The Impact of Covid-19 on People with Care and Support Needs, their Families, Carers and Communities

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Foreword

It gives us great pleasure to share with you the findings of our North West Elected Member Commission which looked at the impact of Covid-19 on people who have care and support needs, their families and carers and our communities.

There is no doubt that Covid-19 has had a devastating impact on people's lives. In our Commission, we wanted to shine a light on the impact on people and particularly how our communities have stepped up to support. There is a great deal we can learn from the experiences of people not just for how we improve things during the pandemic but for how we help support people in the future.

Our findings from The Commission provide some insight into the impact on the care sector and also signal what we may do differently when we emerge from this pandemic. The stories help to highlight the challenges for adult social care and, why now, more than ever, we have an opportunity to get this right and reform a sector in desperate need.

We have been humbled, inspired and, at times, heartbroken by the stories we have read and heard. The daughter providing care to her father whilst continuing to work full-time; the care home doing all they can to protect their residents; the community organisation adapting to a new age of digital service; the mother and father doing their best for their children in supported living. There are some truly remarkable people and organisations out there doing some amazing things despite the most difficult circumstances.

We would like to dedicate this work to them, and the many thousands of people like them.



Councillor Val Armstrong



Councillor Joanne Harding

Co-Chairs of the North West Elected Member Commission examining the impact of Covid-19

NW ADASS Elected Member Social Care Commission Report - Autumn 2020

Introduction

- 1. The Elected Member Social Care Commission was established as part of a North West ADASS [Association of Directors of Adult Social Services] approach to learning lessons from the Covid-19 pandemic. In particular, the role of The Commission was to investigate the impact of the pandemic on people and communities in the North West and what lessons could be learnt for further waves of infection and future service design.
- 2. The Commission investigated the following question:

"What has been the impact of the pandemic on people who use adult social care services, their families and our communities and what does this tell us about the role our communities should play in supporting people to live independently at home?"

- 3. The Commission was established by North West ADASS in collaboration with North West Employers and incorporated the work within the existing North West Adult Social Care, Portfolio Holders Network.
- 4. A steering group was established to oversee the project, consisting of the Chair of the NW Portfolio Holders' Network, two Portfolio Holders, the NWADASS Programme Director, NW Employers and a NWADASS Associate.
- 5. All Lead Elected Members for Adult Social Care [and in most instances Health as well] were invited to take part and will receive a copy of the report. Key lines of enquiry were agreed at the beginning and a call for evidence was sent out through the Lead Member Network. NW ADASS was supported in the commission by North West Employers who provided technical and practical support.
- 6. The Commission agreed key lines of enquiry. The aim of The Commission was not to answer all of these lines of enquiry but they were used as a guide for members to structure their own questions.
 - I. What does the experience of people with care needs in the community tell us about the kind of services we need to develop in the future?
 - II. What do we need to do to ensure informal carers can continue to meet the needs of their family and friends in the long term?
 - III. What is the role of the volunteer in meeting need long term and how can we create a volunteer 'movement' to support people in their community?
 - IV. How can we recruit and maintain greater numbers of volunteers to support future pandemics or crises?
 - V. What has been the impact of new community and voluntary sector services and what do we need to do to ensure the benefits are maintained?
 - VI. What have we learned about how these services develop and get established?

- VII. What are the new ways of working that have emerged during the pandemic that we need to maintain and how do we do this?
- VIII. What more do we need to do to support and value our adult social care workforce?

The Approach

- 7. In early-September NW ADASS published a 'call for evidence'. The purpose of the call for evidence was to obtain stories from people and organisations who had been affected by the pandemic and to identify those who would share their story with The Commission.
- 8. People were asked to submit their story in any format they wanted. A template was provided if required and easy read versions of all materials were produced by Pathway Associates. The materials are able to be viewed on the NW ADASS website www.nwadasss.org.uk.
- 9. The following groups of people and organisations were targeted through social media, local authority communication routes, existing networks and via direct messaging from Councillors.
 - People who require help to live independently at home
 - People who already receive an adult social care service
 - Family members
 - Advocates
 - Carers (eg people who support a family member)
 - Care workers (carers who work in a paid role for a care provider)
 - People who volunteered during the pandemic to support people in their community
 - Community and voluntary organisations
 - Informal groups which emerged in the pandemic
 - Businesses who have supported their community with vital services
- 10. The commission received 41 submissions, which included stories and case studies from 102 named individuals. The responses received included stories from people with care and support needs; carers (paid and unpaid); organisations who had mobilised as a result of the pandemic; commissioned adult care and support services; and community and voluntary care and support services. All stories were read, and a selection contacted and asked if they were prepared to share their experience with The Commission's panel of elected members.

