effectively.

(*Baseline for desired impact has been considered that at least 50% of those surveyed should state a positive experience in terms of ‘All of the Time’)

NISCC SURVEY: HEALTH AND PERSONAL WELLBEING

Managers and workers were asked to comment on their experiences in relation to a series of statements. The table below shows the extent that they agreed the statement applied to their experience 'All of the Time'.

All of the time, I (or my team)	Workers – Early Experiences	Workers – Recent Experiences	Managers – Early Experiences	Managers – Recent Experiences
Received enough support from my manager about any COVID related concerns I had about my own, or my family's wellbeing	50.85%	54.61%	55.56%	54.84%
Was provided with support and resources to help manage my own wellbeing	46.96%	49.03%	43.75%	46.03%
Was able to recognise when I was feeling pressured and could take steps to help me cope with the demands of my role	36.30%	52.99%	40.63%	56.45%
Had access to psychological or counselling support to help me deal any emotional difficulties I experienced if I needed it	22.00%	32.79%	37.50%	47.62%
Understood the circumstances that would require me to request a Coronavirus test	74.08%	85.84%	82.54%	87.10%
Knew how to request a Coronavirus test	68.22%	78.92%	84.13%	87.10%
Requested a Coronavirus test and it was available at an appropriate time/place	22.24%	21.67%	44.44%	39.68%
Received Coronavirus test results and they were processed promptly	23.80%	23.09%	40.63%	32.26%

NISCC Survey: Lessons Learned And Recommendations for Health and personal Wellbeing	
What the workforce said is working – but still could improve further	**What the workforce said they would like to see**
Access provided to resources and support to support personal wellbeing Development of ability to recognise personal pressures and how to access help Improved understanding of when and how to access Coronavirus testing	Availability of Coronavirus testing at an appropriate time/place Promptness of notification of test results Routine testing for staff and service users Recognition and support for personal pressures such as childcare, caring responsibilities, shielding requirements , concerns of pregnant women, physical difficulties for menopausal women in wearing PPE (heat)

NISCC Survey: Learning and Development

Managers and workers were asked to comment on their experiences in relation to a series of statements. The table below shows the extent that they agreed the statement applied to their experience 'All of the Time'.

All of the time, I (or my team)	Workers – Early Experiences	Workers – Recent Experiences	Managers – Early Experiences	Managers – Recent Experiences
Received regular training to keep me updated on changes to practice associated with COVID 19	42.08%	51.44%	67.19%	76.19%
Received appropriate training/guidance on Infection Control	62.27%	65.08%	82.81%	85.71%
Received the appropriate training/guidance on how to use PPE effectively	70.18%	74.93%	79.69%	90.48%
Understood how infection control could protect service users and prevent the spread of COVID 19	86.22%	88.29%	Not asked	Not asked
Understood how to manage social distancing in my role	73.67%	79.77%	Not asked	Not asked
Received appropriate training/advice on how to identify symptoms of COVID 19	60.20%	68.10%	Not asked	Not asked

NISCC Survey: Lessons Learned & Recommendations for Learning and Development	
What the workforce said is working- but still could improve further	**What the workforce said they would like to see**
Regular updates on changes to practice associated COVID 19	Development of guidance specific to areas of care, in particular for supported living.
Appropriate updates or refresher training/guidance on Infection Control and how to use PPE effectively/identify symptoms of COVID 19	Streamlined communications channels to ensure that the workforce receives the latest guidance directly from the Department of Health.
Develop understanding of managing social distancing that is appropriate and effective in social care.	Regular updates on the level of positive COVID tests (both for staff and service users to allow staff to protect themselves and others)

NISCC Survey: Ability to Practise Safely and Effectively

Managers and workers were asked to comment on their experiences in relation to a series of statements. The table below shows the extent that they agreed the statement applied to their experience 'All of the Time'.

All of the time, I (or my team)	Workers – Early Experiences	Workers – Recent Experiences	Managers – Early Experiences	Managers – Recent Experiences
Had access to the Personal Protective Equipment (PPE) I needed for my role	73.74%	87.70%	71.43%	98.39%
Had access to technology to help me communicate with my manager and colleagues	66.62%	70.48%	70.31%	73.02%
Had enough support from my manager to carry out my role	62.50%	65.39%	69.35%	65.08%
Received regular updates from my manager on the latest guidance on COVID working	61.29%	64.62%	76.56%	82.54%
Had enough support from staff in the local Health and Social Care Trust to help me carry out my role	44.16%	46.61%	43.75%	50.79%
Received enough information from my manager about any changes to my role	59.38%	60.60%	76.56%	77.42%
Had opportunities to connect other staff in my organisation	47.18%	56.76%	63.93%	68.25%
Knew how to/was able to access support from a service user's GP practice if it was needed	48.10%	53.78%	22.22%	25.40%

Was able to get help and advice immediately if I was worried about anything when caring for a service user	63.70%	73.43%	Not asked	Not asked
Was able to work well with family carers present during my calls	52.88%	59.94%	Not asked	Not asked
Was concerned that either service users or family carers were not following guidance and would put me at risk	18.73%	23.78%	Not asked	Not asked

NISCC Survey: Lessons Learned and Recommendations on Ability to Practise Safely and Effectively	
What the Workforce said is working –but could improve further	**What the workforce said they would like to see**
Access to PPE Understanding of practical implications of using PPE Support from families and carers in the home setting Use of technology like Microsoft Teams for communicating with manager/colleagues – or to link service users with family etc.	Review of quality of PPE because there have been variations in recent batches compared to initial supplies Provide more local points to collect PPE, or allow staff to stock up so that there are less trips to collect PPE. Time allowed (and paid for) to enable staff to 'don' and 'doff' at start and end of calls/sessions. Service users' families and carers to have a greater understanding of their responsibilities in meeting COVID restrictions i.e. not having larger gatherings or crowding the worker. GPs and other health professionals to have more visible role in providing care and assessment. Managers to come out of offices more and join workers in the community.

2.7. NISCC Survey: Providers' recommendations for improvement that would improve the delivery domiciliary care services during the Covid-19 pandemic

- Providers made the following recommendations for improvement:
- Having one source for information and guidance, whether PHA, NISCC, RQIA or the government. So all emails would come from this one source

(like maybe a Covid-19 leadership group, which maybe would consist of all mentioned above);

- Planned identification of service users who must receive a service i.e. identifying those where there is no family support and services must continue come what may;
- Quick access to testing for staff and service users;
- Recognition of Supported Living providers as separate to domiciliary care and residential care - through development of separate supported living service standards;
- Clear pathways for voluntary sector providers to re-coup costs of Covid-19 related expenditure; and
- The need to improve the terms and conditions of the social care workforce.
- A partnership approach across all sectors, trade unions, service users and family carers.

2.8. NISCC Survey: Summary

Managers and workers were able to add any further comments they would like to add to the review. The following is an overview of the feelings and opinions they expressed:

Feedback from workers and managers indicate that:

- Workers and managers are confident in their skills and practice standards but are anxious that when the surge starts, they will be left alone again to deal with the pandemic while colleagues and other professions are kept safe;
- Staff feel they are not paid a wage that reflects the risks they are taking. Often they are on statutory sick pay if they have to isolate – which they feel is a work-related injury/concern;
- Significant efforts were made by managers, agencies and health bodies to provide training and updates for services during the pandemic but the information was issued from a wide range of sources and at times the advice provided was conflicting;
- The lack of specific guidance for Supported Living presented additional difficulties for all and the support needs of service users make it difficult for them to adhere to the COVID restrictions;
- Extra uniforms are needed – along with laundering services;
- Domiciliary care staff have nowhere to wash/change out of uniforms before they go home to family and this means some workers have moved out of their homes to ensure their family stays safe;
- Some families and service users are not adhering to restrictions;
- Staff shortages mean staff can have to work longer shifts and extra days. Employers are reluctant to bring in agency staff to provide cover; and
- Care workers would like to work in ‘bubbles’ with a specified group of service users because this would reduce the risk of infection

THEME ONE: WORKFORCE

Lead: Patricia Higgins, Interim CEO, Northern Ireland Social Care Council

Methodology

- Literature Review
- Workforce profile from NISCC database.
- NISCC survey of domiciliary care workforce and domiciliary care managers.
- Engagement with NISCC's Leadership in Social Care Partnership group.
- Engagement with trade unions.

3. Literature Review Findings on Workforce

3.1 Literature Review Findings on Workforce: What worked well?

- Rapid Review (Public Health England 2020) identified professional opinions about how to safely deliver domiciliary care- supporting general infection and control practices, use of risk assessments, appropriate training and only when necessary face to face contact.
- Guidance produced by trades unions and professional bodies on occupational health. This drew on evidence- based assessments. (Watterson 2020).
- Professionalism, skills, and knowledge of sector.
- Responsiveness to challenges. (Flatley, Kings Fund)

3.2 Literature Review Findings on Workforce: What did not work well?

- Feeling invisible as front line workers.
- Variable experiences of receiving information, training, and supplies
- Personal health concerns about higher risk of virus transmission.
- Forced to make difficult trade- offs in their work and personal lives (Sterling et al 2020)
- Delays in testing experienced; both availability and response rates for outcomes.
- Evolving PPE guidance and staff shortages. (Nyashanu et al 2020)
- Inadequate workforce pay and conditions despite acknowledgement of need for improvement.

3.3 Literature Review Findings on Workforce: Lessons Learned

- Rapid review found no studies describing the effectiveness of interventions aimed to reduce spread of COVID 19.
- Abject neglect of care workers in the initial pandemic responses (Watterson 2020)
- Inequity of risk faced across UK society e.g. low paid women in care workforce
- Differential UK responses to COVID 19 practices despite international guidance such as WHO COVID-19 guidance on rights, responsibilities, and roles of front-line workers.

- Evidence of increase in mortality rates for domiciliary care service users. (1.7% increase) (Glynn et al 2020)
- Higher risks posed for care workers because of difficulty in sustaining 'social distancing' from vulnerable recipients of care and caring for multiple clients daily.

3.4 Literature Review Findings on Workforce: Recommendations

- Better interventions and policies to support and protect front line social care staff. (Nyashanu et al 2020)
- Enhanced focus on bereavement services for frontline social care staff impacted by death of care recipients.
- Prioritise testing of frontline care workers.
- Greater collaboration of Public Health, Occupational Health to provide service for prevention and treatment of mental health amongst care workers.

4. STAKEHOLDER FEEDBACK ON WORKFORCE

4.1 Stakeholder feedback on workforce: What worked well?

- Dedication and commitment of workforce.
- Staff – providers described their staff as 'amazing', 'resilient', 'creative' and 'innovative'
- Implementing contingency planning and developing systems for management oversight of delivery of services
- Communication with staff and use of technology to provide information and keep staff connected eg Facebook; Microsoft teams
- Importance of a partnership approach with key stakeholders and regular meetings – eg ARC group which included DoH colleagues; Simon Community group which included colleagues from NIHE, PHA, PSNI and PBNI
- Agility of organisations to quickly embrace the use of technology, eg. using online recruitment processes
- Information to date suggests that within the domiciliary care and supported living sectors, there was a very small incidence of Covid among both staff and service users, with some providers reporting no incidence of the virus
- Government financial support for domiciliary care providers as service users and their families took decision to withdraw from care packages
- Text/virtual communication with staff
- Use of social media and closed Facebook groups to communicate with staff
- Rapid recruitment processes
- ELearning modules available to all.
- Staff commitment & sense of responsibility
- FAQS & Fact Sheets

4.2 Stakeholder feedback on workforce: What did not work well?

- Confusing, conflicting and rapidly changing guidance created anxiety both for providers and staff. This was exacerbated by guidance/advice coming from multiple sources.
- Different Trusts had different arrangements for testing and so working regionally it was hard to have consistency of approach as it depended on the Trust's policy. It would have been helpful if the Trusts had more consistency on this.
- Concerns about access to PPE and confusion about Trust provision of PPE.
- Reduction in domiciliary care packages creating financial concerns.
- Reduction in reported unmet need and a lack of clarity as to the reasons for this.
- Exhausted staff and concerns about staff welfare and support for staff in preparation for a 2nd surge.
- Lack of data and intelligence collection to understand the positive contribution of domiciliary care and how well the service had performed during the first surge.
- Staff shortages – shielding staff and uncertainty when staff would return.
- IPC requirements to self-isolate within small teams.
- Difficult to train new staff on practical issues eg manual handling.
- Refresher training requirements not in line with IPC requirements.
- Lack of resource re IPC and testing for this workforce.
- Time for redeployed staff to adjust to different systems and ways of working.
- Resources to support providers during the pandemic – where additional costs have been incurred eg. PPE, IT infrastructure, increased salary costs. Concerns raised about the different approaches of government departments in responding to these additional costs.
- Lack of understanding of the role of supported living services and appropriate support required eg. guidance relevant to these settings providing 24/7 support to people in their own home
- Existing poor pay, terms and conditions for some of the workforce creating stress which was then exacerbated by the pandemic.

4.3 Stakeholder feedback on workforce: Lessons Learned

- Providers repeated their admiration for the resilience and commitment of their staff during the pandemic
- Communication is key – both in terms of clear guidance to providers and also communication with staff
- The benefit of technology in supporting communication and in enhancing independence for service users
- The importance and necessity of real and honest partnership working - across sectors and with the Department was important to ensure services were delivered safely

- The importance of engaging with the domiciliary care and supported living sectors in planning for the 2nd surge.
- Developing resources to support staff and service user well-being – Inspire/PHA/DoH resource developed.
- Age profile of the workforce is a significant risk to service continuity.
- Need to value a workforce under significant levels of stress
- Covid fatigue risks creating complexity.
- Variation across the sector in ability to absorb new/different work.
- The need to support the domiciliary care workforce with better pay, terms and conditions so it is sufficiently resilient to meet the demands of the job.
- All those with a stake in domiciliary care, the private sector, voluntary sector, trade unions, HSCTs, service users and family carers should be seen as partners and involved in the development and delivery of domiciliary care.

4.4 Stakeholder Feedback on Workforce: Suggested Actions

- Clarity on standards for refresher training to be provided
- Systematic workforce planning for this sector is urgently required.
- Having one source for information and guidance, whether PHA, NISCC, RQIA or the government. So all emails would come from this one source (like a Covid-19 leadership group, which would consist of all mentioned above)
- Planned identification of service users who must receive a service, i.e. identifying those where there is no family support and services must continue come what may.
- Quick access to testing for staff and service users.
- Recognition of supported living providers as separate to domiciliary care and residential care - through development of separate supported living service standards.
- Clear pathways for independent sector providers to re-coup costs of Covid-19 related expenditure
- Improvement in the pay, terms and conditions of the social care workforce.
- Health Unions “Bring It Forward” campaign for an early and significant pay rise for all Agenda for Change staff.
- A review of the current mixed economy of care with consideration of greater or total delivery of domiciliary care within the statutory sector.