Numbers of stories categorised by their overriding theme				
People with care and support needs and carers				
Mental Health issues	17			
Mental health and autism	5			
Learning Disability	45			
Physical Disability	5			
Older People	19			
Adult carers	13			
Young carers	2			
Organisations				
Wellbeing	3			
Learning disability	4			
Physical disability	2			
Older People	5			
Young Carers	1	•		

Listening Sessions

- 11. The Commission held four listening sessions over the course of three weeks. Each listening session was themed to provide the greatest opportunity for learning. The Commission heard from 16 individuals and organisations. Each person was allocated 15 minutes to speak with a further 15 minutes allocated to Members to ask questions.
- 12. The stories and case studies shared were often covering more than one aspect of social care which gave The Commission a wide perspective on the experience of people during the Covid-19 period between March and September 2020. Most of the stories received were from the North West's more urban areas which means there could be a gap in understanding the impact and lessons learned in more rural communities.
- 13. In addition to the written stories, The Commission received videos, pictures and diagrams some of which were incredibly positive or brought the stories to life, and others celebrated the creativity employed to keep lives fulfilling. Some of the organisations' presentations really represented the Social Care Workforce in its best light.

Session	Theme
Session 1 – 2 nd October 2020	Community and voluntary sector organisations -
Session 2 – 6 th October 2020	Commissioned Adult social care providers -
Session 3 – 13 th October 2020	Adults aged 65 and over
Session 4 – 16 th October 2020	Adults aged 18-64

What people told us

- 14. The stories told us that, for the majority, life had been extremely challenging over the period of the pandemic and was having a significant impact on people's mental wellbeing.
- 15. Though people understood the situation, some of the stories spoke of the stresses caused by what they saw as an abandonment of need. People found it particularly challenging at the beginning of the national lockdown. Lots of individuals were suddenly left without any service at all. Contact with organisations, including the statutory ones, was difficult, as they had also shut down and phones were not being answered. Councils had redeployed a lot of staff to other duties.
- 16. One person told us of the difficulties they had had in providing care for their father as the usual carers service had stopped. That care was now being provided by her but that the strain of caring and working full time was now taking its toll.

17. Another said,

"It was a difficult and stressful time. We had to choose between contact with our two children in separate supported living or our parents of 88 and 84. It had an impact on all of our emotional and mental wellbeing and we found the situation intolerable"

- 18. People had to find other ways of getting support or connecting with people. Basic preventative services such as Podiatry, Physio, Dental, Optical, Day and Respite access were all mentioned as not being available and being very slow to start up again.
- 19. One parent described the impact of the loss of health services on her daughter,
 - "The loss of health services, such as podiatry, causes her much stress, and the absence of strength & balance classes, has undoubtedly contributed to a loss of physical ability, as well as reducing her social interaction."
- 20. Virtual GP and NHS appointments proved hard to access for some people and the reliance on digital access to lots of things, meant some people were excluded. Referral routes for some services were not clear or disappeared.
 - "The GP practice reviewed my sister's medication without discussion or my normal involvement leading to problems in taking some of it and establishing a new routine as she has Learning Disabilities"
- 21. However, some of the Community organisations responded to the crisis quickly, expanding and increasing the range of provision, to cover food, isolation and medication as priorities. They managed to be creative in terms of using existing infrastructure such as DBS routes, increasing their volunteer base with furloughed staff, and putting in place food provision extremely quickly.
- 22. One person commented,

"The weekly phone calls [from the carers organisation] helped me from feeling alone"

- 23. In some places the Council helped with redeploying staff, creating communication routes and local councillors became a critical part of local networks. Some provider organisations showed they were highly creative in developing alternative activities for people through networks on social media and apps like Zoom.
- 24. One support worker said,
 - "we have tried multiple things for L to sustain her, including, arts and crafts, reading, garden activities, phone calls to family and friends, film days, board games and music It's not the same and led to low mood and crying"
- 25. Many times, family carers who had been contacted by phone, told us how grateful they were for this, how this made them feel 'less invisible' and not so alone in their caring role. Calls from social workers, support workers, helpline staff, a GP, had all made a huge difference to individuals. The knowledge that someone was looking out for the was really important.
- 26. People, particularly those with a learning disability or who cared for people with a learning disability, felt that their lives became more restricted because the rules around their direct payments were not flexible enough to allow them to spend them on things that would be useful.
- 27. One person spoke of their frustration at not being able to buy an I-Pad so that they could keep in touch with friends and family and take part in on-line and virtual activities.
- 28. The mother of one person with a learning disability described how, because their normal services were unavailable, they and people they knew had accrued a large amount of unspent direct payment. They were concerned that this would be clawed back by the Council and that their future payments may be reduced.
- 29. Not being able to visit relatives who live in care homes and supported living was a major strain on people's lives and their mental wellbeing. Several stories told of the difficult decisions that families had to make and the heartache at not being able to see family members.
- 30. One daughter spoke of the stress and upset caused by not being able to see her father in his care home and the confusion at the different approaches some care homes were taking to protect residents.
- 31. A wife of a man living with Alzheimer's in a care home described the agony of seeing her husband's confusion as she was told that she could not sit near to him and hold his hand and a feeling that his condition has worsened as a result of the measures put in place,