THEME 2: SERVICE USER AND FAMILY CARER EXPERIENCE

Lead: Laura Collins, Lived Experience Expert.

Methodology

- Literature search
- Literature review
- Review of existing lived experience surveys for comment on domiciliary care.
- Analysis of helpline data from Carers NI & Age NI
- A framework of the attributes developed by COPNI, as indicators of good quality care (Reliable; Flexible; Continuity; Communications; Attitudes; Skills and Knowledge) and of another framework in the Department of Health's Quality Measures for Domiciliary Care (Health; Hygiene; Dignity; Safety; and Ease at home) has been used to organise lived experience feedback and analyse comments to support the evidential basis for the findings under this theme. The detail of the feedback is in Appendix B

5. LITERATURE REVIEW FINDINGS ON SERVICE USER & FAMILY CARER EXPERIENCE

5.1 Literature Review Findings on Service User and Family Carer Experience: What worked well?

- Broader community response to supporting vulnerable adults.
- Rise in volunteering, help from new care givers and community action.
- Benefits of online support for people with intellectual disabilities living independently (Dutch Model 51)

5.2 Literature Review Findings on Service User and Family Carer Experience: What Didn't Work Well?

- Fear about accessing health care system because of concerns about exposure to COVID 19. (consistent theme across the literature)
- Consistent theme about impact of shielding and isolation on quality of life, emotional wellbeing, and mental health. (29, 30, 53,54)
- Consistent theme of confusion in guidance and its operationalisation.
- Significant stresses experienced by carers and adults with disabilities (26, 49).
- Sense of being unsupported, 'pushed to and beyond limits, expectation of 'stepping in 'to provide care has led to long term exhaustion, impact on physical and mental health (26)
- Cessation of range of crucial services extended beyond domiciliary packages, removing sense of support, and creating sense of 'invisibility'. (26, 49)

- Severe reduction and removal of home care packages without consultation, prior warning, alternative options, or transparency with concomitant increase in requests for help from national helpline (Scotland 27).
- Total lack of clarity about resumption of services compounded distress experienced.
- Consistent theme of additional care and responsibility placed on unpaid carers. (Lorenz -Dant.2020)
- Cancellation of external support services because of concerns about transmission of virus. (40)

5.3 Literature Review Findings on Service User and Family Carer Experience: Lessons Learned

- Unintended health consequence of social distancing measures such as types of food eaten may precipitate heart failure, lack of exercise may lead to falls, impact of social isolation may reduce cognitive stimulation, worsening cognitive and behavioural symptoms of dementia, triggering rapid decline. (Steinman and Perry 2020).
- Lack of social supports exacerbates such problems.
- Using telemedicine technology may be hampered by hearing loss, cognitive impairment, and lack of familiarity with technology.
- Those living alone potentially more vulnerable (38), and experienced negative impact of isolation and loneliness.(48,53) Distinguishing between Activity of Daily Living (ADL) which involves functional mobility and personal care and Instrumental Activity of Daily Living (IADL) which involves life functions to maintain self-e.g. shopping cooking, cleaning laundry.
- Increase in numbers of unpaid carers 4.5 million nationally facing challenges about managing stress and responsibility, impact on physical and mental health and no opportunity of break from caring. (24)
- Unpaid carers experienced new and increased caring responsibilities. (29,30)
- Higher anxiety levels and lower well-being amongst people with longstanding illness. (NISRA)
- Consistent theme about unpaid carers juggling complex lives, experiencing financial difficulties and worried about future. (48, 49)
- Emergence of unmet need for personal care tasks amongst incapacitated older people due to policy expectation of isolation. (53)

5.4 Literature Review findings on Service User and Family Carer Experience: Recommendations

- Development of social care policy and strategy for determining those most in need is a priority.
- Establish mechanism for regular, concise, easily understood information and updates for service users and carers as communication is crucial aspect of alleviating fears and concerns.
- Prioritise services for adults with disabilities whose network of supports suffered significantly
- International lessons about how to support family carers include prioritise testing, have contingency plans in place for emergency circumstances, offer access to PPE for family carers, increase financial support, recognition of main carer on medical notes, increase funding for remote support interventions. (Lorenz-Dant 2020)

6. STAKEHOLDER FEEDBACK ON SERVICE USER AND FAMILY CARER EXPERIENCE

6.1 Stakeholder Feedback on Service User and Carer Experience: What Worked Well?

- Increased sense of home as the safest option for users and carers.
- Commitment of individual domiciliary care staff to their service users.
- Continuity provided by domiciliary care staff – in many cases, it was the only familiar service left.
- Reliability – this was the service that continued.
- Communication between service providers and service users in some cases very good.
- Communication between Trust staff and service users in some cases very good.
- Some providers very innovative in their approaches.

6.2 Stakeholder Feedback on Service User and Carer Experience: What did not Work Well?

- Use of scrubs confusing for users used to particular uniforms/identification.
- Service user & carer fear of infection leading to them cancelling their domiciliary care service.
- Some reports of service users & carers being afraid to cancel because of a lack of reassurance about being able to get the service restarted.
- Difficulties for service users/carers knowing where to go to get packages restarted.
- Difficulties for service users/carers in getting packages restarted/facing reassessment.
- The cancellation of other services such as day-care and short breaks putting enormous pressure on family carers.

- At times, providers didn't communicate well with service users and family carers/very uneven response.
- At times, Trusts didn't communicate well or at all with service users and carers/appears to have been at the discretion of individual staff rather than a systematic response.
- Difficulties in accessing PPE for Direct Payments' (SDS)' employees with regional guidance provided very late into the surge period.
- Guidance was geared towards professional staff or organisations and not designed for service users and family carers who were using domiciliary care.
- Service users and carers not sufficiently involved/included in domiciliary care pandemic response.
- Carers still experiencing significantly increased burden of care, 85% of carers still reporting increased care in comparison to pre pandemic, 72% concerned about their mental wellbeing as a result. (NI Carers Survey)
- Service users and carers experienced significant feelings of isolation during pandemic/of being left alone to cope.
- Service users and carers experienced significant feelings of loneliness during the pandemic.
- Significant reduction in the number of carers' assessments carried out during the first 3 months of pandemic; less than 1% of all family carers had a completed carer's assessment (https:www.health-ni.gov.uk/publications/quarterly-carers-statistics-northern-ireland-january-march-2020)

6.3 Stakeholder Feedback on Service User and Family Carer Experience: Lessons Learned

- Anxiety that some service users have deteriorated during Covid – system finding it challenging to resume/reassess need for service.
- Need to educate general public re domiciliary care and use of PPE.
- Need to recognise the particular vulnerabilities of domiciliary care service users who often experience multiple disadvantages and poorer health outcomes.
- Importance of a holistic approach to considering each individual's support needs in their entirety and recognise the interdependence of many of the services.
- Information on the experience of service users/carers during the pandemic not readily available.

6.4 Stakeholder Feedback on Service User and Family Carer Experience: Suggested Actions

- Trusts to take steps to reassure service users and family carers about current infection control measures in domiciliary care and encourage re-uptake of services.

- Trusts to prioritise offering the restarting of pre pandemic packages of care.
- Trusts to proactively engage in a systematic fashion with existing carers and those who have become new carers during the pandemic to offer support.
- Trusts to be alert to the increased needs of service users caused by the pandemic.
- Guidance to be tailored to meet the needs of service users and family carers.
- Longer term – the full contributions of the benefits and costs of informal care to be calculated and form an integral part of planning processes.
- Support initiatives which ensure the voices of service users and family carers during the pandemic are heard as information on the experience of domiciliary care service users and family carers during the pandemic was not readily available and required extensive research to source.
- Strengthen local processes for ongoing feedback and service complaints to ensure prompt response and resolution.
- Promote inclusion and co-production with service users and carers during pandemic planning and as equal design partners in strategic domiciliary care planning.

THEME 3: SERVICE PROVISION AND BUSINESS CONTINUITY

Lead: Joyce McKee, Adult Services Programme Manager, HSCB

Methodology

- Literature review
- NISCC survey of workforce and managers.
- Learning & reflection discussion with Trust Assistant Directors & Service Leads x 2
- Information from weekly meetings with Trusts Assistant Directors throughout the pandemic
- Feedback from users and providers for domiciliary care surge planning purposes.
- Engagement with trade unions.

7. LITERATURE REVIEW FINDINGS ON SERVICE PROVISION

7.1 Literature Review Findings on Service Provision: What worked well?

- Proactive communication regarding infection prevention and control measures

- Increased uptake of technology such as phone, video, WhatsApp, zoom and telehealth.
- Measures to ensure continuity of care such as Rapid Response Teams, recognition of carers as essential workers, recruitment of volunteers, family members registered and paid as temporary care workers with online training session on safety. (South Korea)
- Funding to boost staff numbers and retention bonus (Australia)
- Community led responses in Hong Kong with emergency support from community to help with medication refills, household cleaning and delivery of hygiene supplies. (Comas-Herrera 2020)
- Emergence of new networks of neighbourhood mutual aid groups. (Bottery Kings Fund 2020)
- COVID 19 emergency response resolved issues around disjointed care.
- Increased recruitment into sector and emergent spirit of community support.
- Agility in adaptation, flexibility, and commitment of social care sector in its response to pandemic (55)
- Introduction of online support services e.g. Ireland's collection of resources for people with dementia, Finland's daily televised 'work out' programme.

7.2 Literature Review Findings on Service Provision: What did not work well?

- Reduction of registration of home care services
- Average of UK 7% staff absences in July 2020. (CQC Covid Insight No.3)
- In Ireland, the 'cocooning policy for people over 70 years of age' ignored the contribution of older people to caring and volunteering in their communities (Price 2020)
- Paucity of quality and timely service data and intelligence. (Bottery Kings Fund 2020)
- Impact of market fragility with reduction in services.
- Perceptions of failure in reputation and leadership as reflected in delayed central government response to COVID-19.
- Highly critical view of lack of government response to social care sector from outset of pandemic. (ADSS 55)
- Significant financial pressures on services in terms of emergency expenditure and sustainable budgets for future (ADSS 56)

7.3 Literature Review Findings: Lessons Learned

- Conceptualising informal carers as part of 'pillar' of health and social care system (Chan et al). Lancet article Vol. 395 June 2020
- Repositioning of home as care model of preference for aged care system in Australia (Royal Commission October 2020)
- Impact on confidence and demand for services

- Need to develop training resources around infection control and use of PPE.
- In Ireland as home care workers are low paid, the impact of increased working hours impacts on entitlements to social welfare, and medical card (Price 2020)
- Uncertainty if COVID-19 impacted on post code lottery of access to social care.
- Development to shape future of personalised home care. (University of York and Home Instead).
- Impact on black and ethnic minority people and poorer communities where substantial inequalities already existed. (55)

7.4 Literature Review Findings: Recommendations

- Government policy to shift demand for home care as system is distorted towards institutional care (Royal Commission Report Australia)
- Embed internal online support activities such as Mindfulness and Wellbeing for staff via technology.
- Integration of home care employers, home care workforce and their advocates into emergency planning process. (Price 2020)
- Building on community networks with usage of volunteers and digital technology. (Bottery Kings Fund and Local Authority Association 2020)
- Undertake further research on how health and care needs have accumulated during pandemic and extent of unmet need. (Hodgson et al 2020)
- Embed service user and carer experience as foundation of social care strategy, policy, and service delivery. (58)

8. FEEDBACK ON SERVICE PROVISION

8.1 Stakeholder Feedback on Service Provision: What worked well?

- Advocacy for the sector
- Financial commitment to IS providers
- SSP guarantees for staff
- Dedicated team (SET)
- Brokerage service maintained throughout
- Flexible use of temporary additional capacity as a result of suspended packages.
- Maintaining slots for reviewed cases.
- Flexibility/devolved decision making
- Autonomy for relatively junior staff
- Flexibility to work from home

- Decision to move to amber (requirements for additional PPE to be worn by staff) seen as protective of staff
- Redeployment of staff to SL
- Good out of hours responses to emergencies
- Daily meetings re availability/impact on service provision
- Linkages with IPC across all directorates
- Good relationships with stores/warehouses
- Close working with independent sector colleagues
- Maintaining an emphasis on reablement where possible.
- Specific teams for Covid positive service users.

8.2 Stakeholder Feedback on Service Provision: What did not work well?

- Need for real time data
- Prioritisation framework not applied consistently
- Timing of announcements, eg 5pm left no lead-in or preparation time
- Messages not consistent
- No co-ordination of messaging across Trust boundaries
- Constant demands for information
- Confused messaging/guidance
- No clarity on what had changed between iterations of guidance
- Lack of data for the sector
- Duplicated demands for data
- Lack of centralised information re specialist procedures eg Aerosol Generating Procedures
- Outdated software could not cope with demands for info – too much had to be done manually
- Lack of real time monitoring, eg requirements for and use of PPE
- Concentration on hospital discharge made scheduling difficult
- Covid teams broke continuity for users
- Supported Living services appearing to fall between stools.
- Lack of specific guidance for the supported living sector.
- Exacerbated existing challenges re geography.
- Not close enough partnership working between stat sector and independent sector.

8.3 Stakeholder Feedback on Service Provision: Lessons Learned

- Apply care home app to domiciliary care
- Need for real time data
- Constant clarification of available funding and how to access it is vital.
- Potential for technology to support better communication with service users and carers as well as being a monitoring tool.
- Remote working for support staff worked well where possible.

- Entire system moving to amber status mitigated the need for specialist teams/runs.
- SL services need targeted support.
- High level of anxiety amongst families leading to suspended packages – big impact on future planning/resource deployment.
- Increased acuity where the client does not want to move to a care home and variable capacity of domiciliary care to absorb additional levels of need.

8.4 Stakeholder Feedback on Service Provision: Suggestions for Actions

- IT support to this service area needs to be a system-wide priority
- Consider if specialist teams are of value moving forward.
- Need to monitor use of PPE and adherence to IPC requirements in real time
- Need to improve contingency planning across all providers.

THEME 4: INFECTION PREVENTION AND CONTROL (IPC)

Lead: Pauline McMullan, Allied Health Professions Consultant, Public Health Agency

Methodology

- Literature Search & Review
- NISCC Survey of Domiciliary Care Workforce and Domiciliary Care Managers.
- Engagement with Trust Domiciliary Care Managers, HSCB Social Care colleagues and Independent Providers (template/social care ECHO Session), Testing Group
- Review of IPC Cell Summaries and engagement with IPC Cell members (PHA/Trust IPC Nurse Leads/Social care rep)
- Engagement with Education Providers (HSC Clinical Education Centre/Leadership Centre)
- Engagement with PHA Nursing a& AHP directorate
- Engagement with PHA Patient Client Experience Team
- Engagement with RQIA
- Engagement with trade unions.