"We celebrated our fifty-fifth wedding anniversary at the beginning of September...I had hoped I could at least hold his hand, but that is forbidden, even wearing gloves. We were allowed a short walk in the garden...he shuffled up the bench and motioned for me to sit down next to him, this was less than two metres so I couldn't, he didn't understand."

- "...he has a total lack of understanding why he is not able to touch me or our elder daughter. The look of abandonment has not disappeared. I appreciate the Alzheimer's has progressed over the past six months, but its progress has accelerated because of the loss of emotional support"
- 32. Someone with a mild cognitive impairment said,
 - "I feel isolated. I just want a hug from my children, grandchildren and great grandchildren. We are a close family...The days seem very long."
- 33. Another relative spoke of how upsetting it was to see their relative start to relate more with their carers than with them due to a lack of visiting.

What organisations told us

- 34. In the listening sessions we heard from a number of organisations that demonstrated how quickly things could happen and how open they were to change. Many of the examples shared were models which could be used going forward.
- 35. The various organisations that submitted stories each spoke of rapid adaptation to the needs of the people who used their service and their community and of innovation driven by necessity and a sense of moral obligation.
- 36. **Northwich Isolation Group** spoke of the website they launched within 48 hours and 2,100 people joined the group. The Group used existing infrastructure to move quickly with one organisation providing all the DBS checks and used protocols such as not entering a property. They broke Northwich into 4 areas, formed street level WhatsApp groups to communicate, checked referrals every morning. They made links to housing providers and the wellbeing team to reduce dependency. The service launched in 7 days and provided support to 403 families, provided 2,000 food parcels.
- 37. Snow Angels Cheshire West and Chester Set up for Winter in 2012, normally to support around 200 people through winter but this trebled in size during the first wave of pandemic to 560 people with 200 volunteers. They were able to respond quickly due to support from the local authority with seconded staff and links to other agencies, plus newly created links eg to Chester University, and a special school. The biggest issues they faced were related to loneliness and isolation, so volunteers providing lots of practical help but transport was an issue and had to be prioritised. Referrals came from GP's, adult social care and the adult children of older people.
- 38. There were many examples of community organisations creating services or adapting their service to become more flexible to best meet needs and based on what they felt would work.
 - "We trained our [new] volunteers, updating our handbook for COVID-19...most were doing volunteer befriending, lots of dog walking, shopping, prescriptions... we managed to hang onto young people, usually doing evenings and weekends"
- 39. Tameside and Glossop Community Navigation/Social Prescribing is an existing commissioned service but spoke of taking a more flexible approach to meet people's needs prioritising food, medication and friendship. The service had 1,500 existing people using the service and recruited more volunteers to support the work. They described the freedom of not operating to a criteria

- and opened up to provide their service to veterans, older people, those isolating, those with mental health needs. Their referral routes indicated 50% from GP's with a smaller percentage from adult social care, smaller numbers also from Fire and Rescue, Police and self-referral.
- 40. They also gave a great example of a small voluntary agency repurposing computers, laptops and tablets. Other examples were shared of a group purchasing of Wi-Fi at low prices for those unable to buy.

"Some existing community groups struggled with getting income, impacting on their capacity and resilience

41. **St Aidens in Blackburn with Darwen** provided several examples of how being brave and making decisions to just do something at times of emergency, could support carers to access care critically needed, during the day, for respite. As an integrated statutory agency, they were given more backing and support and greater flexibility to take managed risks using systems, protocols and risk assessments and highly creative use of Shared Lives placements.

"We did introductory (Shared Lives) visits in gardens, virtually and through risk assessments"

- 42. Many spoke of the move to the provision of services online and of the benefits and challenges this brought. They spoke of a concern about those people who may be excluded and struggle to access digital services now and, in a future, where digital services and information will be more common.
- 43. **Unlimited Potential/Empower You**, a community based voluntary organisation commissioned to deliver exercise services to people with a disability in Trafford and Salford, quickly adapted to provide these services online through virtual exercise groups. They described how using a digital platform, such as Zoom or Facetime, actually encouraged more people to access the service and that for some, particularly people with autism, virtual platforms provide a more suitable way of interaction. They spoke of some of the challenges individuals or smaller community and voluntary organisations face in the move to digital such as online payments and having good Wi-Fi but saw the potential for a more flexible and person centred approach to day services which blends building based activities with virtual access.

"We worked to reduce loneliness, develop friendships, some structure after day services closed down. A routine provided comfort, helped with mental and physical health, brighten up the day with sessions online."

- 44. Warrington Speak Up Self Advocacy is a commissioned service to support people with a learning disability. They used their building with a lot of space to put together small groups while safe and able to do so. They tapped into other organisations to share activities digitally such as McIntyre and Pathways. They felt that digital access is really important to maintain people's involvement.
- 45. Anther advocacy service said

"We continued 1:1 support by test, face to face, through Zoom, the phone, Skype or conference calls, being careful where people lived with other people"

46. Organisations, particularly those commissioned, described their frustration and confusion at ever changing national guidance and communications from Councils which focused too much on COVID-

19 as opposed to what services were available and how people could help themselves. They also described the importance of creating formal and informal networks with peers and other organisations to deliver the best outcomes for people and how necessity has driven innovation.

47. **UBU Supported Living in Blackpool** told of the people who they provide a service for missing personal contact as everything had shut down with no information and no activities. There was information available from the Council, but this was all focused on COVID-19. They have put a lot of effort into people accessing digital means to engage with activities.

"We put a lot of activities on [Microsoft] Teams - disco, cooking, dancing, music connecting. On reflection, our staff needed help and training to use the technology."

- 48. **MacDonald Care** run two care homes in Bolton and Bury and they described how existing relationships and networks had helped get them through some of the challenges of the pandemic for example the Teaching Care Homes initiative in Greater Manchester, and the partnership they have with Salford University. The homes called upon the existing links they have with organisations such as The Woodland Trust, Age UK, The Octagon Theatre and Bolton Library to provide materials to help maintain resident's quality of life such as equipment to project films. They described the upset they shared with relatives about not being able to allow visits but how they had facilitated window visits and outdoor garden visits and shared their plans for visits using their newly installed garden 'pod'.
- 49. Having the right workforce was key for them,

"We want forward thinking staff, staff who will become leaders of the future. We had extra staff who could do complementary exercises, keep the residents stimulated and well. We use value-based recruitment methods."

50. During the listening sessions, people shared the things which had emerged that they felt should be maintained and those which should be reconsidered.

To maintain

- Contact on a weekly basis was very much valued and made a difference to individuals. One person gave an example of being contacted by their GP as they were vulnerable, and this had significantly re-assured them.
- Joined up Council, NHS and Provider contacts made it easier where community organisations needed consistent advice and support.
- Significant numbers of volunteers came forward to engage in community and basic needs support. A new group of people began to be involved younger with little previous volunteering experience.
- Access to activities on internet, including free courses etc to calm down thoughts and anxieties, keep fit, keep connected. Some organisations had freely shared material and activities eg Pathways and McIntyre.

- Good communication from Councils to organisations and from organisations to individuals increased resilience when trusted partnerships worked together and at speed.
- Paid carers being creative and flexible about activities.
- Carers centres switching to online or phone support, individual and group support.
- Agencies working well with each other, helping with referral routes and making connections.
- Openness about policies then sharing and explaining.

To reconsider

- Choices had to be made between which family member to support carers where they cared for say an adult child plus ageing parents, faced an impossible situation.
- Mental Health and often mobility deteriorated with increasing loneliness becoming more apparent over time. This continues to be the case for many people, who have not ventured out much at all or who are still protecting themselves or other family members.
- Lots of support disappeared NHS, Social care and family/friends and information was very hard to find. Much of the communication by the public sector organisation was focused on COVID-19 and stopping the spread of infection. There was very little to help people re-shape their lives in different ways for the future.
- Referral routes were not clear especially for those organisations that had to swiftly step up their response in a community. Making contact with housing providers proved important.
- Digital exclusion for some was apparent. Even if people had a Direct Payment to buy 'kit', some Councils response was over bureaucratic and inflexible. We heard of people being told they could not buy an iPad an obvious choice to help with dealing with the Pandemic. However, one council had a community scheme to repurpose computers/laptops.
- Difficulty in paying safely online, as some people did not have the means to set up arrangements such as PayPal, direct debits or there may be issues with capacity especially for People with a Learning Disability. For example, if someone wanted to pay for an on-line fitness class, an online supermarket delivery slot, order clothes or other online goods.
- Needs of Carers many carers had stepped in to fill gaps in services and found the strain of reorganising their lives, perhaps working from home plus having to manage gaps in support for their loved ones, really hard and were now exhausted.