9 Literature Review Findings on Infection Prevention & Control (IPC)

9.1 Literature Review Findings on IPC: What worked well?

- GOV.UK Guidance @Coronavirus: Provision of Home Care
- IPC Policies on- line via CQC website.
- Infographics on putting on and removing PPE
- Case studies of providing 'Close Personal Care'.
- Rapid Review from Public Health England (June 2020) established there were no studies describing risk of transmission when delivering domiciliary care.
- Introduction of daily surveillance practices involving caregivers and patients to report screening of symptoms. (Rowe et al 2020)
- Establishing precautions in patient setting by offering instruction and education about handwashing.
- Undertaking disinfecting practices in patients' homes e.g. surfaces, knobs, and handles at beginning and end of visit.
- Limiting the number of shift changes and multiple patients per care worker.
- Dissemination of knowledge about transmission routes of COVID 19 underpin decisions about health and safety for care workers in UK e.g. usage of sanitizers, PPE (Watterson 2020) supply, use, suitability, and replacement.
- On-line support systems for mental health and wellbeing.

9.2 Literature Review Findings on IPC: What did not work well?

- Sense of lack of pandemic preparedness
- Shortage of PPE equipment impacted on psychological and mental wellbeing of frontline workers.
- Shortage of staff due to self- isolation and unavailability of testing.
- Fear and anxiety amongst professionals about bi-directional transmission.
- Delay in testing.
- Working practices of multiple clients and care from multiple care workers.
- Limitations to stock supply of PPE with picture of decreasing availability. (CQC COVID Insight Report 3 and 4)
- Sub-optimal hand hygiene adherence observed (McDonald et al 2020)

9.3 Literature Review Findings on IPC: Lessons Learned

- Challenges in enforcing social distancing.
- Regular updating of PPE guidance would cause less confusion.
- Improving PPE supply and regular infection testing would reduce transmission to vulnerable people and care workers.
- Importance of risk assessments to determine appropriate PPE needed
- Improve availability of testing at point of care
- Absence of guidance for supported living contexts.

- Importance of strategy to increase availability of PPE with inbuilt governance, multisector involvement. (Thomasian et al 2020)
- Promotion of conservation through enhancing community telehealth capabilities, streamlining usage, scaling up minimal contact testing e.g. mobile units.
- Practices which involve cycling sets of PPE for daily use, wearing face shields over respiratory PPE to reduce clinically evident surface contamination.
- Techniques to sanitise disposable PPE should only be used if validation of fit, seal and barrier protection can be confirmed.
- Consolidate all production lines for PPE into a single channel for essential frontline staff.
- Recognition that virus laden aerosolized droplets can be transferred through heating, ventilation, and air conditioning systems. This has implications for providing care in 'confined' spaces. (Colburn 2020)

9.4 Literature Review Findings on IPC: Recommendations

- Adequate pandemic preparedness for sector and service users.
- Establish pandemic control and management policy.
- Clear policy for procurement of PPE.
- Use technology such as 3D printing and computer techniques for rapid prototyping of PPE equipment (Thomasian 2020)
- Establish broader policy to cover overhead costs borne by care workers required to shield.
- Focus on gaining data about outbreaks of COVID-19 in social care as a basis of identifying high infection risk and effective infection control measures (Hodgson et al 2020)
- Recognition of infection control standards as fundamental human rights issue (57)

10 STAKEHOLDER FEEDBACK ON IPC

10.1 Stakeholder Feedback on IPC: What worked well?

- Distribution of PPE once available
- Joint working with independent sector to scope level of need/requirements
- Clients/carers felt safe in their own homes
- 'Care in Your Own Home and Coronavirus' leaflet was produced by PHA in April 2020 and circulated to all Trusts and independent providers through RQIA for circulation.
- Establishment of central hub/point of contact for provision of PPE for independent sector providers
- Clarity around what PPE was required for each visit, including terminology used to describe it (e.g. Red/Amber/Green or Level 1 or 2)

- PHA advice/FAQ
- Established links with IPC colleagues and mechanism for raising concerns via regional IPC Cell
- NISCC COVID Social Care ECHO was very helpful and informative to domiciliary care managers in clarifying queries about IPC considerations
- Advice and training regarding infection prevention control and PPE was readily available from NISCC & Trusts, independent sector providers, HSC Learning Platform either online/webinars or via video/leaflets.
- Establishment of the regional IPC Cell provided an opportunity for Trusts/independent providers (via Trusts/RQIA) to raise and clarify queries
- Establishment of product review group to assess PPE before distribution regionally
- IPC – greater linkages with IPC Nurse Leads
- A number of NI specific guidance documents were produced to clarify queries that arose during the first surge
- NI Domiciliary Care Guidance (NB: this is different from UK Dom care guidance in terms of sessional use of PPE)
- Car Sharing Guidance
- Family Carers Guidance
- Hydration/skin integrity guidance when wearing PPE

Testing:

- Knowledge and understanding among domiciliary care workers and managers about the circumstances when testing should be requested for themselves or their staff is high >85% in both groups
- Knowledge of how to request a coronavirus test is high and has improved during the pandemic. However this could be improved further among domiciliary care workers (68% to 78%)

10.2 Stakeholder Feedback on IPC: What did not work well?

- Lack of advice re testing for service users and staff group.
- Variations in demand for PPE support, not centralised.
- Confusion, especially at start of pandemic, regarding what PPE was required
- A perception that the advice, provided from multiple sources, varied adding to the confusion and anxiety among management and domiciliary care workers
- PPE not readily available in the community especially at the start, difficulty accessing it in a timely manner and initially a perception that PPE was not required in domiciliary care
- Recall of PPE in different Trusts at different times (now resolved)

- Issues with PPE(e.g visors) and some personal care tasks e.g. visors steaming up when showering and concerns re masks (NB: the query re masks was followed up and resolved by IPC Nurse leads and Regional IPC Cell)
- Queries remain around the disposal of PPE within the home of the client and the impact this has on household waste

IPC advice/training

- IPC advice was updated and amended multiple times since the beginning of the pandemic (NB: The PHE IPC guidance was updated 30 times, often over the weekend, since January 2020 and not all changes were relevant to NI.)
- This caused confusion and delays in communicating local interpretation of the guidance to different sectors including domiciliary care. The volume of constant information was overwhelming.
- IPC training (eg Tier 1 & 2 on the HSC Learning platform) was developed pre-Covid so does not include specific references/examples to Covid response nor did it include donning and doffing of PPE.
- The majority of the IPC advice/training was only available online and this was reported as an issue for a number of domiciliary care staff who did not have IT skills or did not have access to online facilities.
- Variations in how HSC Trusts/organisations interpreted the PHE IPC Guidance (e.g. sessional use of masks) caused confusion if independent providers crossing different Trust areas.
- No specific IPC advice/guidance developed for Supported Living settings.

Testing

- The availability of testing at an appropriate time/place is still not clear based on feedback from domiciliary care workers/managers (as per results of the NISCC survey)
- The promptness of processing test results is still not perceived as being prompt enough by domiciliary care managers/workers (as per results of the NISCC survey)

10.3 Stakeholder Feedback: Lessons Learned

- Clear concise advice required regarding what PPE is required in domiciliary care.
- Consider if a specific generic email accessible by key people should be used for as the HSC Trust single point of contact for Independent Domiciliary Care Providers to liaise with on PPE issues, in the event of staff absence.
- Important to monitor demand and usage of PPE within the domiciliary care sector to help inform PPE modelling.

- PPE needs to be readily available in convenient locations for the domiciliary care workers to access as required.
- Different independent providers report varying degrees of difficulty sourcing PPE directly.
- IPC strategic leadership framework should include support to the domiciliary care sector.
- IPC product review group has ensured all PPE is now tested before regional procurement and use.