Conclusions

- 51. These conclusions are based on all the submissions, contributions, evidence and personal conversations from the stories of up to 102 people and 11 organisations, many of whom supported hundreds of people.
 - The needs of carers, who are a critical part of community support systems, are highlighted. The evidence demonstrates much greater pressure on them, either to fill gaps, to manage the

complex family dynamics in any lockdown, or to cope with the loss and bereavement of contact or lives. This is stacking up problems of exhaustion and collapse of carers and their essential contribution.

- Mental health, anxiety and depression are prevalent because of the isolation, in those whose
 lives have been substantially restricted due to COVID-19. Normal support systems such as
 friends and family have been difficult to access in person because of the length of time many
 areas in the North West have been restricted.
- Direct Payments and Personalisation individuals and their carers are having to think of different ways to use their Direct Payments, but with little positive guidance to help them. Some people who have not been able to spend their direct payment are now fearful that the money accumulated would be taken away from them without a strength based discussion about more personalised ways to ensure support needs are being met.
- Human Rights Older people are especially being affected through the difficulties in communicating or visiting loved ones in care homes or supported living settings. It is noticeable that more decisions are being made for people in supported settings without them being consulted. Residents in care homes could be spending many, many hours isolated in their rooms in order to reduce infections spreading but with little to occupy them. People with dementia now having stronger relationships with their paid carers than with spouses or family.
- Providers needing to be as flexible as possible in identifying alternative ways of providing, without fear that Commissioners would penalise them for delivering services differently. Some providers have experienced problems with indemnity or insurance when doing things differently. A focus on outcomes can lead to more devolved responsibility for how this is delivered build trust eg where a mental health service might have developed into more of a wellbeing approach.
- Creativity needs to be encouraged. There have been good examples of different ways in which support can be delivered – maybe not quite the social contact that people are craving but close enough to be satisfactory for now. This could also lead to new ways of services being delivered in the future.
- Some communities have demonstrated enormous capacity and responding at speed. Where
 this has happened, some work to understand these strengths and build on them would have
 long term benefits
- This time provides a unique opportunity for the most personalised type of support for individuals, given many traditional services have shut down.
- One of the key approaches to emerge from our examples has been the development of a 'blended' approach which is seen to be a change for the way services are offered in the future. We also need to ensure that there is accountability of providers to evidence and explain what they have done to change delivery focused on outcomes rather than tight specifications.

Recommendations

- 52. We have set out our recommendations in a way which allows for Councils to consider what they might want to commit to at a local level and what might be worked on together at a regional and national level.
- 53. In addition, different organisations may have different roles to play going forward, to improve the experience for those who need social care support. We have identified four key organisational roles Providers (whether commissioned or voluntary); community groups; the Council; integrated and health agencies. Where examples of the best emerged, a system wide, trusting and open relationship was developed at speed and hundreds of vulnerable people were reached within a few days and weeks. For any recommendations accepted, we should seek good practice examples form any of the 23 NW Authorities to share.

Recommendations for Councils

- I. Councils should say a public 'thank you' to adult social care and support services (commissioned and voluntary) and unpaid carers for the hard work they are doing and the sacrifices they have made, and continue to make, during the pandemic and beyond. The Commission heard of the work done by organisations, paid and unpaid carers and volunteers to maintain vulnerable people in their communities so that vital NHS capacity was freed up.
- II. Take active steps to build the capacity of the community and voluntary sector to provide health, care and wellbeing services. The Commission saw and heard evidence that services developed in and by the community are not only able to respond quickly on a large scale for those who are vulnerable, but, if commissioned correctly and over a long period time, could deliver more responsive and personalised services to people. The Commission found that given the flexibility to create services to meet needs (in these circumstances driven by necessity) organisations were able to develop person-centred responses.
 - a) Reward and acknowledge the work that community and voluntary sector organisations have done over the period of the pandemic eg recognition awards, certificates of achievement.
 - b) Build on the energy and commitment shown throughout the pandemic by establishing community and voluntary sector fora to support the health and care sector.
 - c) Start commissioning for outcomes and allow organisations the freedom to develop creative ways of supporting people to live the lives they want.
 - d) Through 'innovation funding' type initiatives, provide community and voluntary sector organisations with opportunities to develop and test outcome-based services.
 - e) Set out in clear terms the role Councils want the community and voluntary sector to play in meeting people's health and care needs and the support you will provide to achieve this eg in your Market Position Statement.
 - f) Provide training to community and voluntary sector organisations on things like accessing funding though the council and partners and creating digital services.

- III. Councils should strengthen the wellbeing support available to informal/unpaid carers.
 - a) Establish a process of regular wellbeing checks with unpaid carers. For example, consider how a range of local organisations including voluntary, health and care, Police, Fire and Rescue and Housing providers can work together to check if more vulnerable people are coping. Combining capacity, data and knowledge could enable wellbeing checks for each carer who is under pressure ensuring early intervention to prevent carer breakdown.
 - b) Identify the triggers which could lead to 'carer breakdown' and provide proactive support to them.
 - c) Invest further in carers support and wellbeing services and look to carers and the community to design these. These are likely to include respite, peer support, counselling, flexible day services, information, advice and digital services.
- IV. Councils should seek to substantially increase the use of direct payments, making them quick and easy to obtain, and allowing for much greater flexibility for people in how they can be used. People should be given the freedom to choose and control how their money is spent to a greater extent. The guidance is clear that payments must be used for meeting people's needs and there is no need to specify how to spend funding.
- V. Councils should use their place-based leadership role to facilitate communication with and across organisations helping vulnerable and isolated people. For example, ensure that referral pathways for those in greater need are clear and accessible; information about how people can help themselves and join up the dots locally.
- VI. The pandemic has shown how many people have volunteered in their community when they know they can make a difference to individual's lives. Build on this new capacity and energy to create stronger preventative and community solutions.
- VII. Councils should expect and facilitate their providers to be creative. Many care agencies were able to safely protect individuals but needed access to PPE, technology, the ability to swiftly change practice. They needed advice on safe contact with families, the ability to meet in groups, enabling service users to pay for their own services, promoting decision making, and reducing deterioration especially physically and mentally.
- VIII. Councils and other organisations should accept that digital becomes one of the primary mechanisms for service delivery in the future. In particular:
 - a) Organisations who plan to use digital services should ensure these are co-designed with the people who will be using them.
 - b) Councils should develop a digital inclusion strategy, alongside their commissioning strategies, for all ages and abilities which demonstrates how they will increase take up and ensure people are not disadvantaged.
 - c) Councils should provide greater and more immediate support to people who are now accessing services online, perhaps for the first time, in the same way that some private sector companies have done. For example, 'digital navigators'

- d) Councils should support voluntary and community organisations with online payment solutions and develop options in their local community.
- IX. Councils can provide more local leadership and should collaborate with care home providers and relatives to design approaches to safe visiting in care homes which allows visiting to take place safely and in line with government guidance and the NWADASS statement on visiting. Spouses in particular were even prepared to self-isolate in order to facilitate contact and protect others, yet this never appeared to be discussed with them.
- X. Councils should work with providers and people who use services to redesign day services and to shape the market to allow for greater choice, flexibility and accessibility for people. For example, more blended approaches to service delivery utilising digital, home and building based delivery; using a network of organisations who together can meet people's requirements more fully. An example was Wildlife Trusts across the NW who had designed and shared activity packs and stimulating content for online or groups to engage in.

Recommendations with regional and national significance

The following actions The Commission felt required either regional or national attention:

- I. Identify and share best practice in particular in relation to infection control; facilitating visits to care homes and supported living; the use of Direct Payments; working with volunteers; day service provision; and, outcome-based commissioning.
- II. Bring the needs of informal and unpaid carers to the forefront and recognise this group of people in strategies and approaches relating to the adult social care workforce, living well at home; and preventing deterioration and hospital admissions.
- III. Facilitate the development of new models of care based on the experience of the pandemic. For example, day services.