10.4 Stakeholder Feedback: Suggestions for Action

- Where possible, guidance should be interpreted and communicated at a regional level to ensure consistency.
- Interpretation of IPC advice/guidance needs to be produced in manageable, understandable formats.
- One central point (e.g. PHA website) for all organisations to access up to date relevant information/advice regarding IPC/PPE.
- Clear agreed pathways regarding information flow of guidance and any updates to organisations.
- IPC advice/Guidance/Training should be consistent across organisations and available to download for staff who do not have online access.
- Webinars/videos should be made available to provide Covid specific advice – these should be agreed regionally via the IPC cell where possible.
- There is a need to manage expectations regarding timeframes for accessing testing/test results.
- Need to continue to improve communication with regard to access to testing. There may be merit in considering viability/appropriateness of a large-scale community testing of domiciliary care service users/staff on a rolling program.
- Further communication and guidance on prioritisation of testing for this sector (users and staff)
- Suggest regional oversight of independent sector access to PPE.
- Consistent infection prevention control (IPC) strength based promotional messaging to support domiciliary care providers, managers, workers & residents (including specific advice in relation to Covid)
- Review and consolidate all sources of advice regarding PPE for domiciliary care in NI
- Consistent up to date strength based infection prevention control training (IPC), includingthe use and disposal of PPE, for all domiciliary care workers
- Consistent interpretation of IPC advice across the region

- Encourage strategies to optimise the use of PPE (in line with the Rapid Review of Effective Utilisation of PPE undertaken in May 2020 in NI)
- Clarify the process for Trust/independent providers to escalate queries regarding PPE products (the report on the PPE concerns email may do this)
- Consider a central point of contact for independent providers queries re sourcing and provision of PPE, including communication links between the different Trust reps
- Review the current position in relation to disposal of PPE in domiciliary care to ensure consistency of practice including any steps that can be taken to minimise impact on household waste.

OVERALL RECOMMENDATIONS

RECOMMENDATION	ACTION	KEY LEAD
1. Improve recognition and profile of the domiciliary care workforce	• Domiciliary care staff member to feature at ministerial briefing as with other staff	DOH/OSS
	• Further letter from Sean Holland - targeted specifically at domiciliary care staff	DOH/OSS
	• Domiciliary care providers to consider sending thank you cards/letters to domiciliary care staff	Domiciliary Care Providers
	• Promote positive media stories about domiciliary care	DOH/OSS
2. Improve recognition and support for family carers	• Open letter of appreciation to family carers from Minister of Health.	DOH/OSS
	• Trusts to be proactive in offering and flexible in the permitted uses of carers' grants to relieve stress for informal carers.	Trusts
	• Trusts to be proactive in offering direct payments to family carers both for service user care and as a specific response to carer need and again be flexible about permitted uses.	Trusts
	• Trusts to include the prioritisation of carers' assessments and re-assessments in their rebuilding plans to mitigate against fatigue and adverse impact on wellbeing.	Trusts with HSCB Monitoring

RECOMMENDATION	ACTION	KEY LEAD
	• Trusts to attempt to identify those who have newly become carers because of the pandemic and refer into carer support services as required.	Trusts
	• Mechanisms /initiatives to be established to hear the views of domiciliary care service users and family carers during the pandemic.	PCC
	• Strengthen local processes for ongoing feedback and service complaints to ensure prompt response and resolution.	Domiciliary Care Providers
	• Promote inclusion and co-production with service users and family carers in pandemic planning and strategic planning for domiciliary care.	Trusts, HSCB, PHA, DoH
3. Workforce support	• Domiciliary care providers to use the framework of the Covid Staff Wellbeing Framework to provide support to their staff	Domiciliary care providers with HSCB support and monitoring
	• Using this framework, domiciliary care providers to increase awareness of availability of psychological support for their staff	Domiciliary care providers with HSCB support and monitoring
	• Online NISCC resource on staff wellbeing also to be promoted to domiciliary care sector and to family carers.	Domiciliary care providers and NISCC
	• Information on coping with bereavement supplied to domiciliary care workers to support them with impact of service user deaths.	Domiciliary care providers and NISCC

RECOMMENDATION	ACTION	KEY LEAD
	• Providers to focus on increased communication with their staff, not just for practical information but for emotional support.	Domiciliary care providers
	• Providers to ensure opportunities for peer support also available – staff 'get togethers' on virtual platforms have proved supportive.	Domiciliary care providers
	• Providers to provide additional uniforms to staff free of charge where needed to support staff with laundering	Domiciliary care providers
	• Providers to scope and provide, where possible, any available changing facilities for staff that would avoid need to change in home environment	Domiciliary care providers
	• Recognition of a predominantly female workforce who are more likely to have additional caring responsibilities	Domiciliary care providers to ensure a sympathetic and flexible approach to this.
	• Recognition of the possible personal financial difficulties of this workforce where other household incomes may have been lost due to the pandemic – need to ensure that workforce know how to access financial advice and support.	DOH/OSS to provide resources information to domiciliary care providers.
	• Explore the provision of mobile devices for the domiciliary care workforce to provide immediate communication support during Covid alongside the potential for IT solutions in domiciliary care for the future	DoH & HSCB

RECOMMENDATION	ACTION	KEY LEAD
	• Repeat a workforce survey in 3 months' time to monitor workforce impact & wellbeing.	NISCC in partnership with trade unions and providers
	• Continue the work on developing a proposal for the Minister of Health's consideration to seek improvement in the lowest pay for social care staff employed by the independent sector.	RASC
	• Continue the work on developing proposals for the Minister of Health's consideration for standardised improvements to the training, development and career pathways of the social care workforce across the system.	RASC
4. Infection Prevention and Control	With the support of the regional IPC cell, and/or the PPE Cell:	
	• Review and consolidate current IPC and PPE guidance relevant to domiciliary care, available from multiple sources, to ensure regional consistency and version control.	PHA
	• Ensure a consistent, clear interpretation of IPC advice in domiciliary care settings across the Trusts/ independent providers	PHA
	• Consider all IPC training for domiciliary care currently available in NI to ensure it is up to date, Covid specific, strength based and regionally consistent	PHA

RECOMMENDATION	ACTION	KEY LEAD
	• Co- produce and promote appropriate IPC training for family carers.	PHA
	• Consider information flow/communication pathways of new and updated IPC guidance to ensure appropriate distribution in a timely manner	PHA
	• IPC strategic leadership should include support to the domiciliary care sector	PHA
	• Where they don't already exist, create a generic, specific Trust email for independent providers to contact Trusts regarding PPE issues, with links to the PPE Cell	Trusts
	• Review the best placement of PPE supply points across Trusts and develop a mechanism to monitor usage both on an organisation and regional level.	Trusts/PHA
	• Weigh all evidence relating to the infection control benefits of cohorting of staff and service users alongside the potential disruption to existing relationships and staff work patterns and make a recommendation for implementation by all providers of domiciliary care.	PHA
	• Weigh all evidence relating to the infection control benefits of separate teams for Covid positive service users alongside the potential disruption to existing relationships and staff work patterns and make a recommendation for	PHA