The Commission's Closing Remark

- 54. The pandemic has challenged people, Councils and services in ways which will not be fully known for some time and possibly years.
- 55. The evidence heard by The Commission told of the direct impact of the pandemic and the lock down on people's lives and the extraordinary lengths organisations and volunteers went to, to support people and protect lives.
- 56. The evidence also spoke of an underlying feeling of abandonment and a sense of unfairness. Our witnesses presented a picture of trying to do their very best to live life, stay safe or to protect the people they serve but with little recognition from Government and benefitting little from national messages which focused primarily on protecting and thanking the NHS.
- 57. We firmly believe that adult social care services which includes Councils, independent providers, unpaid carers and the community and voluntary sector played a vital role in protecting lives. and will continue to support people affected long after the virus has gone. We believe that the role Adult social care plays in people's lives and in living rich lives in our communities, must be

recognised and placed on an equal footing with the NHS with a fair funding settlement and long-term plan.

- 58. We owe this to the thousands of people who have care and support needs and those working tirelessly to support them in an environment which often seems unfairly weighted against them.
- 59. It is social care's time. If not now, then when?

Publication and Distribution

- 60. The report is published on the North West ADASS website.
- 61. The report will be sent to the Adult Social Care Portfolio Holder and the Director of Adult Social Services in each of the 23 North West local authorities. Whilst the recommendations in this report are suggestions, The Commission would be interested in responses from local authorities.
- 62. The report will be sent to those people and organisations who submitted evidence to The Commission with a view to building a long-term relationship with them.
- 63. In addition, the report will be shared with the following people and organisations:
 - North West MPs.
 - National ADASS
 - The Local Government Association (LGA)

APPENDICES

Appendix 1

North West Elected Member Commission Participating Councillors:

Eleanor Wills, Tameside

Gina Reynolds, Salford

Graham Gooch, Lancashire

Iftikhar Ahmed, Rochdale

Joanne Harding, Trafford (Co-Chair)

Jude Wells, Stockport

Keith Cunliffe, Wigan

Laura Jeuda, Cheshire East

Maureen Quinn, St Helens

Mustafa Desai, Blackburn with Darwen

Paul Cummins, Sefton

Rebecca Knowles, Warrington

Val Armstrong, Cheshire West and Chester (Co-Chair)

Appendix 2

Council Model Motion

The following is suggested wording for Elected Members.

"Does this Council recognise the lasting impact of loneliness and isolation felt by vulnerable people during and after the pandemic lockdowns and commit to supporting a national long-term solution to the funding of Adult Social Care"

Appendix 3

Acknowledgements

The Commission would like to thank the following people and their organisations for their help and support.

Denise Isherwood, North West Employers, for providing technical and administrative support to The Commission.

Lawrence Clark, Pathway Associates, for the production of easy read materials.

Lynn James-Jenkinson, Pathway Associates, for promoting the 'call for evidence' to people with a learning disability and supporting the many submissions we received.

Paul Grogan, Think Design, for the production of the 'Call for Evidence' materials.

Sue Lightup, North West ADASS Associate, for the hard work in reading and analysing evidence, liaising with witnesses and bringing our findings together.

Appendix 4

Contributors

Our thanks go to all those individuals and organisations who contributed their stories to the project and especially those who presented at the Listening Sessions 2^{nd} Oct -16^{th} Oct (listed below). People's experiences were sometimes emotional and very sad – they bravely shared them with us. * denotes they spoke at one of the listening sessions.

GL* – spoke of her husband in a Care Home with Alzheimer's disease and now related more to the carers than his wife.

CB* – who told us about the Northwich Snow Angels community organisation supporting 640 older people.

GC* – who told us how isolated he felt coping with his mental health needs and only left home four times but found enjoyment in the free online courses.

L – who explained what it was like to be a young carer of his disabled mum and valued the weekly phone call and weekly food parcels.

JA – whose family of four included complex family dynamics, a young carer and a son with MH needs.

A – whose daughter was dealing with her autism and their social worker was much valued.

H* – who as well as having a full-time job, took on the care of her father with dementia, from paid carers, to keep him safe and really struggled to find help and access to services.

MW* - who lost her husband, became ill with COVID-19, and needed her daughter to come and stay and now suffers the effects of long COVID-19.

DG – who is the carer for his wife with dementia but can't get support from family and friends

McDonald Care* – who owns and manages two care homes and demonstrated great resilience and thought, in caring for residents and their families, included a short video.

 $UBU^* - a$ supported housing setting who fed back the experience of four of the people with a learning disability living in that setting and the many changes they had had to make to their way of life.

St Aidens* – an integrated health and social care service explaining the way services had to adapt to the new rules but still provide some kind of respite support for people with a learning disability, with eight case studies of crisis need.

GR – describing the problems in working out how to support and keep contact with her two children in supported accommodation and her parents in their 80's and how upsetting it was to choose.