RECOMMENDATION	ACTION	KEY LEAD
	implementation by all providers of domiciliary care	
	• Providers of domiciliary care to encourage strategies to optimise the use of PPE in line with PHA guidance	Domiciliary care providers
	• Providers of domiciliary care to monitor uptake and implementation of IPC training/advice.	Domiciliary care providers
	• Any additional time for Covid measures for domiciliary care workers such as donning and doffing PPE to be assessed and if an average time indicates additional time is needed, Trusts to meet these costs.	Trusts with HSCB support to ensure regional consistency
	• Regional testing group to consider all evidence relating to a rolling testing programme for domiciliary care staff and service users and make a recommendation	DoH
	• Ensure prompt access to testing for domiciliary care staff and clear messaging regarding how to access testing.	DoH
	• Ensure prompt timeframes for test results for domiciliary care staff.	DoH
5. Meeting Need of Service Users and Family Carers	• Trusts to proactively contact all those whose domiciliary care packages have been stood down since the start of the pandemic to enquire about current need.	Trusts

RECOMMENDATION	ACTION	KEY LEAD
	• Any reassessment of need should include a full consideration of the sustainability of the current arrangements with particular regard to the physical, mental and social support needs of any informal or family carers.	Trusts
	• All service users and family carers who have had their services stood down or reduced must be informed of how they make contact with the Trust if they experience subsequent difficulties.	Trusts
	• Trusts should proactively contact anyone on their caseloads who was not previously getting a domiciliary care service but where it is likely that the pandemic may have created a need for additional support. This is likely to be particularly relevant for older people who may have lost physical condition because they have been shielding or staying in their houses.	Trusts
	• Trusts should proactively contact and engage with GPs, with media outlets and with local voluntary and community groups to make sure that access pathways for support are publicised.	Trusts
	• Tailored co-produced Covid related guidance to be produced for domiciliary care service users and family carers.	DoH/PHA

6. Financial support for providers	• Establish mechanisms for continued review of additional Covid related costs for domiciliary care. • The offers of financial support for providers should be set out in one document. • This document should be accompanied by clear, regionally consistent pathways for claiming financial supports.	DoH/HSCB DoH/HSCB HSCB/Trusts
7. Communication with Providers	• All guidance/ policy/ procedure/ information for domiciliary care to be electronically available and hosted in one place and on one platform • New guidance to be signalled to providers in advance. • Revised guidance should have the revisions and required changes highlighted. • Guidance should be as short and succinct as possible with action points clearly identified. • Regionally consistent guidance is preferable to variable local guidance. In particular, Trusts should strive to have common guidance. • Separate supported living guidance should be produced.	DoH to lead. Explore NISCC as host with agreed pathways from RQIA, PHA, HSCB & DoH RQIA, PHA, HSCB & DoH RQIA, PHA, HSCB & DoH RQIA, PHA, HSCB & DoH Trusts with HSCB support and monitoring **Published 21.10.20**
8. Data	• A core data set for domiciliary care during the pandemic should be agreed across Trusts and regional agencies that takes into account the time and effort involved in producing	RQIA, HSCB, DoH, NISCC & PHA to work with providers to establish data set. DoH to lead.

	data and the quality of the current data systems. Expectations for providers to provide this core data set should be made clear. Requests for data outside this core data set should be made in exceptional circumstance only. Work to be modelled on the care home app.	
9. Systemic Issues & Future Planning for Domiciliary Care – this review's evidence on the following issues to be provided to the Department of Health's NI Reform of Adult Social Care team (RASC)	• The importance of home and providing adequate support in the home setting. • The need to improve the pay, terms and conditions of the domiciliary care workforce. • The need to consider the future model of social care provision including the respective roles of the statutory, private and voluntary sectors. • The role of the community and voluntary sector in providing supports to people. • The support needs of family carers. • The need to analyse and include the benefits and costs of informal care in future service planning and as part of the costing of the social care economy. • The resourcing of adequate data systems. • The collection, analysis and use of data in domiciliary care. • Meeting complex care needs in domiciliary care provision.	RASC RASC RASC RASC RASC RASC RASC RASC RASC

	• The need for supported inclusion and co-production of service users and carers in planning and policy decisions. • The need to consider how best to obtain evidence on likely population need for domiciliary care services to support forecasting and future planning. • The need to review and update the definition of domiciliary care in partnership with all stakeholders.	RASC RASC RASC

Appendix A

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Appendix B

DOMICILIARY CARE: COVID LIVED EXPERIENCES

COPNI Domains https://www.copni.org/media/1119/domiciliary-care-in-northern-ireland.pdf Page 29 – "Research on developing quality indicators specifically for domiciliary care has focused on measuring care provision in six main areas:"						
	Reliable	**Flexible**	**Continuity**	**Communication**	**Attitudes**	**Skills & Knowledge**
Definition	consistently good in quality or performance; able to be trusted					
PCC Shielding Survey 2020			'I look after my husband who has a multitude of conditions but mainly his dementia is very frustrating. He usually goes to a day centre 2 days per week and I get 2x2hrs minders in so I can go out by myself but none of this is happening.	I would go as far to say those caring at home were forgot about. The suspension in my eyes should have been reviewed after 1 month'.	'[My family members who are shielding] miss being able to have the carers and cleaner in with whom they love conversation on a daily basis'.	She has fifteen minutes to prepare and cook a meal. No one could do that. Or when I asked for cooked food I was served up half raw food burnt on the outside and raw in the middle. And I don't blame them

			He has a 2 min memory so doesn't remember about lockdown which he finds frustrating and being asked the same thing repeatedly is exhausting for me. He is not safe to leave alone and therefore I am with him 24/7 with no end in sight. I can't put in words how difficult it is for me'.			– they are being asked to work a miracle. So if I don't have something for the microwave or a sandwich, I don't eat'.
	Reliable	**Flexible**	**Continuity**	**Communication**	**Attitudes**	**Skills & Knowledge**
Service Users	Domiciliary care was provided when needed. However, the demand fell away because people were either at home and content to take on additional caring responsibilities or have moved	Re-assessment of needs. The 'system' was taking the view that all of these packages had been paused so long that all trust Domiciliary Care packages would only be re-implemented	The Domiciliary Care Service has kept going throughout the pandemic.	At present guidelines are vague and are being given various interpretations by domiciliary care management. Telephone calls from care managers in Health Trust, etc. to enquire if we needed any help	Older clients are afraid to complain in case the service is stopped, and they are also afraid of repercussions	

	in with relatives and friends.	following a revised and up to date re-assessment of needs. This creates more anxiety.				
	Reliable	**Flexible**	**Continuity**	**Communication**	**Attitudes**	**Skills & Knowledge**
Disability Action Survey-family carers	“Can’t go to day care. Personal assistant not able to carry out usual tasks. No alternative day activity/social support offered…”	“I am expected to work from home and care for my daughter who requires supervision round the clock…”	“Respite care for the disabled person I care for has been taken away, no additional support…”	“Social worker hasn’t been in touch to see how he is…”		
	Reliable	**Flexible**	**Continuity**	**Communication**	**Attitudes**	**Skills & Knowledge**
Dementia carers		Doing something helpful that isn't specified on the care plan can make all the difference	Issues with changes in packages or accessing new packages and how that is managed	Difficulties with communicating and changing poor practice Information should be publicly accessible and transparent	the individual kindness of care workers makes a big difference	

	Reliable	Flexible	Continuity	Communication	Attitudes	Skills & Knowledge
Disability Action Survey – service users	"Day centre closed, domiciliary carers cancelled, respite cancelled until further notice…"	"Social Worker informed me I would be going to nursing home if carers couldn't be able to provide care to which I informed her that I would not in any circumstances move to a nursing home as I did not wish to die..."	"I used to get 4 carer calls a day which has been cut down to just a morning call…"	In response to the impact of the pandemic, a co-production framework that fully engages with the expertise of disabled people and their carers is essential	"I had to reduce the amount of Domiciliary calls as I was worried about some carer's lack of hygiene and they were dismissive of the dangers of COVID-19"	
	Reliable	**Flexible**	**Continuity**	**Communication**	**Attitudes**	**Skills & Knowledge**
Age NI				Purpose of domiciliary/home care - a more flexible approach, involving families/individuals in the shape and type of delivery is needed		
	Reliable	**Flexible**	**Continuity**	**Communication**	**Attitudes**	**Skills & Knowledge**
Carers NI	care packages stopped or reduced due to staff	issues around the flexibility of DP which a lot	More recently, family members having to return to work can only do	Many carers having difficulty getting hold of social workers.		

	shielding/self-isolating	of carers have raised with us	so if care packages are re-instated or increased - many are having to consider leaving work in order to provide the level of care their loved one needs	Others have left numerous messages and have not had a response.		

Domiciliary Care Services for Adults in Northern Ireland (2019) (CC7b return) Appendix B - page 25: definitions– 5 mutually agreed measures for domiciliary care					
	Health	**Hygiene**	**Dignity**	**Safety**	**Ease at Home**
Definition	the state of being free from illness or injury.	conditions or practices conducive to maintaining health and preventing disease, especially through cleanliness.	the state or quality of being worthy of honour or respect.	denoting something designed to prevent injury or damage.	absence of rigidity or discomfort; freedom from worries or problems.
PCC Shielding Survey 2020	'We cannot have anyone come into our home and provide respite which means mum and dad don't get any break, and the shielded cannot get out properly…as it's too dangerous'. 'Just help people who don't have the help they desperately need. If I hadn't paid someone to go buy my shopping for me I think I'd have starved.'	'We would have liked PPE for the carers. I bought the PPE myself for them'.		'Expecting someone who is shielding and vulnerable to accept up to 30 different carers into their home every week was placing us under greater risk of getting the virus'. '[The most important thing to me as shielding restrictions ease would be] the ability to pay my partner for care would make a difference (this has turned out to be the safest option for us – we had to give up carers)'.	

				As shielding restrictions ease would be 'having help in to get washed and dressed so I have dignity'	
	Health	**Hygiene**	**Dignity**	**Safety**	**Ease at Home**
Service Users	Mental Health issues, including feelings of isolation and loneliness because of no close contact with others. Depression and feeling tired and unwell most of the time			the lack of PPE / PPE not be being used correctly Worried about relatives particularly those in nursing homes adding to depression – Not feeling well and being afraid to contact GP	Being frightened of dying and no one knowing (if living alone); or falling and not being able to get up
	Health	**Hygiene**	**Dignity**	**Safety**	**Ease at Home**
Disability Action Survey 2020 - family carers	"I have taken over all assistance with care. This involves being available during night and day which is pretty tiring. I'm also assisting with all aspects of personal care preparing food and all kinds of assistance…"		"I am totally exhausted looking after them…" "Very stressful which adds stress to mental health…" "High anxiety…"	"Having to help disabled person shower who takes seizures and he is normally assist x 2 and I'm doing it on my own"	Respondents who had a disability or long-term health condition also raised concerns about the impact of increased caring roles of loved ones.
	Health	**Hygiene**	**Dignity**	**Safety**	**Ease at Home**
Disability Action	Right to Medical Treatment: Publish without delay the Department of Health	"I cancelled my trust morning care call as the carers wore no PPE and		"Have no help on ventilator and legally need 3 people to hoist safely…"	"I'm quadriplegic and my wife is my carer 24 hrs a day neither of us have left our home since 14 March

Survey 2020 - service users	'COVID 19: Ethical Advice and Support Framework' and to commit to ensuring this is cascaded to all healthcare professionals	failed ever to wash their hands coming into my home and I am immunosuppressed …"			and its effecting our mental health in a big way…"
	Health	**Hygiene**	**Dignity**	**Safety**	**Ease at Home**
Age NI			often people are so grateful to get any support, and do not know or feel able to ask for something different (in terms of the level and type of support provided).	Older people do not tend to think of themselves as "rights holders".	
	Health	**Hygiene**	**Dignity**	**Safety**	**Ease at Home**
Carers NI	The needs of the person being cared for have become more complicated during covid. The mental and emotional impact this is having on carers is immense.			Quality of care provided has been an issue for a few - so little time in the house and rushing to other jobs - standards have slipped.	Fear that as carers have been seen to be coping without the same level of care package that it won't be re-instated to pre-covid levels.

Laura Collins , 12 October 2020

Appendix C

Quotations from the Northern Ireland Social Care Workforce Survey

"At times during the initial lock down process this pressure was intense especially around potential Covid scares and testing of service users and subsequent testing of staff team members. Thankfully no one tested positive but I was very aware of the impact of staff having to self isolate and the impact on these staff members and their families and also service provision. At the time as indicated this was pressurised but with lock down came a degree of certainty in which this as far as possible there was a sense of order and control with the job role and within the community and clarity in the health messages from government."

"We were just left on our own to get on with the work in the peak. We still carried out our duties to service users. Pathetic that the people getting the bigger pay packets ran and hid, GPs closed their doors, physios, podiatry, nurses, even stopped coming out to service users that had a super pubic catheter! "

"Whilst working in an alternative role during suspension of my Sitting Service role. I was used to deliver Meals on wheels. During this time I came across 3 children near a home I was delivering to. I noticed that they were gathering stones but did not know the reason for this. As I was getting into my car they called me and gave me two stones with a rainbow painted on them and said thank you. This act of kindness left a lasting impression on me."

"PPE makes me feel a lot safer but the heat that builds up when wearing it can make work more physically challenging especially when pregnant."

"I felt that everyone gained more respect and kindness towards each other which is so important. I am very fortunate to work in my role, I have no issues, I love going to my job! "

"I felt the unit I work in was left abandoned, with staff on sick leave and staff shielding, our work load trebled and no extra staff or support was given. What I'm proud of is our standards of care and support to the service users never changed. Unfortunately this has left the staff carrying the workload mentally and physically burnt out. I'm so worried about a second wave. As I'm also a Carer for my son and mother. I feel very sad about what lies ahead."

“I am feeling drained and nervous about the 2nd wave. We are getting equipped to work from home - a lot community staff now are. It is strange going to be with so many isolating and during Winter with viruses we usually get into our system. I’m face to face in homes so who knows what they will recommend. Its strange times!

“Thanks for your interest - it makes us feel less alone and respected when asked how it has been.”

“We have adequate PPE but staff are still put at risk by service users and their families not following guidelines.”

“Since having a very large learning curve and stress I am now able to recognize that my health and well-being now comes first and have decided to seek employment elsewhere along with everyone else, I will be looking after myself”
“Reducing the amount of paperwork and reports that need completed sometimes just to prove to funders that we are still working as hard as ever if not harder “

“Additional finances to acknowledge the work of the care / support staff “

“Now we are worked to the bone. No staff wellbeing - just staff worried sick they will get it because they can't live on SSP. Company washing their hands of the staff. “

“If we voice any concerns regarding the risk to staff it is treated like staff don’t matter and have alternative reasons for concern . I have had to count work as my bubble so I can’t see my family, but then when I’m in work I’m exposed to a lot of shopping and managers that are not being careful.”

“As a manager of a service, I found the information and guidance provided by the PHA and healthcare trusts often conflicted and changed in a matter of hours leaving the communication to staff difficult and confusing for all involved. “

“Personally I believe the GP practices could have played a more proactive role i.e.. local testing under protocols at GP practice, instead of the large numbers of people driving to Craigavon?”

“I also fully believe HSC workers and Health Care professionals who had to provide a service should receive a financial recognition by this Government.”