DP* – described the way a local community response emerged days after lockdown in Northwich to support isolated and vulnerable people with food, medication and isolation eg 2.000 food parcels

Warrington Speak Up* – providing testimony from 18 contributors including 6 short video clips which describe how limited life became and how important small groups and Zoom were to keep spirits up.

Unlimited Potential* – video clips of their work with individuals to maintain wellbeing, motivation, mental health and fitness during lockdown enabling vulnerable adults to have meaningful activity.

KC* – Felt very alone and bored, tried to find things to occupy him, at one stage attempted self-harm.

CD – in supported living, had his story told by his support worker. He got upset when he couldn't see mum or his girlfriend and do the usual things.

Age UK Trafford – presented views from a range of people who had support with shopping, fuel, essential medication, looking after pets and having someone to talk to.

GMH&SCP* – provided examples from Tameside and Glossop Together – using Community Navigators, Social Prescribing and other community support through volunteers to vulnerable adults and OP.

IH – whose normal care of her sister with learning disabilities in sheltered housing was disrupted and wasn't able to have contact for 12 weeks but discovered the GP had reviewed medication not realising the disruption this unplanned change would create.

CHAPS — Cheshire Autism Action support — described how all activities were suspended and noticed people's mental health decline dramatically, even though technology was employed to help.

CB – Whose son with autism and schizophrenia lives independently but could be on the phone to his mum up to 20 times a day and really appreciated some contact from a carers helpline.

KM – whose wife has CBD and he does most of the physical tasks for her. He really valued the limited carers support available, the PSPA charity and support group for her rare condition.

Anon – who described looking after her 88 and 95-year-old relatives needed help with finances, short term memory, and their hearing loss to cope with day to day things and fill gap left by paid carers reducing contact.

SB* – whose 32-year-old son with learning disability lost all day activity, although local shops were supportive and some day support returned, was concerned about the flexible use of their direct payment.

HD – caring for her disabled and vulnerable ageing husband, managed to keep her local paid carers going, although problems with PPE, normal physio and respite support through the months.

P – with learning disability and mental health needs, been in hospital and had 3 tests for COVID-19 which had a big impact on family

LP – who experienced low mood and crying after losing the normal routine.

DD – who has mental health issues, autism and Asperger's, was lonely and depressed, support staff have helped but missed normal activities and going out.

KS* - whose daughter with learning disabilities and physical disabilities had a very full life, volunteering, swimming etc which all stopped and concerns that PA's couldn't support. Was concerned about the flexibility of direct payments.

The Fed – Jewish organisation with very active community hub, went from 4,200 visitors in Aug '19 to 121 visitors in Aug '20. Really struggled to find a way to support their users.

VS – 92-year-old described being stuck indoors, feeling vulnerable but has learnt FaceTime, and appreciates the weekly phone call.

DG - described the loss of health services, e.g. podiatry, causing much stress and the absence of strength and balance classes has undoubtedly contributed to a loss of physical ability, as well as reducing her social interaction.

Appendix 5

Useful References

The following links provide useful contextual information.

The LGA 7 Principles of Social Care Reform https://local.gov.uk/adult-social-care-seven-principles-reform

The ADASS nine statements to help shape adult social care reform https://www.adass.org.uk/adass-publishes-nine-statements-to-help-shape-adult-social-care-reform

Advocacy Covid-19 and beyond Sept 20 - https://www.adass.org.uk/media/8173/advocacy-during-covid-and-beyond_final_20200817-002.pdf

Using Technology to improve personalisation -

https://www.adass.org.uk/media/7892/4009 adam report final.pdf

ADASS – planning and preparation for a Flu Pandemic 2018 -

https://www.adass.org.uk/media/7885/adass-pandemic-flu-report-information-requirements-for-reprioritisation-final-march-18.pdf

Flu Pandemic guidance also makes reference to the ethical and decision making aspects while in a national pandemic.- https://www.adass.org.uk/media/7886/guidance-for-dasss-planning-for-pandemic-flu-final-april-2018.pdf

This guidance has a useful section on the importance of Communication re Social Care and from the DASS perspective. Much of this is relevant for Lead Members - https://www.adass.org.uk/media/7884/adass-pandemic-flu-communications-report-final-april-2018.pdf

Delivering integrated care at Neighbourhood level - https://www.adass.org.uk/neighbourhood-integration-project

Government advice on visiting people in Care

 $\frac{https://www.gov.uk/government/publications/visiting-care-homes-during-coronavirus/update-on-policies-for-visiting-arrangements-in-care-homes}{}$

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All of the materials and resources used in this work are o	available on the North West ADASS	website.
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